

# **USERS AND HEALTH WORKERS STRENGTHENING SOCIAL PARTICIPATION IN THE BRAZILIAN NATIONAL HEALTH SYSTEM**

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## 1. Brief introduction

Social participation, including users, workers and managers, both in Brazil and in the world, has contributed for the construction and strengthening of public policies in different fields of action. In the health field, in Brazil, the construction of the *Sistema Único de Saúde* (SUS) [Unified National Health System], based on the principles of universal care, equity and comprehensiveness of care, results of a wide mobilization of sectors, including organized civil society, health movements, health workers, managers and the academy<sup>1</sup> (BRASIL, 2011).

Along the time, there have been several initiatives for social participation widening and strengthening within the health field in the world. Since the International Conference on Primary Health Care in Alma-Ata (WHO, 1978), the World Health Organization (WHO) has sought to construct strategies for the consolidation of a bigger community participation, by means of different mechanisms, aiming to guarantee universal access to health.

In Brazil, social participation in the health system was established in 1990 by means of conferences and councils, which are collegiate instances forming a social control system. Since then, social participation and control are widely reinforced in policies, programs and resolutions. It was established that, in these participation spheres, the percentage of participants comprises 50% of users, 25% of health workers and 25% of service suppliers.

Recently, in May 2014, the federal government established the *Política Nacional de Participação Social* (PNPS) [Social Participation National Policy], in which it "acknowledges that social participation is a right of the citizens and an expression of their autonomy, proclaiming that mechanisms of representative, participatory and direct democracy are complementary"<sup>2</sup>(DOMINGUEZ, 2014, p. 11).

In practice, the PNPS organizes the existent national level instances of social participation, defining guidelines for their functioning and encouraging federal public management bodies and entities to consider its deliberations. It

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<sup>1</sup>BRASIL. Ministério da Saúde. Conselho Nacional de Secretários Municipais da Saúde. **Participação Social no SUS: O olhar da gestão municipal**. Brasília: Ministério da Saúde, 2011.

<sup>2</sup>DOMINGUEZ, Bruno. As vozes do Brasil. In: Controle social: participação direta amplia expressão da sociedade. **Revista Radis**, Ensp/Fiocruz, n. 144, p.10-17, Set, 2014.

also innovates when widening the dialogue opportunities by means of virtual platforms in the Internet, through which any citizen can express his ideas and opinions concerning public policies<sup>3</sup> (DOMINGUEZ, 2014).

In this context, we, members of the People's Health Movement (PHM) Brazil, have realized that the awareness work related to the advocacy of public policies by means of the citizenship participation is an important strategy for its strengthening and for cultural change. However, there is a lack of knowledge-based evidence on how the participation of different actors in the health field happens, as well as on the reasons why it has apparently been weakened, depending on the context, among other aspects.

For this reason, we proposed the development of this research, from which, besides collecting and analyzing data and information on the theme, it was possible to identify obstacles and potentialities, as well as to identify strategies that might contribute for a review of social participation in health in the present times, leading to the strengthening of this cornerstone of our health system. Concerning the results of this research, we intend to produce knowledge and generate reflection on the involvement of the civil society for reaching "health for all".

In this report, we will describe the way the research was conducted, the results, their contextualization within the sphere of PHM global research and, lastly, the implications of these results for the second phase of this investigation. In the second phase, the intention is to implement an intervention using phase 1 findings.

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<sup>3</sup>DOMINGUEZ, Bruno. As vozes do Brasil. In: Controle social: participação direta amplia expressão da sociedade. **Revista Radis**, Ensp/Fiocruz, nº 144, p.10-17, Set, 2014.

## 1.1 Research objectives

### General objective

- Analyzing the contribution of users, health workers and managers for the accomplishment of social participation in SUS, aiming at its strengthening.

### Specific objectives

- Identifying the understanding of users, health workers and managers concerning their participation in the resolution of health issues, emphasizing on universal access and equity;

- Analyzing the understanding of users, health workers and managers of the “Health for All” concept;

- Analyzing the structures, functions, processes and strategies which influence the participation of users, workers and managers for reaching resolution for health concerns;

- Identifying factors involved in a more effective social participation, including difficulties, potentialities and resistances; and

- Stimulating the reflexive analysis, among researchers and research subjects, for the improvement of the practices towards universal access and equity.

## 2. Process and methods

### 2.1. *Research team*

The research team was mainly formed by PHM activists who had already worked together in the Movement's actions. Besides them, we searched for partnership with people who were interested in the theme of social participation, either because they were already working with it and/or had affinity and interest for it. We have also gathered students who were interested in the theme and in the PHM as well as available to help in the work, seeing this as an opportunity to bring new, young people to PHM.

Our team was formed by:

- 2 coordinators, PHM activists, teachers at UFRGS (Camila and Cristianne);
- 4 researchers, PHM activists (Denise, Eliane, Kátia and Patrícia) – one of them left due to health problems;

- 2 collaborating researchers, teachers at UFRGS (Roberta) and UERGS (Vânia);

- 5 collective health students/residents (Mariana, Neuza, Cristiane, Nilvo and Francine).

The coordinators conducted the preparation of the project, its submission to ethics committees and supervision of the whole research. They also participated actively in the results systematization. The researchers collaborated in different steps of the investigation: project preparation, organization of the field work, data collection and systematization of the results. The students participated mainly in the data collection, as well as in the organization of the collected material and the systematization of the results.

We also counted on the participation of a PHM activist from afar, based in Belém do Pará (Marta Giane). We believed it would be interesting to analyze social participation in a distinct context, in another region of Brazil. She conducted some interviews in Belém, but their content has not yet been analyzed.

Lastly, we had a transcriber (Heloísa) who transcribed all interviews in full. This was the only paid work in the team.

## *2.2. Process that led to the research plan of phase 1*

The preparation of phase 1 research project began in a two-day workshop in October 2014. Along these two days, we discussed the proposal of the global research and how we could adapt it to our context. Thus, we jointly decided to address the theme of social participation in the National Health System (SUS), as the participation of social movements and civil society is included in it. We believe that it is important to study and act upon this field, as there are signs that the format of social participation adopted by SUS, entitled social control, is a little weakened or "tired". Moreover, the establishment of formal spheres of participation, such as those existent in Brazil, with health councils and conferences, is a major achievement and should be valued and strengthened, including by means of the research.

Following the workshop, we moved on to the process of joint construction of the project, which involved intense communication within the group. In this process, new people also joined the team, until we formed the group described in item 2.1. Factors related to the experience in certain territories of the city were

considered in the choice of places to be studied. As several members of the team were teachers of two universities (UFRGS and UERGS), those health districts which had an agreement with these universities (respectively, Glória-Cruzeiro-Cristal and Lomba do Pinheiro-Partenon) were chosen, considering that the accumulated knowledge concerning these districts could benefit the work.

### *2.3. Chosen methods*

We have opted to conduct an exploratory study with a qualitative approach, as it would be more appropriate to reach the work's objective.

Concerning the choice of the study's location, we defined that it would be Porto Alegre, as this is where most of the PHM Brazil members are located. The municipality of Porto Alegre is divided in eight district managements of health and had, in 2014, approximately 150 Family Health Care Centers (FHCC). Each one must have, according to the municipal health plan, a local health council. Each district, on its turn, has a district health council. The study was developed in two of these districts: Glória-Cruzeiro-Cristal and Partenon-Lomba do Pinheiro, as they have an agreement with the universities to which the researchers are linked.

The Glória-Cruzeiro-Cristal district has an estimated population of 160 thousand people and 27 health care centers, being 8 Basic Health Care Centers (BHCC) and 19 Family Health Care Centers (FHCC), comprising 35 Family Health Strategy (FHS) teams. The Partenon-Lomba do Pinheiro district has 180 thousand inhabitants in the territory and 22 health care centers, being 8 BHCC and 14 FHCC, comprising 28 FHS teams. One FHCC can comprise more than one FHS team.

Three Family Health Care Centers (FHCCs) were selected in each district, according to convenience (management agreement, welcoming from the teams and population and previous contacts of the researchers with the involved communities, considering their potential contribution for the research). In each health care center, four people were selected to participate in the research: the health care center coordinator (or local manager), one worker and two users. Concerning the workers, we tried to include all professional categories listed in the FHS and different levels of involvement in the health councils. Concerning to the selected users, one person was appointed by the team in each health care center due to his/her participation in health concerns, being a health counselor or

not, and another one was identified by the researchers by means of direct contacts with the communities, from an initial exploration of the territory, being members of community associations and local institutions, including neighborhood associations, churches and schools. Lastly, the managers of both districts were also included, aiming to include different perspectives, according to the population-assistance-management triad. The project was presented to the two district health councils previously to the interviews.

The interviews were conducted in the health care centers, following a semi-structured script (Appendix A). The district managers were interviewed in the respective management headquarters. The following topics were addressed: understanding of the "health for all" concept (with an emphasis on the concepts of universal care and equity), perception of participation in health concerns, factors that make the participation difficult or easier, reasons to participate or not in the collective resources provided (such as health councils, without excluding other possible spheres of participation), and perception of the representativeness of the councils and other spheres of participation.

In summary, there were four interviewees in each health care center: two workers, being one the coordinator, and two users. In each district, 13 people were interviewed, including the district manager. The total of participants was 26 in the two managements. The interviews were audio recorded and transcribed in full, following the agreement of the participants.

Also, the researchers and students involved in the data collection participated in the Local Districts and Health District meetings, recording their observations in a field diary.

The project followed the ethical norms of the Brazilian National Health Council and was approved by the Research Ethics Committees of the Federal University of Rio Grande do Sul and the Porto Alegre Municipal Health Department. All participants signed an Informed Consent Form.

#### *2.4 Adaptation of the international guide to the local context*

The international guide content was used as a basis to establish the objectives of the research that would be conducted in Porto Alegre; however, the group considered the local needs, as well as the Brazilian reality when choosing the "social participation" theme. The global research themes that were more

appropriate to our research were: campaigns and advocacy, movement building, knowledge generation and dissemination, and capacity building and training; however, not in a straightforward way. Thus, we chose to analyze the contribution of the research in each theme after the results systematization.

### *2.5 Review of phase 1 initial work plan*

Along the development of the research phase 1, we had to revise some plans. In the project, we had planned to invite the participants for a conversation circle following the individual interviews (one encounter in each FHCC or, at least, one in each district), to address the theme of social participation more widely. Besides bringing new information, the conversation circles would allow us to reinforce or not the perceptions that emerged in the interviews, to clarify ideas and opinions and to obtain information emerging from the interactions among the participants. For the conversation circles, we intended to use guiding questions (Appendix 2).

Yet, to finalize phase 1, we had planned the accomplishment of a meeting for which all participants would be invited. In this meeting, the research team would comment on the aspects identified from the interviews and the conversation circles, encouraging the participants to express themselves and contribute for the final analysis of the research. This was aimed to prepare, in a future phase, an intervention for the strengthening of social participation on health concerns in the study location.

The conversation circles were not conducted due to two reasons: we were afraid that they would be repetitive (depletion of the contributions' content) and lack of time (compliance with the schedule). The meeting with the participants was not conducted due to lack of time, but it will be accomplished in phase 2.

### *2.6. Developed actions*

Initially, we developed a workshop with the research team in order to jointly think about the project. Between the workshop and the beginning of the project, which only started almost a year later due to the need of approval by the ethics committees, we had several meetings to discuss the research and plan its conduction. Other people joined the research team along this process.



Shortly after the approval by the ethics committees, in September 2015, we began the contacts with the district managements to select the health care centers that would be visited. We also started the observation of the district health councils meetings in both districts that were included in the research. Soon after, the team started to visit the services in order to know the staff and to interview the people. The interviews were accomplished from November 2015 to January 2016. The members of the team participated of the local health councils (when they were active) of the selected services as well.

In January 2016, the team developed a workshop to discuss the process of analysis and, later, two meetings to share the work of content analysis and systematization of the results.

### *2.7 Major challenges found along the research process*

We can list a few:

- The long waiting time for the approval in the ethics committees delayed the beginning of the data collection for a long time.
- The PHM is small, and in general, members have little time available to dedicate intensively to a new task. Lack of time is a major problem.
- The responsible person for the research (Camila) was in sick leave and maternity leave for a total of 8 months (from March to December 2015).
- We wish we could have done a nation-wide research, but the communication with PHM members from other states still is difficult. Thus, we have opted for inviting the other groups to develop a part of the research also, that is, a subproject. This way, the PHM group from Maranhão state and the colleagues from the ACT-BR NGO prepared their projects, according to their own reality. We made some interviews in Belém do Pará; however, it was not possible to analyze the material due to lack of time. Working from afar and keeping a good communication is a huge challenge.
- Communication with the main investigators of the research is easy, as the coordinators speak English. However, the production of documents and reports must be doubled, so that we have at least one version in

Portuguese to be shared locally and another one in English to share with the global group. This is a constant challenge as translation takes time and/or has costs. For instance, this report was translated with resources from the research.

- The use of the MAXQDA software to aid in the qualitative analysis was a challenge because only one person was familiar with it. In spite of having developed a workshop on the software, several people from the team had problems and spent too much time with it.

### **3. Analysis**

#### *3.1. Collected material*

The following material was collected:

- Interviews (10 hours, 41 minutes of recording)
  - In the districts Glória-Cruzeiro-Cristal and Lomba do Pinheiro-Partenon, 13 and 16 people were interviewed respectively, totaling 29 interviews
- Field diary with observations from the meetings of the district and local health councils
- Field diary with observations from the visits to the health care centers

#### *3.2. Data analysis methodology*

We have opted to make a content analysis of the interviews, complemented by information from the field diaries.

We used content analysis from categories or thematic axes, which were pre-established according to the objectives of the research. Other categories were created along the data collection and the analysis, in an inductive process. Information from the field diaries, resulting from the observations, was used to complement the content of the interviews. The MAXQDA software was used to help in the organization of the data according to the categories of analysis.

## 4. Results

### 4.1. Profile of the interviewees

Among the managers, 6 local managers, the coordinators of each selected FHCC and 2 district managers were interviewed. Among the 8 managers, 6 were women and 7 were nurses. The age ranged from 28 to 39 years, showing that relatively young people are presently taking over management positions. The time of work in them ranged from 2 months to 4 years.

Among the 6 workers who were interviewed, 5 were women. Their professions were: 3 nursing technicians, 1 dentist, 1 community health workers and 1 physician. The age ranged from 29 to 50 years. The time of work in the FHCC ranged from 9 months to 6 years.

In the group of users, 10 out of 17 interviewees were women. The age range was wide: from 19 to 78 years (means of 49.7 years). In relation to their occupation, six were retired/in sick leave and 3 were unemployed.

### 4.2. Managers' perspective

#### Perception of participation

All managers acknowledge social control as a legitimate form of participation, as a democratic sphere of debate and deliberation, mentioning the municipal and local health councils and all the participant segments (managers, workers and users). However, it was possible to notice that the users' participation is especially valued and, sometimes, social participation was defined as the users' participation. It was also highlighted the perception that social participation provides the articulation of community leaders with workers and managers, as well as that it reinforces the interaction between community and health team. For the latter, it is a tool that helps in the understanding of the needs of the community while, for the community, it helps to understand the skills and limits of the team.

(In) social participation, I see that it is the users' role to contribute with the construction of their health and of their health care. (It concerns to) their view on health, their needs, jointly with the health care center counterpoint. (Local manager 6)

(Participation is) to be able to articulate the health service with the community. I believe that it brings great benefits for both sides – the community to understand the real situation

of the health service, and the health services to understand what the community needs and expects from the health care service. This leads us to be able to reflect upon what we are providing, about what the community would like to receive, what our service is able to do, to offer, and to be able to foster this interchange. (Local manager 5)

It was remarkable how much everyone values the councils as highly important for the construction of health and social projects, in spite of the fact that, in practice, they often do not have good experiences in them. Some believe in its potential, but cannot realize, in practice, an effective way of functioning. Yet, the health council is perceived as a sphere of construction and education, in a wider perspective, and not only complaints and demands. It was also noticeable the perception of being a sphere for the managers and the workers to guide the users concerning the functioning of the assistance and to clarify their doubts. The wide function *versus* the specific function, both present.

(The health council) is where we achieve more exchange among the users; it's where we are able to show how the service..., why it works this way, what is their understanding of that. It is a moment of interchange. (Local manager 6)

Social control is seen as a tool to reach health for all. According to a district manager, sometimes it makes the work of the managers difficult, but its importance is acknowledged.

Social participation is the cornerstone of SUS. Only with it we will be able to construct a SUS (National Health System) for all. (Local manager 6)

It is interesting that the managers also acknowledge that social control is a guideline of the Ministry of Health, being considered as a goal to be reached. They also know that it adds points in the evaluation tools and brings financial resources to the municipalities.

Besides the established spheres (councils), some managers also acknowledge other ways of participation, such as the mobilization sphere for the indigenous' health. In the managers' discourse, the idea that people of the community need to mobilize, request, fight to achieve improvement in their health was clearly evidenced. Many of them mentioned social participation as comprising social determinants (territorial, social, political problems) and, therefore, suffering the influence of issues linked to the territory. As an example, the presence of earlier social movements and the history of fight for land in one

of the districts (Lomba do Pinheiro) were identified as factors that make this region more active in social participation.

Lastly, clearly there is a perception that the user realizes the social control as a form of resolving specific issues linked to the assistance (having or not a physician, referral to specialists, for instance) and much less to address wider and more permanent issues.

### Understanding about concepts of health for all, universal care and equity

In the managers' conception, in a general way, universal care and equity are essential principles linked to the concept of health for all. These concepts have always been associated with the concept of comprehensiveness, which emerged in all comments, with the notion of social determination of health. The managers showed a good knowledge of the PHC principles.

In relation to universal care, one understanding can be as “open doors” and providing facilitated access to assistance. Referring to equity, the perceptions are those of the skills to recognize people’s needs and identifying the most vulnerable ones, who deserve distinct care.

According to the managers, there is a perception that the achievement of health for all depends on the understanding and the appropriation (including use) of people on the health system and that, for this reason, it is considered a utopic goal.

(Health for all) is a utopia. Why is it a utopia? Because we depend a lot on what each of us has constructed along our trajectory. When we don't have sensitive providers, we cannot have health for all. When we have a user who doesn't understand, or a worker or manager who doesn't understand what the National Health System is, we won't have health for all. (Local manager 1)

Lastly, the notion that health for all must be built with the participation of all was specifically uttered.

I think that health for all is health thought by everybody, planned by everybody and with wide access to everyone. That would be our ideal, which for sure we haven't reached yet. (Local manager 6)

### Their role in participation

In the case of district managers, they participate in all meetings of the district council. In the local councils, their presence is highly appreciated, however they are not always able to be present neither it is always necessary. The local manager represents the district one in the meetings of the local council. However, the presence of the district manager in the meetings of the local council is highly acknowledged and valued. The district management must be represented in the municipal council as well.

The understanding of the manager's role is that he/she must foster the participation, both from the workers and the users. Local managers also mentioned other roles, such as mediator of interactions and conflicts between the segments, of mediator between the community and the higher instances of management, of supplier of information about the service in the health care centers, and strengthening the link between community and team.

Concerning the local managers, some participate in other movements besides the health council. For instance, Local manager 1 mentioned her participation in the movement for the health of the Afro-Brazilian population.

### Difficulties for the participation

It called our attention that everybody mentioned the small number of people who participate actively. When all is said and done, participation means the presence of a few counselors who do not represent the community as a whole. A generalized lack of motivation was evident. People are motivated by specific agendas, as the lack of physicians or nurses in the health care center and lack of medication that affect them directly, which represent a real need. Another reason for the poor interest by the users is the lack of information. The team lacks motivation as well (and also is not mobilized for that) with the insufficient participation of the users, sometimes even with an intense effort of dissemination work in the community (leaflets, banners, oral communication).

When they have a particular need, they come to the health care service, they look for the staff they need. When there is no physician, when there is no medication (available), when there are no nurses, when we don't have the appointment they want... Some even lack the will to come here because they think that it's not going to serve any purpose, or

they don't know. I think that, besides the lack of interest, there is lack of knowledge, lack of information (about) this movement, of its importance, of its power... In my view, these are the two major aspects (that make participation difficult). (Local manager 2)

We often observe the search for the resolution of one's particular problem - "my appointment, my specialist, my exam" – and our difficulty to understand it in the sense of aggregating the service, strengthening the community. Strengthening the need that the community needs a park where children can play, that it needs to mobilize itself to have a community center, so that we can develop collective activities. (Local manager 4)

One of the reasons for the low level of motivation was the passiveness of people after they have already achieved what they needed. In one of the studied regions, the grassroots participation used to be quite strong and they had several achievements, but later it decreased, as if there were no other causes to fight for. There is also a perception that the neediest people are those who are the most participative ones, as they are those who have more needs.

I believe that, along the time, people having services at their disposal - "Oh, I already have this; I don't have much to fight for". It seems to me that when you don't have something, when you have a need, you are more motivated to search for that. (District manager 1).

The lack of motivation to participate in social control, particularly by the youngsters, and the lack of an effort specifically aimed towards this group, with compelling actions for this population group, was specially highlighted. The managers emphasized that there is little renovation; it is always the same leadership and there is the perception that the sphere of participation is becoming void.

We are not bringing them (the youngsters) along. In fact, we don't work with them; we don't have experience in the health care services, not that I recall, that brought this public closer. We still emphasize the hypertensive patient, the diabetic patient, on the disease. And the younger public, here in our region, due to violence issues, drug addiction... Our service would have to be attentive to and coming closer, bringing these youngsters and thinking about offering group discussions, workshops. So, it is a series of questions that ends up discouraging. I'd like to attract these youngsters, who I don't bring closer in any other way that would be more attractive for them, and I want that they come to a meeting, that they go there and don't understand lot of what they are saying. They come to one meeting, they don't come to the next one... (District manager 1)

I think that the sphere of participation of the user is becoming void. There are few users who participate, and the users who do it are those who already participate in social movements for some years and that have been walking this path in decades of activism. What I observe is that the youngsters don't have any insertion in these spheres that much. (...) Thus, we are frustrated and have a feeling that things aren't moving forward, because it's always the same two, three, four people who are present in the meeting. (Local manager 1)

Besides youngsters' poor participation, it seems that even the older leaderships lack motivation due to the lack of responses and results.

The older (leadership) have also made this sphere void. There aren't many who continue in this sphere of discussion because they see that there are no changes, that their participation has not generate change, has not resulted in whatever they want for their community, their family or for themselves. Thus, I think that they have left these scopes for not seeing any developments. (Local manager 1)

The lack of belief in the power of the people, or that people do not know the power that they have, has also been mentioned.

There is a certain discouragement, a lack of motivation due to a thought by the citizens that they aren't going to be able to change a lot of things. "Well, I'm not going there because it's not going to change; I'm not able to do it". There is this thinking still, that they don't have the power or that they don't know the power that they really have. (Local manager 3)

The problem of insecurity and violence in the territories is one of the difficulties for participation in the council meetings, mainly in the evening, driving away the youngsters and those from teaching institutions (students, residents, teachers, preceptors). Another difficulty is the time of the meetings. When they happen during the working hours, those who work cannot participate. But even when the meetings are developed in noncommercial hours, like in the evening, the participation does not use to be much bigger (due to violence concerns, other duties, not being registered as extra working hours etc.).

The workers, who are already overloaded with their assistance tasks, do not feel motivated to take over another task without the payment of extra hours, since the present structure of human resources coordination does not allow it. Local managers, who are also workers of the health care centers, feel overloaded by the assistance activities and this lowers their motivation to be more actively involved in community activities that could foster the participation and lead to higher integration between community and team.

The local manager, who is also a worker from the health care services, feels isolated in relation to the community, missing an alliance.

As workers, we are left by ourselves in one side. We don't see the compliance of the community in the other side. Thus, it's like an overload, and then we lose the encouragement and the strength to fight for that. (Local manager 2)



The managers also perceive the users' culture and, in a general way, it is highly medicalized, in a way that there is no interest in health promotion and education, being this another reason for the low motivation.

We still have the culture of medicalization. It's too complicated to work with health prevention and promotion because there is a whole culture of the users related to medicalization. And when we speak about health, about some program or a certain health situation, to really promote (...), we observe a voiding of the space. (Local manager 1)

Inflexibility is observed in the structure, in the functioning of the councils. The councils' meetings often have a single agenda and the user ends up being "voiceless", as the debate is centered on the workers and the managers, due to their greatest mastery of the issue under discussion. The composition structure is also problematized by the participation of the population, quite often approaching unexpected subjects, showing lack of knowledge about the meeting process.

Some issues that are quite hard we address with a group, next another one comes, and it's open, you can attend and will be heard and maybe next the agenda changes. We try to keep this agenda and I offer "Look, we can debate this in another occasion; you can go to the management center." I believe that things are really difficult. (District manager 2)

Lastly, in the management structure of the Glória-Cruzeiro-Cristal district, it was mentioned the lack of a permanent (not transient, as it is presently) coordination group to support the councils with dedicated workload for this. One difficulty for this supporting coordination is the lack of more active local councils. And when this coordination exists, as in the Partenon-Lomba do Pinheiro district, it is easily worn out and demands permanent renovation, what requires more work and energy.

Another difficulty related to the councils' structure is the scheduling of the agenda in the meetings: for the district council, it is necessary a written document plus a petition signed by the inhabitants and users for the due official inclusion of the agenda and the protocol numbering.

### Participation spaces

The report of several intersectoral and decentralized participation spaces is expressed in the interviewees' utterances. Amongst them, it can be registered

other councils (elderly people, children and adolescents, social work services), forums and assemblies aimed towards indicators of health, sanitation, transportation, culture, urbanism, community associations, churches, schools, community groups, social health movement of the afro-descendent population, participatory budget (PB) and regional administrative center (RAC). Specific events, gathering people around a specific theme, are also mentioned.

I participate of leaderships in the afro-descendents movement and I'm the coordinator of the afro-descendent health committee in this region, and we have brought and involved a lot of different movements and several segments of the society in these types of discussion. (Local manager 1)

There is the social work council, there is the participatory budget, we also have here a device from the municipal government, it is the social-environmental... It's an agency of the municipal government that is working in the transferring of people because there is a re-structuring of housing here... Thus, people have been sent to other places, anyway... There is a strong social participation there too. I don't know the neighborhood association very well, but churches are an important social device. Evangelical, catholic churches, the schools. (Local manager 3)

(...) that derive from a much bigger network... and that them, in order to participate, they have to be in different places. So, we speak of several (spaces), the managing committee, we speak of participatory budget, culture, urbanism, of everything that is linked with health, it's not health separately. Thus, we have to go to the local health council meetings, district or municipal health councils, but we have other spheres of social participation that they also need to be engaged in to understand the whole. We have managing committees, Partenon (neighborhood) managing committee, Lomba (neighborhood) managing committee, where we find several departments to discuss the territory. So, it's a space where the management is always present. (District manager 2)

We have the assemblies in the places, in the communities; we also try to be always close. We have the issue of Lomba (neighborhood) community vegetable garden. (District manager 2)

There are scopes of indigenous health, of the indigenous people. When there are events, meetings of the tribal chiefs, which happen in an indigenous village here in the state, we always try to be present, at the beginning, to be seen, to see, to support... They usually tell us in advance. We have a monthly meeting with the tribal chiefs of our indigenous villages, which are three, together with the Special Department of Indigenous Health, which is the SESAI, which is at the federal level, to articulate, to see how the health issues and other ones are being dealt with, and next we think about all the health issues of the indigenous people. (District manager 2)

We don't have any strong associations here; we don't have a really existent neighborhood association, one that is participant, active. We don't have a community center, a neighborhood association in this community here. We participate of the groups, the groups' gatherings in the community... or of the community here. And the actions throughout the year fostered by us. In the past weekend we promoted an event related to the afro-descendent population, we were open an entire Saturday to welcome people, with previous booking and open demand. The service was open and we welcome the population and participated of the activities throughout the day. (Local manager 4)

Some managers recall their participation in the students' movement, markedly in their years as residents (collective and forums). The managing

committee is apparent both in an intersectoral way with different departments and as a space of teaching-service integration with the universities, which is highly appreciated by the managers.

Yes, municipal health conference, state health conference, I was a resident at Hospital Conceição and I was always included in these spaces, the *Gaucho* Collective of Health Residences, the National Forum of Health Residences. (Local manager 3)

It's a space in which we, as management, are always present. We have PUC (university) managing committee, which is very much concerned with teaching and research, and the exchanges that we make and the issue of the territory with PUC teaching and research, and of which the social control participates. I think it's quite important, we have guaranteed the seat of counselor of Partenon and one of Lomba to have a seat at PUC managing committee, for instance, to understand what teaching and research are, and how they are included in the territory. Anyway, so that they can understand the whole issue. (District manager 2)

In the year of the data collection for this research (2015), there was a health conference and, in the city of Porto Alegre, district conferences also occurred, under the responsibility of the district managements and councils.

### Potentialities of the participation

The valuing of the counselors' role by the managers strengthens the performance of the Municipal Health Council (considered as active, present, knowing its function), which is highlighted due to bringing the Municipal Health Department closer to the population and their demands, which must follow a local flow of approval to be taken later to the central level.

We have a very active, very present municipal council, with a good understanding of its function. And it supports the managements a lot in relation to that and quite often it comes to the district council to support, to help. (District manager 2)

We don't take these more important issues forward without approval of the local council. And this is clearly an appreciation of the management, which is an appreciation of the municipal department, which demands us to have the council minutes approving a specific situation. (District manager 2)

The management acknowledges the importance of the users in the claims:

It's essential because we can channel their energy to search for positive things, because I think that we represent the manager, but overall sometimes we are overloaded by needs that the team doesn't reach, the team's hands are tied for a situation when it cannot acquire, cannot move forward, in relation to the administrative sector, to the supplies sector, and I believe that the community here strengthens this. They search it with a voice that is much stronger than ours. (District manager 2)

The closeness with the territory strengthens a more communitarian perspective, of valuing of community leaderships, which must represent the

demands and needs of the community in a process of joint construction of actions, which requires preparation of the coordinator to lead, to listen, to respect the different cultures and opinions, as well as flexibility in the actions. In relation to the potentiality of the territory, it is important to highlight that the FHS favors this approach a lot, between community and health team of health, also favoring social participation.

They are heard the most in the local council; I think that due to the fact of being closer to their homes, to the family. And I think that the closer to your place, your family, your reality the discussion happens, the richer and the higher is the participation. (Local manager 1)

I believe that it's quite a strong facilitator, you are quite close to the community, you have a limited territory that is easier for you to know, to know the details of the hardest access, the family with higher vulnerability. If you think about providing health knowing the community within this context, you are able to open the doors more widely to the community to come to the team and search for the service and to participate. (District manager 2)

We had our pre-conference, we started to disseminate and speak about it months before... and to organize it, because the pre-conference, as it is related to the region, it was conducted by us. It's from it that they bring the first lines and we have been working in this for a long time with them. They participate from the beginning on. How we are going to organize it, how it is going to be, how the axes will be discussed, how we are going to organize the groups, we have always included them in the organization. It's not anything that just appears, that we make it and then we tell them "You have to be there in such a date". No, not at all, we made a point to gather them together with us. (District manager 2)

One of the district managers highlights the importance of the management having an open space for the user:

They have an open space with us; they have this quite open relationship. We have this opening with them, thus they don't need to keep the claim or the demand to be made to the councils. They have a space for debate and construction and it's quite hard sometimes, and some are harder than others... Because sometimes it's distorted... We are in a construction process... In a while things go this way and we need to bring them back... And those who are there need to understand this. Those who are coordinating the council need to understand this. (District manager 2)

The work is more effective in places with a tradition of fights, claiming and militancy, which generates a virtuous cycle in which the more you demand, the more you are remembered and, therefore, taken care of. Specific agendas and situations, with specific interest, however, as already mentioned, foster higher participation.

As the management, we see that where there is an active council, the requests, the claiming are more addressed, they are more remembered. (District manager 1)

In this period we had a great participation of users, because there was a shortage of providers in the health team, and the community lacked them a lot. So, we had more than

30 people participating in the local council meetings and it was quite interesting. But then we observe that when something that they need a lot, specific issues, is missing, they flock... However, when you come and speak about a meeting, for instance, of the local council, the district council, that you are going to speak about a health issue... they don't attend. (Local manager 1)

I think that Lomba (neighborhood) is a little more articulated, due to all the previous social movements. I believe that due to the fact that the people who presently live in Lomba, for the longest time, for all having a long time of conquests, for having moved there, for having taken some land and having constructed the community. (District manager 2)

The potential of the population mobilization is appreciated:

In my experience in (...), which is a health care service close by, there was a community there where they didn't want to participate, they didn't belong to the district area of the service, and they attended to the district council meeting and requested to participate and they were able to. It was a group of people, at least a thousand people who, added to a health care service, thanks to their mobilization, and they didn't know that they could, they would like to, but they didn't know. Then we told them, "Look, these are the steps, you have to request." (Local manager 3)

Social control, in the managers' view, is characterized as a privileged sphere of information source (and power?), listening, integration of the actions developed in the community, where one can know their rights, having the power to decide (voting) and developing the co-responsabilization in the construction of public policies.

Because it's within the councils that we can also hear about things that we don't hear about inside the health care service, including the social work of some community leaderships accomplished here in the region. We know about them in the council meetings. This communication that we have within the council, with the movements, is quite interesting. It's super valid for us; it doesn't matter if we have only two, three people... We always leave the meeting with some new thing. We always leave with a new qualification, which enriches... And us, as workers, if we know about the existence of that movement, we also have the role of sensitize the people that come to the service later, because we welcome everybody every day. Thus, welcoming is not only taking care of, medicalizing, it is also advising, advising that there is a community leadership, advising that there is a movement in the community, advising that there is social work in the community. (Local manager 1)

The protagonism of groups for assistance and health education, especially for the elderly, is highlighted, and they become stronger and opinion makers. Similarly, the importance of the participation of higher education institutions (with their trainees and residents) is highlighted.

There is a group, *Hiperdia*, which is a group of elderly people since we started the service, since this team started to work here in 2011. And it was formed and strengthened and nowadays this group of elderly people participates of all the actions promoted by us in the service, but they participate as opinion makers, as the community within the service. They develop activities for the community that result from the actions. They are invited to participate of activities organized by the district management. They are invited to

participate with their activities. They had the idea that they needed to be more active in health education issues, they decided to organize walks in the community to speak about hypertension and diabetes, about care, and to distribute the seasoned salt recipe that the group prepares in the actions where they participate. So, I believe that this is to be active. It's having the proper health care. I am able to know, I must know and I can disseminate the information. Thus, I think that they are the best example. (District manager 2)

We bring the coordinators, the providers, the residents, the trainees (to the preconference), then the entire academic issues also, they being together in the organization. They are people who are going to foster in the care point, either in the services, either in the residents, either with PUC (university). (District manager 2)

### Health councils' representativeness

The fragility of the representativeness in face of the established structure in relation to the role of the users is remarkable. All the interviewees, at some moment, highlight the small number of involved people, mainly in the meetings, characterizing this factor as a limitation for an adequate representation.

It's always the same two, three, four people attending to the meeting. (Local manager 1)

Clearly, had we had a bigger participation, this representation would be a little higher (District manager 1)

I think that the difficulty is for us to bring others to gather to them. (District manager 2)

Yes, I see this, unfortunately, even by the way that the council was formed. It took a long time and it was formed this way, but it's almost as if we had said "Please, for the love of God, be a candidate to be a representative at the council, so that have the council formed." Thus, the two current ones, who are the heads of the council, we can see that they are not familiar with the process, they don't know a lot, perhaps are not even interested. Every time they come they ask "When is the next meeting?" We had a full time schedule of meetings, but they don't even know the dates of these meetings. Since the past three or four meetings that we had, since it was formed, we were never able to establish an agenda for the next meeting because there was no quorum, so there was no agenda... (Local manager 2)

Even though the structure includes one coordinator, one worker and two users in the local council group, all the interviewees point out the fragility of the representation, particularly the users', in such a restrict group. The user is not considered as a legitimate speaker for the segment, as a council member, for the interests of the community.

The local council is a place where we can explain how our service is, why some provider (a physician) is missing, the appointments, the demands etc. But speaking about this to two users, this is not representative. It isn't, because there are four areas and the two council members are from the same area. And I even don't know if they do everything within their area. (Local manager 2)

It's always the worker who coordinates the meeting. They are two users, they don't coordinate the meeting, they don't bring the agenda, and it's very discouraging and bad. (Local manager 2)

Here, we, as management, administration, we know each local council and we know how each of them works. Thus, we know if they are really being represented by the community or not. (District manager 2)

The search for the local council is not reduced to one person only. Because quite often one person may not represent a whole community. (District manager 2)

We sense that basically it is a struggle of the council members; you don't have participation from the community as user. (Local manager 5)

The situation of having secondary interests to the role as a representative for a segment, either for personal or political questions, was also mentioned.

I don't see political ambitions, things like this, to leverage the political career, for instance. I believe that those who are in the social control of this locality really want to see the best for the community, for the health service, yes. This is my initial impression, but based on what I hear. I haven't participated in any meeting yet. (Local manager 3)

Advantages that we have: the partnership with them and the joint debate. And when I say "them", it's really the council members, the people who are officially the council members, and that the person who is there often has other, major interests or has an influence in the community in another way, and this exists indeed. And this is why we use to call more people, so that it's not one person representing the whole community. (District manager 2)

So, we know that (political interests) are also in the way and that we always try to differentiate and to distance (ourselves). Anything that we need, we always invite them to have the meeting here, so that it's official, so that it's an official council space, of management, and not a meeting there, of the councilman in the community. Well, he can be present, he can, the space is open, but we try to make it more according to the councils' guidelines. If we are going to speak about health, then we don't speak about it there, with counselor John Doe. [...] So, it's a work of ours, because we know that this happens at some moments, and then, well, the person represents other interests, not necessarily the community's. (District manager 2)

The need to renew the list of representatives, both in terms of age and other characteristics, is a relevant issue.

We have a community with several sub-groups, with distinct vulnerabilities, desires, needs. We have most vulnerable people, the less vulnerable ones... thus, several people can be, and that each one has their small territory represented at that moment. (District manager 2)

A great part of the youngsters, for instance, the ones from the community, I am young and a worker, but the youngsters of our community don't participate and I miss that a lot, of having young people representing in these spaces. (Local manager 1)

All these questions demonstrate the weakening of the community spirit, so characteristic of present times. Thus, the poor cohesion in the community weakens its representation in the councils.

## Strategies to strengthen participation

According to the managers, courses and qualification on social control can improve the participation; however, this happens only in a transitory form. Moreover, the observation of the seasonal participation is a factor that intrigues and mobilizes the managers.

We have been working on this a lot, we attended to the two courses, one at the end of last year, one this year, one in each territory... and it improves a little, and next it decreases again. (District manager 2)

The strengthening of the local and district spaces seems to be an endless dilemma, a critical node, that is under debate in different settings within the management and academy spheres. Having a specific group of coordination to support the local councils was mentioned as a strategy, as well as the presence of institutional supporters, who could become more involved in this function.

We already have a basic problem in the district council, that is who should mainly support the local councils. Thus, here we already have a transient coordination for some time. They are providers who are available to come here to coordinate this district council, and we have already tried some times and it doesn't move forward, in order to have an election, to have a coordination, not transient anymore, to be really thinking, having part of their working hours, for instance, to dedicate to the council. Because there the workers will be, the users will be and so will the management. It's this group, I believe, that needs to support the local councils, not the management. (District manager 1)

The manager is overloaded for being in the most different spaces. Just like the workers, they use working hours for this activity. The user, however, needs to work and to attend as well. Changes in the schedule of the meetings, as well as in venues, however, didn't seem to be effective to enhance the participation.

We tried to be as flexible as possible; we had it in different hours of the day, in different days. We had meetings during working hours, it didn't work, they said "Oh, let's come in the evening," it's too complicated. "We are afraid, it's late..., let's make it during the day", it didn't work... We changed the venue, instead of having it in the health service, we had it in the RAC, in order to see if we would have a higher commitment, and it didn't work either. Next we had it in another time of the day [...] we promoted it at 6 PM, it didn't work. "Oh, let's make it at 5:30 PM, when people have already left their jobs and come straight to the meeting," it didn't work either. And then we kept the schedule. (Local manager 2)

We changed our local council hours following the community request and, even so, we don't have such a great participation... But we are trying to adjust it in the best way to improve the users' participation. Maybe having the local council working during the weekend, but even so we are not sure that it will work out. (Local manager 1)

In relation to the workers, they need an appeal to participate, like the compensation of working hours.



We know that most of the workers don't come voluntarily to these spaces; there must be something in exchange. Thus, it's up to the manager to think how this should be done, if it's going to generate an hour bank, if it's going to generate overtime. (Local manager 1)

The teams are not motivated to participate, being necessary a constant work, including in the team meetings, having been highlighted the role of the service manager.

I think that the teams could be a little more committed. [...] just like the community misses incentive, the team lacks incentive as well, and it's necessary to have a constant effort of stimulation, we can work on that in team meetings. (Local manager 3)

I think that we need to have greater dissemination; if we want the community to participate more, to be more engaged, I must motivate my team. I have to motivate my team so that they motivate the community. To motivate my team, I have to learn as manager, I have to show them the data. I have to show "Look, this is what is making the difference." "We need to increase the number of appointments, the number of tests collection," "We need to identify more people with tuberculosis." (Local manager 3)

The closeness with the community is also understood by the managers as necessary to strengthen the participation. A proactive attitude from the management could facilitate this closeness.

We see some spaces to which we were not invited, we articulate "Well, why aren't we in this space?", "Why weren't we invited?"; we would like to participate. There is also this issue of us being able to be proactive at some moments, "Why we have not been proactive, why health or management has not been thought (in that space)?" (District manager 2)

The social interaction, the team with the community, it's not only at that work moment... as Mehry says, "Not in the hard work, but in the light technology", of the interaction, I think it's important. (Local manager 3)

The investment has been great in dissemination actions, with information on the relevance of the meetings, constantly recollecting the council's objectives, both with the team and the population. Often it is in a written form (posters, fliers, social networks) and direct contact in the service and in the streets, especially by the community health workers. Yet, the managements made an effort to visit the local councils to stimulate the participation in the district councils.

We are part of social networks; we invite them through social networks. [...] We have a Facebook page of health service, we invite them there, and we post invitations in other services, in the Facebook pages of other services. Community health workers are the ones who disseminate the meetings in the community. We invite the users to participate in the meetings at the reception desk, as well as in the clinical offices. We also make informative posters available. (Local manager 1)

I think that there must be a greater dissemination in the community, through the community health workers, through events... I am very much in favor of promoting "Christmas", "pink October", "blue November", the "women's month" in March, Children's

Day... and to announce at the service not only clinical events, but social ones as well. After all, the service is also a social device. (Local manager 3)

However, these strategies have not been effective, and, even so, the managers mention that it would be important to strengthen even more the dissemination, including the results of some actions that sometimes are not made public.

We used to promote joint efforts; we used to produce fliers, posters. We used to place posters in different places, strategic points of the territory, commercial stores. Everybody who came to the service for an appointment, for a procedure, we advised them, we spoke about it. Some patients always come to the service, we know several of them, we used to tell them, to invite them, creating a huge expectation, and then, in the very day of the meeting, no one attended. (Local manager 2)

We visited all local councils, the council members and us, to explain, to encourage them to come to the district council meeting... What is the goal, we need to organize the plenary, there is an election for the new coordination... to accomplish this jointly. (District manager 2)

From the moment when perhaps we could widen this dissemination, and from the moment when perhaps the results dissemination would be wider, I think that this would encourage, because it's something that works. Sometimes these results are not well disseminated. I think that perhaps this would be a way to encourage the user to attend. (Local manager 5)

The forums and assemblies seem to have bigger attendance than the council meetings, probably due to the structure (in the evening, specific agenda, regularity in accordance with demands) and for being a call organized by the community itself.

When they need the assembly, and this happens sometimes, the community says "We want to have an assembly to catch more users, because they don't attend to the local council." "Ok, the coordination organizes it, you tell me..." I try to be present... The assembly is at 7 PM in the health service and we mobilize the community to discuss such and such. For instance, because "Oh, no one is attending to the local council and we need to discuss with the wider community," with a higher number of people, and we support them, we go there. The coordination is together with the worker so that we can discuss with the community. (District manager 2)

The methodology of the council meetings seems not to favor the participation. The agenda is planned to bring knowledge to the users, that it is not only appointments that make a health service, but planning, promotion, administration and management as well - but these are not that attractive. We speak about showing data and indicators, of joint construction and not only forming a place for answers concerning the demands, which, however, are valued as well.

We call them to say "Today we are going to speak about what is the e-SUS," for instance. "We are going to work today on how the schedules are made in the health service and the services that we offer here." We induce an agenda, we do this, but we still bump into this issue of (poor) participation, of lack of interest. (Local manager 1)

Capacity building was mentioned, but no active methodological strategies were mentioned to potentialize the process. Also, the intersectoral participation of education and the importance of coming close to the youngsters are highlighted.

Each management had two, three people who were attending to the course; it was a few month-long course. The meeting was Friday and Saturday. So, it was a monthly meeting to think about social control in the city, to think about strategies to fix more and having higher participation. The course was for one manager, for one worker, for two users of each region. It was a course that was not only for the management, it was a wide course. (District manager 2)

This is why I ask, "How are the universities, how are the schools, how are the residence programs developing this?" Because it was there where we began to study, to debate and it was there that we started, that yes, I needed to become more involved to be able to contribute. (District manager 1)

The youngsters, how is it developed in the schools? How do the universities as well... because it seems to me that it is in these spaces that we have to work the citizenship. I don't know if the curricula contain a question in this direction, because we really see a distance. And perhaps we have to ask to the young people, ask to this profile, to this audience. (District manager 1)

For 2016, the strategy will be different. We intend to sensitize the adolescents and children a lot to sensitize their families and making this invitation. It's a possibility... make this invitation to participate of the meetings. (Local manager 1)

#### 4.3. *The users perspective*

##### Perception on social participation in the health sphere

In general, the users indicate to be unaware of the importance of social participation in the existing formal spaces or they do not believe in the importance of participation. Their statements express such lack of knowledge and disbelief:

I have no idea. (User 2, Divisa)

It's negligible in the council. (User 1, Divisa)

There are several reasons for the lack of participation – self-indulgence, disbelief, lack of interest, lack of commitment, among others - but also all kinds of difficulty, over all lack of time:

(...) I don't understand these things very well (...); I don't want to know, to look for. (User 2, Divisa)

[People] are afraid of the involvement, of the responsibility. (...) They have their chores, they arrive at home and they don't want to leave anymore. (User 2, Glória)

[I don't participate] because I was always working, since I had my daughter, I was always working and studying, trying to run after the wasted time. (User 1, Lomba do Pinheiro)

The hours are not appropriate. (User 1, Divisa)

(...) We have to inform people that we have that to do it for ourselves, that it's not a matter of waiting until the public power does anything. (User 1, Santa Tereza)

This last user questions how the health councils are organized in other places and who participate: "(...) Who attends to the district council? Most are students and people who work in the health sector... I see very few people there" (User 1, Santa Tereza). She also mentions that perhaps he should make a tour in other councils to see how it is, because "it doesn't work here; this is a one-person only council, one user only (...) the council belongs to the workers, not to the population" (User 1, Santa Tereza).

### Understanding of concepts of health for all, universal care and equity

In general, the users are unaware of these strategies and their effects:

I never heard of that. (User 1, Lomba do Pinheiro)

Look, the acronyms, names are quite pretty (...), but I like the effect, the result, the answer. (User 2, Glória)

I think that "health for all" is everybody having health. (User 1, Lomba do Pinheiro)

(...) this is something that we would like to have, but it's idealized, a way of masking another thing. (User 1, Santa Tereza)

However, when speaking on them, they associate these strategies to the access of services and health providers available in the territories where they live. In this sense, on one hand they criticize the scarcity or the quality of the services provided - "(...) I think that we need more, we need more (...), [as] some doctors give up and allow people to die seating" (User 1, Lomba do Pinheiro) -, but they also acknowledge that the health services provision improved a lot thanks to the creation of SUS - "(...) SUS is a conquest, it has precariousness (...) [but] imagine if we didn't have it (...)" (User 2, Morro da Cruz) - and, more recently, to the Family Health Strategy - "(...) I feel that it's improving, (...) the family doctor is having

better results and care has improved (...) and he is seeing everybody. (...) I feel that the family doctor requests the tests when they are ready, you already come back, in a shorter time” (User 2, Glória). They also highlight the fact that people are using more the services for being mandatory in relation to Family Allowance, for instance, which compels the users to have a vaccination chart, for example.

In this sense, a user defines Health for All in a very particular way: “It's SUS that is for all, [as] it doesn't matter if the person has money or not, if he/she is rich” (User 1, Morro da Cruz).

And only one user among the 17 participants defines what he understands as “universal”: “It includes everything, all religions, races, everything (...) without any discrimination at all” (User 2, Santo Alfredo).

Concerning equity, a user defines it as what “(...) everybody receives equally” (User 1, Divisa), even though alerting that it's not easy to get in the health services, since it is not possible to care for everybody equally.

The users criticized many aspects in general, regarding the lack of quality of the health services provided. Some report the long waiting time (over a year) for a medical appointment with a specialist, others report the precariousness of the health services (without the necessary equipment for examinations, inexistence of drugs or problems in the physical structure) and the problems referring to contemporary life (robberies, burglary, thefts, attempts of aggression, stealing, destruction of health providers' cars, among others).

### Difficulty to participate

Among the difficulties mentioned by the users leading to the lack of participation in the activities proposed by the Health Council, these are some:

- the lack of previous dissemination of the activities: “(...) we are not even told, (...) we don't even know” (User 1, Santo Alfredo);
- the schedules offered (considering that several people work);
- Fatigue (after a day of work, people want to stay at home watching TV), as “a lot of people like me would like to participate more, but I cannot,

because unfortunately we are a slave of the system that we have. Either we strive, work and pay the bills or..." (User 2, Lomba do Pinheiro);

- security issues (hours and places where one cannot go in certain hours of the day or the night);
- cultural issues (so they are not involved in demands that will require commitment/responsibility, for self-indulgence and not desiring to become involved with issues that are not of their own interest): "(...) that's why I didn't want to be a council member, because at the moment when you are committed you can't fail, that commitment is scheduled, that day you have to be present." User 2, Glória;
- Low participation of people ("a meeting with three, four people is not a meeting for me." User 1, Morro da Cruz);
- Lack of knowledge and the disbelief related to the Health Council and the health policies - "(...) they don't believe in anything anymore" (User 1, Morro da Cruz); "(...) it's no help saying 'look what happens;' if they steal, they do whatever they want and nothing happens." (User 2, Glória);
- Lack of physical space for the meetings.

Several users mention that the motivation to participate is directly related to the access to information. They mention the importance of the team encouraging the participation of users - "to make something to call the attention" (User 1, Santa Tereza) - and disseminate ahead of time what will happen, when the meetings will be held and which agenda will be discussed. After all, as one person says: "(...) there are a lot of unwary people like me." (User 2, Lomba do Pinheiro).

Another user mentions that it is necessary "to distribute something for free" (User 2, Morro da Cruz) so that people feel motivated to participate, as, according to him:

It is amazing how health, which is for the sake of everybody, does not raise interest, because they think that it's an obligation that everything must function well. And this is not exactly like this, as things function well if we show interest for them. (User 2, Morro da Cruz)

Another user mentions that his motivation to participate is the will to transform, to change:

(...) if I am able, during my trajectory here, to change one or two people, I'll be pretty happy in life. (...) This will of wanting to change something, making the difference within this group of people. (User 1, Santa Tereza)

When asked if they participate of the Health Council, some reply that they don't, as:

Nobody ever went there to invite us, you get it? (User 1, Lomba do Pinheiro)

I didn't know that there was somebody who could guide me in the neighborhood, an association, I didn't know anything. (User 1, Glória)

The community is not that participative in health councils, but when required by the Neighborhood Association or the Participatory Budget, people are present.

Although some are quite active and report that they act in a systematic way in the neighborhood where they live, others, as it seems, are unaware of their rights, who are the health council members and the possible mechanisms for the maintenance of what is foreseen in the legislation of SUS:

(...) I asked who the president was and he was seating right at my side. So, I don't know him. (User 4, Glória)

(...) When they invited me to be a council member of the service here, I didn't even know that the local health council existed. (User 2, Morro da Cruz)

(...) The only thing that works here is the association ... either it [name], who is the President, or me, the vice-president. (User 1, Santa Tereza)

But stopping me in the street to say things, that they do, to know why there is no medication and why we didn't do anything... but doing what? There isn't much to do... (User 1, Morro da Cruz)

(...) One person said: "Well, if you don't look for your interests, do you believe that the city government will look for what to do for you?" (User 2, Morro da Cruz)

(...) I only observed from a distance, because I didn't understand anything. (...) Because I don't understand these things very well (...), I don't want to know, to look for. (User 2, Divisa)

I didn't really care for this subject. I never fought for my rights, of wanting to know what I have or don't have. (User 2, Santa Tereza)

### Participation spaces

In spite of the difficulty to participate in the councils, most of the interviewees participate in an active way in associations or councils, such as: Regional Social Work Council, Municipal Environmental Urban Development Council, Unemployed Workers Movement, Participatory Budget, Local/District Health Councils, neighborhood associations and others.

## Strategies to strengthen participation

In general, the users indicate that participation is essential for reaching the desired improvements. When asked if it is worthy to invest in social participation, the answers are always positive (sure, certainly, yes):

Certainly, because if the other ones don't fight, I'm going to fight for those who don't want to [fight]. (User 1, Morro da Cruz)

I don't think it is worthy, for me it's necessary, it's essential. Because when you don't know how to claim for your right, you don't have that right, isn't it? You have to require your rights; if you don't, you don't have rights. (User 2, Glória)

Participation will benefit each one and all. (User 1, Divisa)

According to this logic, following the effective "discursive order", all repeat, without questioning, that everybody should participate, despite the fact that, personally, each one has their own reasons to not participate actively:

I believe that the more people participate, (...) the easier it will be to improve the issues that need to be improved. (...) I was always busy, but I think that [people] should be interested in social matters of the neighborhood. (User 2, Lomba do Pinheiro)

I would like to understand why the inhabitants don't attend to the councils, why they are not interested in it. (User 3, Glória)

It's... the problem is the (lack of) attendance of the users in the meetings. (User 1, Divisa)

Among the strategies to strengthen participation, several suggestions were made:

- creating mechanisms of pressure within the community so that people participate - "we have to close the general service, even though this costs us something, so that the population feel it" (User 1, Santa Tereza);
- talking with people ("word of mouth", User 2, Glória), informing/ distributing fliers, requesting them to commit;
- calling the community;
- accomplishing meetings;
- strengthening participation, disseminating more what is already being done;
- having more physicians and more drugs;



- researching to know what people need;
- going to the streets, "being outside" (User 1, Santa Tereza), reaching the people;
- demanding more from the people - "I think that the work is a little weak (...), I believe that we could demand much more" (User 2, Glória);
- Bringing the new generations on.

However, at the same time that they indicate some strategies, they doubt of their own power:

Well, I don't know if it's worth doing what we do here sometimes. We fix lunch, dinner, we collect food, we give it to the people, we donate cloths, we speak with the people, but so far nothing has changed. (User 1, Santa Tereza)

(...) Then I say, "Oh, my! What are we going to do? If you don't want to come, don't come. (...) The dates of the meetings are made public, [but] it's useless to run [after the people], because it seems that they are doing this for obligation. [After all], people need to be interested in things, isn't it? (User 2, Morro da Cruz)

(...) we already used fliers, we walked, [but] very few people joined us. (...) I wouldn't like to act like the politicians, fixing a meal, a coffee, because then there wouldn't be enough room for everybody. (User 2, Glória)

#### *4.4. The workers' perspective*

##### Perception of the workers on social participation in health issues

Even though it is a limited reading of social participation, the interviewed workers use to identify it as social control, a space in SUS.

Worker 1, a nursing technician, understands that her performance is committed to SUS and recognizes that the City Health Council of Health of Porto Alegre is quite an active council. She understands that it is about a process in evolution that happens step by step, and believes a lot in this partnership finding the participation of councils, users, workers and managers very important.

[...] Considering that I'm a member of the District Health Council, I represent the District Council in the City Council, and I'm quite a diligent worker in the meetings, because I don't like to lose the focus of the subjects, so to speak. I like to be always updated on the subjects, so what I observe is that the City Health Council of Porto Alegre has had a wholehearted performance concerning the strengthening and the empowerment of the health councils in Porto Alegre. (Worker 1)

The community health workers (CHW) are strategic workers in the construction of the bond with the families and the community. Worker 4, the CHW, understands social participation in a way related with her tasks and a different inclusiveness from the other respondents:

[...] I think that social participation is the community, everybody participating, being part of a system, just like our health service, where people come to look for care, but also could participate in other ways: participating in the local council, bringing their claiming and demanding, asking for other things as well, passing things that can be improved to us, solving their doubts, I believe it's this. (Worker 4)

For the CHW, the community participation was decisive for the construction of the health system where she works:

[...] This service of ours is the first one of the (Family Health) Strategy. We are here for 20 years. [...] I didn't participate in these movements of the community. My coworkers told us about the fight, there are pictures, things that happened and we heard about, through the community [...]. Here in the service there was social participation indeed; the community presidents gathered [...] there was a demonstration of the community, there was a strong fight and they had achieved the health service here. (Worker 4)

Worker 5, a nursing technician, understands that her daily work is social participation in search of health promotion:

[...] I think that social participation is when you participate actively in programs that already exist in the service, talks, our routine here as employees, this is participation too, isn't it? (Worker 5)

[...] We promote groups in the service, like family planning, in which we teach methods of TSD prevention, contraceptive methods, the ones that are available in SUS. The street group, which we haven't been able to organize lately because our team is a little depleted, going to the streets and invite people to come to the service and listen to their needs and, according to the need, trying to direct into some program that we have here in the service. I believe that this is social participation, as a professional and as a person as well. (Worker 5)

Worker 6 was a resident in the same service where he was hired as a physician, thus totalizing seven years of work as a family doctor. He understands, also, his own work as social participation:

[...] Well, as a family doctor by trade, this is an inherent, integral and active part of my work process. Thus, one of the most remarkable differences of my field of work is the insertion in the territory, is to understand the context of the population, and to understand that territory and territorialization are not a geographic space only; indeed, it is social, political, of relations, where we are going to see a vast range of vulnerabilities. So, in our territory we have areas with a reasonably good quality of life and areas of complete misery, including invaded areas, green areas, upon which we need to have this special look. Since the beginning of the year, we receive medicine students from the university,

and the difference that I ask them is this, to participate in home visits, to be closer to the community health worker and understand the distance that we have from theory, that we learn in the academy, with the reality where our patient is. [...] So, social control and social participation are basic, so that the population is an integral part of this process and not passive, they have an active performance in the process. (Worker 6)

### Workers' understanding of health for all, universal care and equity concepts

In general, the workers, when defining what they understand as “Health for All”, include the concepts of universal care and equity. One of the interviewees, a nursing technician (worker 1), remembered the Alma Ata conference: “in that health promotion meeting, which was “health for all in 2000” and this didn't happen in 2000 and we are in 2015 and it's a goal yet, we are running after it”.

The notion of social determination of health appears clearly in the contribution of another interviewed nursing technician:

[...] This way, for all, is the whole education also, in health, teaching people to prevent diseases. I hear colleagues saying that (in area 4) there isn't even sanitation, it's open air sewage, this is health too, isn't it? (Worker 3)

For the community health worker, “Health for All” is defined with the concepts of universal care and equity, which sometimes are mixed:

[...] I believe that it is for all, just like equity, for everyone, treating everybody the same way, with respect and as a right of all. I think that health is a right of all, no matter the situation or condition, color, religion, it's for everybody, it's universal. I believe this is it. It's everybody having access, no matter the social class. Everybody having the right to access, but in accordance with the necessity, priority, but that the access is for all. [...] I think that it would be this, creating programs for target publics. I think that this would be “health for all”, isn't it? Everybody having access and able to receive care. (Worker 4)

Even though people know these concepts, there seems to be a lack of reflection on them, as the nursing technician number 5 illustrates:

[...] We practice this here every day, but we never stopped to think what “health for all” is, what “social participation in health” is. I believe that we do everything automatically and we don't stop to think and not even question what our work is. (Worker 5)

The doctor says what he understands on the goal of “Health for All”, of his implication and his ethical commitment:

[...] It's what motivates my professional life, otherwise I wouldn't be here, I had several opportunities, but this is what I believe, so this is where I stay. Besides, as a training

service, this also encourages me, because it's the participation of new people who are entering into the work market, even if they are not going to work in primary care, but they are going to work in health, not necessarily in SUS, it can be private or health insurance, they are also acquiring experience. [...] Then, "health for all", I think that it is each one of these providers who are here, because I work in a team that believes in this. Each one of those who are there believes in this. And they try to donate the most of themselves for that, thus I believe that this is what motivates us to have hope.

### Difficulty to participate

One difficulty for a bigger and more effective social participation that was unanimously mentioned by the workers was the small number of users attending to the local councils meetings.

Worker 1 speaks about the difficulty for a higher effectiveness of the local councils and identifies the lack of users as a weakness.

[...] what we miss here is people who compose our plenary assembly, people who aggregate, who become participants... more people from the community to participate in our meetings, this is what we miss, because the core of our local council is quite participative. (Worker 1)

She highlights too that the schedule of local council meetings favors the participation of workers of the service:

[...] Here we don't have problems with the schedule because our local council meeting happens during our working hours, it's at 2 PM, a time of the day that is quite accessible, nobody has to leave at night. What is a little more complicated is to apply for the district councils, as usually our district council meeting is in the evening. (Worker 1)

The dentist complements her perception on the real possibility to act and demand for what still is very limited, in spite of having been established as users' right. She understands that people, in the end, feel discouraged to participate.

[...] This is how I see it: just like often someone doesn't want an empowered worker, I think that the worker who participates in a meeting, who questions, is not well regarded. The worker who complains... Any empowered person creates embarrassment. They understand that the family model is good, but people don't really have the power to change. [...] I speak following my own experience, saying that things don't work, disagreeing. Thus, I believe that the population is the one who has the capacity to change things, but they are discouraged. Then, you have the council, but they say to the council that it doesn't solve anything, and then this takes the incentive from them. I think that this is why the councils are frustrated. (Worker 2)

Worker 3, a nursing technician, reflects on the difficulty of training of the service local council:

[...] But we were not really able to complete our local council yet because they didn't have any candidates. There were candidates and when we explain which is the function, that they have to participate in the meetings, there are monthly meetings, there are local and municipal council meetings, this team with all the other agencies, people give up. People give up either because it takes too much time or because the meeting is in the evening. They end up not participating. But now we'll be able to complete the group, we already have two candidates. [...] We'll go to the streets, we'll speak in the groups here, and we have groups with a lot of patients. We disseminate and raise their interest. We call them separately, those who showed interest, and explain what the local council is, and this is when some will give up [laughs] and others keep coming... (Worker 3)

The nursing technician explains why she doesn't use to participate in the health councils:

[...] No, because usually they are out of the working hours and this makes it very difficult because I study every night. I work full time, from 8 AM to 5 PM, so it's impossible for me to participate of something that happens out of work. And people cannot participate because there is another detail: those who work here, those who don't live in this area, different from the community health workers (whose access is much easier), because usually these health councils, mainly the local council, they happen here in the region and the providers who are not the community health workers live outside of our area of work. Then, it's much harder for us to come here in the evening, right? (Worker 4)

Another interviewee, also a nursing technician, understands that the schedule time for the council meetings is impracticable for the users, who are, most of them, poor people who work during the day:

[...] Those who need health are poor, isn't it? And usually those who are poor need to work and the working hours of the service are the hours when these people are working. So, how can we reach these people to bring them here in order we can teach, in order we can work on health, in order they can look for help? It's us going towards them. Thus, if we had a third shift or if we created street groups to work out of the working hours of this population, I believe that we would have an effective tool to bring them to the service. (Worker 5)

This same worker relates the difficulty for a higher participation to the difficulty of access of the users to the SUS services. The waiting time, the difficult access, takes the incentive from the user to participate: "I think that the difficulty is also, and this is important, not being able to create a bond of the patient with the service that SUS mentions; everything takes too much time".

The doctor understands the situation of both the service user and worker regarding the availability of time to participate and raises the question of the lack of familiarity of their own rights:

[...] Thus, since the guy who works, we produce health for those who are not workers, because our working hours are the same of the worker, but he has the right to compensate his absence at work with the declaration of attendance... But they don't

attend anyway, for fear of retaliation, of losing their job... they lack information regarding their own rights... Myself, I don't know half of my rights, even being educated... guess them! (Worker 6)

Another problem that was raised was the violence in current days in Porto Alegre, which is also an obstacle to social participation, according to the CHW:

[...] There wasn't such a violence, it started from a short time ago on, and after that we didn't have any other meeting. [...] I, my colleague and I have already gone, we searched, we looked for all the community leaders of our territory and we invited them, but no one participated. It seems that only one person participated in the meeting, other people didn't come; we looked for the leaders, we invited them, but they didn't attend.

Several respondents mentioned the lack of motivation as a difficulty. The community health worker speaks of herself concerning the local council, in spite of the community welcoming her work:

[...] In general, I am very frustrated. Sometime ago I thought about leaving the council, because when I came to it my intention was that we could do other things to improve, but I don't see this, because I don't see the community together, and I see that nothing that could be done is being accomplished. So, we are very frustrated. I thought about leaving, but there wasn't anyone to replace me. My colleague and I decided to "stay for another couple of years to see whether our colleagues resolve and take over". Maybe someone else, with a different way of thinking is able to have new ideas.

The dentist lacks motivation concerning the workers participation in the local council and understands that this disbelief is probably an intention of managers and administrators themselves. This worker observes the lack of motivation on part of the council members and the workers related to social participation with this perspective:

[...] and I saw that, in this time, which is not that long, that increasingly more people are not motivated to participate of the council... Some because they don't understand that well which is the council function, they see it as a mere moment of complaints, not collaboration, or sometimes there are users who are quite engaged in participating, in pursuing things, but they bump into the management, or things that we organize do not work... and this leads to poor motivation. So, within these four years after my graduation, which is not such a long time, I already feel not motivated for some things. There is a time when we think like this, let's only do the basics because if we have more ideas we will be frustrated. And I believe that this happens with the users, when we see that social participation, in practice, is quite poor.

And she exemplifies:

[...] I see that, according to this perspective that I spoke about, going quite motivated to the council meeting. Let me give you an example: we received a demand, which I took to the council, of having an oral health technician, which is a category which number increased a lot in family health [strategy], that our team didn't have. I prepared the whole

explanation, a full project, took it to the local council, they agreed on how good this would be for the service. They took it to the district council - "Ok, ok... but you are not going to have it", you know? Things like this. Initially, I used to see the council as this link, this communication channel with the management. Things that the worker doesn't get, well, let's try through the council... and we are frustrated.

Concerning social participation presently, the CHW understands that the community lacks motivation. Personal interests, representing real needs, appear as specific reasons for the participation, due to specific demands.

[...] They don't participate, there is no participation of the community, and I think that previously they used to have more, they were more interested. Now, at this moment, they are not coming, we call the community, the community doesn't participate. [...] I remember, for instance, there was a time when one of our doctors was going to leave and the community was going to be left without a doctor. We called a meeting and the whole community participated, a lot of people attended to the meeting. When there is a meeting of Family Allowance, for instance, we call the community. "Hey, today somebody from Family Allowance is coming" and the community attends because they know that it's something that interests them. If they don't come, if they don't participate, they can lose it; it's a way to receive some money, an extra help, so they don't want to lose it. They liked the doctor who left a lot, so they came, but only when things like this happen, more extreme, otherwise they don't participate. (Worker 4)

The nursing technician understands that the difference between the impairs and what leads people to participate is tenuous, because the difficulty itself points to what needs to be more developed.

[...] certain selfishness also, people use to help when they see themselves in that situation and need to be helped. When they face a problem and don't have access to the service or when they have a health plan and lose it and fall into the reality of SUS. I believe that when the person faces this reality of difficulty, they end up being a little more solidary or ends up participating more of things related to health. I believe that the difficulty is this, plus time of people.

The doctor is concerned with the little involvement of people with the community, the individualism of our times and argues on the importance of education to potentialize social participation:

[...] I think that knowledge and empowerment, right? We live in a society where the less knowledge I provide to the other, the easier, he will fight less for his rights because he is not even going to know them. Nowadays, each one is seeing his own problem and the spirit of community is being lost, with some exceptions, but it's being lost. So, it's like this, "what am I going to earn with this?" is the question made and, if I don't have a straight impact in this action, I don't see much importance in involving myself, even though it may come back to me in another indirect way. This has a lot to do with education. (Worker 6)

The dentist comments that not allowing the workers to use the hours bank is a step backwards. It's a discouragement making somebody to wait one hour between the end of working hours and the time of the council meeting.

I think that small attitudes like this of not allowing the use of the hours bank, of one hour for the worker to participate of the council, is a step backwards, is a discouragement to participate in the council. And this situation goes on.

### Representativeness of the council members

Concerning the representativeness of the council members and social participation, the community health worker speaks of her commitment in the local council and about another council member, a very active leader who lives in the neighborhood, quite connected to her community:

[...] It's well represented, yes. People I know, at least, who are representatives for the community... they are well represented [...] O. is quite an active person here in the community, she has quite a good representation in her community because she, besides being here in the council, she is also a member of OP (Participatory Budget), so she makes a lot for her community, including now they already have electricity, they didn't have it... they have acquired a lot of things... she is very good.

The dentist understands the representation of the council members of the community as quite good:

[...] I don't see our council as people who go to the council to get an appointment in the service. Just like in other places, I don't think so, I think that they are people who follow the flow of the service, the two people who attend, and it's not for personal advantage! Because I know that in other places it's different, we know, because I have already worked in other places and "Oh, you have to see this one now because he is from the council, ok?" They are here for the community, really. I think it's for an ideal... for believing.

### Other spaces of participation

The nursing technician speaks of her participation in other spaces:

[...] I participate of GTH, which is the *Grupo Humaniza SUS*, here in the management, since 2012; I participate of this space where we also speak on different subjects, including social control that also enters in this scope. And I also participate now of the PAN, which is the Psychosocial Attention Network [RAPS - Rede de Atenção Psicossocial] of Partenon. I participate in several spheres. And I participate of the commission of permanent education of the city council at the level of social control. (Worker 1)

The community health worker speaks of the participation of the community out of the councils, in other activities, and understands that it is easier when there



is some related party: “We used to prepare a Christmas party for the community, then all of us took part on it, we all worked together, we invited the community”.

The nursing technician speaks of her participation in other spaces, which she characterizes as charity:

[...] But it's not specific to health programs. For instance, here in Porto Alegre, we have the little Christmas letters of Santa Casa, of the Postal Service, there was a program like this in college, and I took part on it. But it's more related to charity. Health, only during my working hours. (Worker 5)

### Potentialities of the participation

The doctor understands that the important conquests of the community are due to the local council:

[...] Because I believe in the process and I want to be active and I encourage them all to be active. The council is active today, indeed it was recreated, it didn't exist for quite a long time and some members of the team participated, members and residents at the time, participated in the process. We have few, but quite active council members, some itinerant members, who pass by the council and leave, but we have acquired a lot of things through this, at least we have been fighting. So, from refurbishing these courts to the pavement of a few streets here, reorganization of some areas of garbage disposal, everything is done through the local council.

Referring to the potentialities of participation, worker 1 believes in her professional responsibility and that the guidance provided in the appointments are essential for the effectiveness of the system:

[...] I have the duty to clarify things when the users come to us, and the place and the spaces to clarify things related to social control is within the council spaces. I think that participation is very important, the participation of the worker. And the strategy for the strengthening, in my opinion, I believe it's the guidance, increasingly more capacity building.

The nursing technician speaks on the tools that facilitate the participation. The city government and the state themselves provide several courses for the workers:

[...] we learn new things related to health and this motivates the employees a little more to expand this knowledge to the population. I believe that the will to help... and here, in the Family Health program, there is this contact; this bond with the patients facilitates this effort a lot. We are able to help in relation to health because you create a bond with the patient, you see them every day, they are always the same users, we have the freedom of being able to go to the area to make home visits, all of this facilitate, are tools that facilitate.

The dentist understands that it is a slow work and that things were more precarious before the SUS and the FHS. Presently, the communication with the users is greater. It demands a continuous work.

[...] I think that it's a work that has to be done little by little; I believe that things have already been worse. The communication through the Internet, everything that we have nowadays facilitates the access. We even have a Facebook page of the Family Health Service, we post some things. We exchange ideas with the users. Thus, I think that it's a work to be accomplished little by little; it has to be a continuous work.

Worker 1 emphasizes the importance of knowledge dissemination for the continuity of the process of social participation in the councils, because the guidance for the community can facilitate and potentialize the participation of the users.

[...] increasingly more people have more programs in our country, from the Ministry, there are more things, and I think that this has to be passed to the users, to the workers, because it's not because we are workers that we know everything. There are things that I think that need to be clarified, because the more capacity building you have, better your view of things will be and better you can be informed when you raise your hand in the district council, you will be able to speak on the subject. Because it's useless wanting to speak on a subject if you are not familiar with it.

Worker 6, a doctor, speaks of the strengthening of the population bases as a strategy of social participation in primary care and of the importance of health promotion and education since childhood:

[.] This is why I say that it has to come from the foundation. In order we can change the present in the future, we need to educate better. If educating a child is hard, reeducating an adult is a bigger challenge. It's going to impact on this adult if we act in the basis, right?... Sometimes it's too many demands, for a few people to reach this, then, several times in primary care all we can do is treating diseases. Hardly ever prevention and promotion, we cannot promote health.

In general, the workers believe in the power of social control and in the exchange between managers, workers and users that happens in the council. The nursing technician, for instance, says that it's worthy participating of this democratic process, in spite of the apparent weakness of these spaces:

[...] I believe that this participation has to exist indeed, it's a democracy, we fought so much for this in our country that I believe that we have to strengthen this each time, because what we observe in the present, that sometimes a force emerges, something, to weaken these spaces and I think that our fight is this, I think that we cannot allow it to weaken at all. I think that the country fought so much for a democracy, that I believe that we cannot allow these spaces to weaken.

The community health worker also understands that it is worthy working for a higher involvement of the users with SUS:

[...] I believe that it's worthy indeed, and I believe that there is a gain, but I think that we should have a bigger partnership, because I, as a worker, I can't do a lot. There are things that I think that the community would obtain much more if they really gather, they would obtain much more. Because the worker can't be in certain places, we are working, so we are here more to help them, but I think that we could have much more if the community really were interested.

Interviewee 6 stresses that his community is participative in other activities, not necessarily in the health council:

[...] The community, it participates in other ways in the service as well, it's not only a matter of the council. The events that we promote, the creation of the "orchard", it's something that we made two, three months ago, bringing plants. Thus, (the community) has an active participation in the service, it's a community that participates, but thinking only about the council, which is a more structured thing, more deliberative, I think that there is some lack of motivation.

### Strategies to strengthen the participation

Worker 1 understands that the creation of local councils is strategic for the community participation and that the capacity building for educators is very important:

[...] In 2013, there was a capacity building activity on social control for educators, of which I was part as well, and we have been working in this process since then. This year we already had several meetings, we have monthly meetings in which we are working in the local councils. [...] We are evolving and our goal is this, to evolve, to strengthen the councils, because we understand that if the local council is strong and well advised, I believe that it strengthens the district one and automatically strengthens the municipal one, which gathers the entire city.

Worker 3 believes that, if the users participated more, many things could change:

[...] They (the users) don't know the force that they have. Or they know it but it's that thing of comfort, you are not leaving your home, your comfort, to come here. [...] I think that there must be a change in the heads of the people, right?

The community health worker speaks of the FHS users, who have a poor participation in the local council meetings, and the strategies to facilitate a bigger participation:

[...] Concerning the participation of users, it's limited because if the user doesn't come, it becomes limited. They have to participate, right?, and that's what happens... I think that the population complains too much that this and that is lacking, but at the time of fighting

for that, they don't do anything, right? It's easier to call 156 [municipal government number for complaints] to complain, but when we invite to come here, they don't attend. [...] We already changed the hours, we already thought like "Oh, these hours are bad, if she is a mother it's hard... at this hour in winter..., I think that it's lack of will, of commitment. In my opinion, I believe that the Brazilian people are too used to have everything at hand. I think it's time to fight. One needs to fight to abolish corruption, needs to fight for health, has to fight. It's easy to be complaining and not doing anything. I think that they don't do anything... (Worker 4)

According to the interviewee, one of the service strategies is the guidance to encourage having the claims made to the local council:

[...] When they complain, we ask them to come or, when the community health workers visit their homes, when it's time for the meetings, they remind them that "we are going to have a meeting in such day at the service... if you want to participate..." They explain what the reason is for it. One week ago, we were in the reception and I was thinking how I could deal with the people so that they would attend. I remember that there were a lot of people in the reception room and I called the community, I told them "look guys, we'll have a council meeting such day, you can come here and bring on the issues... Because it's not only a matter of complaining against the service, you can speak about the garbage, that it's too bad in your streets... the sewage... So, guys, we can do something through some work, a different kind of work, call the city departments... And I asked my coworker to make some fliers informing the dates, the days of the meeting and I delivered one by one... Presently we have meetings; we go out to see if somebody is going to participate. (Worker 4)

With regard to the strategies used to mobilize people, the nursing technician suggests expanding the service working hours:

[...] How are we going to have access to this public to bring them here, in order we are able to teach, in order we are able to work in health, in order they are able to search for help? It's us going towards them. If we had a third shift or if we created street groups working beyond the working hours of this population, I believe that we would have an effective tool to bring them to the service. (Worker 3)

## **5. Discussion**

### *5.1. Subjects emerging from the research*

#### Summary of the main results

The results point to the following conclusions:

- In a unanimous way, the little participation of users in the spaces established for social control (health councils) was evidenced as a reason of difficulty and lack of motivation to participate. On the other hand, the participation of users in other spaces, like assemblies and forums called for by the community itself, seems to be bigger.

- The lack of representativeness of the council members, especially of the users segment, was mentioned as a major difficulty. The little commitment in the community, the present lack of “community spirit”, weakens the representation in the council. Even though this is the perception of most of the interviewees, some workers perceive that there is a good representativeness in their services. However, they know that this is not always the case in other services.
- The idea that people (people in general, but the idea was directed to the users/people of the community) need to demand and fight to conquer something was strong, as things don't come out of favor. The communities which are presently more active present a tradition of grassroots fights.
- The notion that participation is truly effective when there are real needs was made quite clear. When the subjects, the agendas reach the reality of people, that's when they participate in the councils. When the subjects are more generic, without any particular interests for people, participation is scarce.
- The workers understand their daily work as social participation, from a notion of insertion in the territory and proximity with the community, what provides an exchange in the quotidian, no matter their participation in the council meetings.
- The Family Health Strategy is recognized as a facilitator of participation for providing closeness with the territory and bond with the community.
- For managers and workers, the council can be seen, also, as a space to know the other existent movements, beyond social control.
- Different kinds of difficulty were mentioned:
  - The poor participation of users is the most emphasized one.
  - Rigid structure: agenda construction, not being allowed to speak about what is not present in the agenda, specific schedule and rules of functioning.
  - Lack of information: several people mentioned that most of population is unaware of the possibility to participate in the councils.
  - Disbelief, lack of motivation and lack of responses: mentioned in all segments. There is a general lack of motivation, in part caused by

the lack of response in relation to previous mobilizations. Moreover, people are not motivated by current political times.

- There seems to be a general lack of interest: people do not understand how social control functions nor the potential that they have in this system to generate changes. There is a lack of empowerment.
  - Time of the council meetings: if they happen during working hours, it is difficult for those who work; if they happen in the evening, it creates difficulty related to security and access.
  - Violence: quite present in the discourses. It is moving people away from the streets and often hindering participation.
  - The workers claim that it would be important to add working hours to participate in the councils as a way of compensation. They will hardly be motivated to participate out of the working hours if they don't have some compensation.
  - Clearly, the workers seem overloaded themselves, what takes the motivation to participate of another activity, in this case, health councils.
  - The difficulty of access to the health services, in a general way, decreases the contact of the team with the community and harms the participation.
- In spite of the difficulty, all find control social quite important and believe in its potential. It can be said that, unanimously, social control is quite valued. Thus, they find it valid to think about strategies to strengthen participation:
    - To extend the dissemination and the information for the population concerning the councils and the possibilities of participation.
    - Providing capacity building, mainly for the segments of workers and users.
    - Strengthening local councils, so that the district and municipal ones are also strengthened.
    - Strengthening the closeness with the community by means of work with groups and the work of community health workers. Another way to promote closeness is extending the access to the services, offering extended working hours, for instance.

- Investing in the partnership with education institutions: the presence of students and residents in the services brings innovation, motivating both the workers and the community.
- Attracting the young population. Using digital tools more: e-mail, Facebook etc.
- Participating more in spaces besides the council, mainly when the call comes from the community itself.
- Investing in the education from the basis, working in the schools, in the citizenship education with children.

### Reflections

The conclusions above led us to the following reflections:

- Concerning the small amount of people, especially users, present in the council meetings, which was raised as one of the major difficulties, it is necessary to make a reflection on representativeness. If those present people, who are in the role of representation of the users, really represented the community, the concern with the amount itself would not be so important. However, the concern with the amount of people seems to demonstrate that the communities, intrinsically, have little cohesion and lack mobilization to have legitimate representatives. The notion that the critical node shouldn't be the number of participants, but the way of representation, deserves more attention. Perhaps the way should be in the sense of creating and strengthening processes in the core of the community itself, so that there is a collective that is closer and strong, resulting in more effective representation. The representation of the community by two council members in the local council assumes a basic process of organization in the community, previous and permanent to the choice of these representatives.
- Why do the assemblies called by the community attract more people than the council meetings? This must lead us to reflect on the feeling of belonging of the people, especially users, in the process of social participation. Do the council meetings make sense to people? Do they feel that they are really part of the health council?

- This research showed a perception, on the part of the managers, that people do not fight anymore because there are no needs to fight, due to lack of will. It is significant to reflect upon this. On one hand, there seems to be quite a distorted and simplistic view, which does not consider the complexity of the origin of people's needs, which continue existing, even though they may be different in comparison with the past. On the other hand, it is an interesting perception, which, in some way, points to the lack of meaning or reason to fight, even when there are needs.
- Among the strategies mentioned to strengthen social participation, there are courses and capacity buildings. It is necessary to think on this, as there have been several of them and the results either were not satisfactory or were not supported. We believe that it is important to use the power of grassroots education to assist and involve the users and their culture in the construction of these spaces.
- Participation, as such, can be a fallacy. It is necessary to reflect deeply. Countries that had major conquests in the reach of "Health for All", like some in Europe and Canada, not always had strong grassroots participation. On one hand, this belief in the grassroots popular participation places in the user, in the people, the responsibility for mobilizing, while the macro political and economic context is increasingly oppressing, increasingly creating more difficulty, against which people should fight. There seems to be a contradiction here: the need to demand *versus* basic rights, which theoretically would need to be taken care of no matter people's capacity of mobilization. Satisfying rights is a responsibility of the State for its citizens. It is not fair to place on them the responsibility for having to mobilize to have their basic rights attended.
- Nowadays, it seems that the community and solidary spirit is weakened. These are times of individualism and insecurity. How to strengthen this spirit in the hegemonic capitalist system? One way is the investment on the intrinsic processes of the communities, on healthy attitudes and on grassroots popular education, starting from the local level.

## 5.2. *Relationship with the 5 thematic areas*



The relationship of this research, accomplished in a local sphere, with each one of the thematic axes of the global project, is described next:

Campaigns and advocacy: in our environment, they can be developed, mainly advocacy, within the health councils, which is the formal mechanism for social participation in SUS. Thus, renewing and strengthening social control means that developing advocacy and campaigns would be facilitated.

Movement construction and strengthening: understanding the fragility of social control, shown in this survey, we are able to think on better strategies to strengthen social participation in health with better representativeness, including social movements.

Knowledge production and dissemination: in this study, there was a strong emphasis on the need to strengthen people's information on social control. This was mentioned as one of the key points to strengthen participation.

Education: workers and managers emphasized the importance of specific education aimed towards social participation. Some experiences were mentioned, but they do not seem to be sufficient.

Global governance: it was not developed here.

### 5.3. *Implications for phase 2*

It was clear in this research that social control, as it is established, is weak. It is possible that the model has had its day and that people are tired and lack motivation due to the constant lack of results. This way, it is important to work for its renovation, using new tools that strengthen it, as the study showed that people from all segments believe that it is worthy investing on the strengthening of health councils to warrant social participation.

Thus, the idea for phase 2 is to jointly construct with the participants of this survey an intervention aimed to strengthen social control considering the results of phase 1. This way, People's Health Movement is present in Porto Alegre as an ally of those who fight for legitimacy and valuation of health councils, promoting activism by means of research and other socially relevant academic activities.



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## **APPENDIX 1**

### **Script for semi-structured interviews to be applied in the interviews with users, workers and managers**

- A) What is your perception on social participation concerning health issues? Could you mention some forms or examples of participation? How do you see your role (as health user, worker or manager) in social participation? How is your participation?
- B) Do you participate of health councils? Why? Do you participate in any other space where you can have an influence on health issues?
- C) Is your opinion, which factors make the participation of people easier and harder concerning health issues? (Explore aspects related to place, time, security, representativeness in the councils – do those who are there represent who should be represented? –, work dynamics etc.)
- D) Do you think that it is worthy investing on social participation? Which strategies could be used for this strengthening?
- E) What do you understand by “health for all”? (Inquire about concepts of universal access and equity, in case they are not mentioned).

## APPENDIX 2

### Script for conversation circles

*The conversation circle will not follow a rigid script, but the questions below will serve as guiding questions, not necessarily following the order presented. The conversation circle will be an opportunity to analyze the interaction among people, the utterances dynamics and positioning, being able to result in new questions along the meeting.*

- A) In this territory, have you had mobilization involving inhabitants, community organizations, schools, NGOs etc? How is this process developed?
- B) How is the community interaction with the health team? How does the team participate in the processes of community mobilization?
- C) How is the joint planning and coordination of your region with the municipal social programs and projects?
- D) Which are the strategies adopted individually and by the team for facing the local reality complexity?
- E) Is there a local health council? If not, was there one? Why there is none?
- F) Which strategies could improve participation in health?