

# shaping health



Exchanging on social power in health

Learning from international experience  
on approaches to community power,  
participation and decision-making in health

## Case Study: Community Voices from Cidade Tiradentes, São Paulo, Brazil

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## Executive Summary

This study discusses citizen participation in health promotion in Brazil, analysing institutionalised and non-institutionalised forms of citizen participation in the making, managing and monitoring of the Brazilian Public Health System (*Sistema Único de Saúde*, SUS), constitutionally established in 1988. The study was implemented within the Shaping Health project led by Training and Research Support Centre (TARSC) with support from the Robert Wood Johnson Foundation Global Ideas Fund at CAF America. At the local level, it explored participatory dynamics taking place in health facilities management councils (hereafter termed 'local facility councils') in primary care health units (*Unidade Básica de Saúde*, UBS) located in Cidade Tiradentes, a poor neighbourhood in the east of São Paulo, Brazil's largest city.

Citizen participation is a key feature of the Brazilian SUS. Half the members of participatory councils are elected to represent citizens (also referred to in Brazil as 'SUS users') and the remaining half are represented by government, health workers, and service providers. The councils are mandated by law at all levels, that is the union, federative states, and municipalities. They create formal spaces for participation, but these may still be distant from most citizens. In line with the decentralisation principle guiding the Brazilian SUS, several municipalities installed sub-municipal participatory councils, a move fully supported by the National Health Council. Especially in large metropolitan areas, local health councils (LC) were established at neighbourhood /district levels, while local facility councils (LFC) were established within primary care health units and hospitals in the SUS. These sub-municipal councils strengthen links between users, providers and managers, help monitor the local network of health facilities and involve communities in health policy processes. In São Paulo, LC and LFC are established in terms of a 2002 municipal law. Each LFC is comprised of a minimum of four and a maximum of 16 elected councilors for two-year mandates, with the number depending on the complexity of the health facility.

São Paulo has been an innovation hub for Brazilian health movements who have pressured for the inclusion of health as a universal right, now enshrined in the Brazilian 1988 Constitution, and for a public universal health system, termed the SUS. São Paulo was in the frontline of developing the Family Health Strategy, an ambitious programme that restructured primary healthcare nationwide since the 1990s. Yet, being a large city with high levels of social inequality, the expansion of health services has been uneven, with more public health services offered for those living in central and wealthier areas. São Paulo's rapid and unplanned urbanisation - mostly in the 1970s - has forced large portions of the population to occupy the city's outskirts with little or no access to basic public services. This picture is slowly changing with improvements in the access of residents of poorer areas to public health services in areas such as basic appointments and hospital admissions. This is helping to reduce the inequality of access to services.

Cidade Tiradentes, our case study site, is a poor district, with almost a third of its population living in informal settlements (also referred to as *favelas* or slums). Its population health indicators are lower than the city average, with its inhabitants suffering from problems related to early pregnancy, chronic conditions and infectious diseases (such as dengue fever, syphilis and tuberculosis), as well as the stigma of social violence. Nevertheless, it has a long story of social mobilisation, including for health-related issues.

Previously published literature and evaluations of the performance of health councils have suggested that these mechanisms have contributed, in a modest way, to incorporate the demands of civil society in health policy making and to extend social control and citizen oversight over this policy. According to this literature, an authoritarian political and state culture have made it difficult to recognise and respect citizens, which added to the fragility of social dynamics in forums, and have weakened social participation in health policy making and management. Since the 2000s, evidence has emerged of state entities or citizens generating more favorable conditions for inclusion of people in more vulnerable

conditions through social and political mobilisation. Decision-making processes have also incorporated debates about distributive justice issues and applied a rights-based approach to health. This study explores further the participatory dynamics at the local level, through the workings of the selected LFCs, and examines the social contribution to health policy and to monitoring and managing local health service delivery.

We hypothesised that this local-level community participation works better in the presence of a two-way dynamic, one coming from the community to the local health facilities, through the institutionalised participation channels such as the LFC, and another going from the facilities to the community, through non-institutionalised participation channels, that provide entry points for citizens to have a voice in the health system. One example of the latter is the inclusion of health-promotion activities under the umbrella of the Family Health Strategy. We visited four LFC in the district of Cidade Tiradentes in four different primary care health units: Fazenda do Carmo; Carlos Gentile; Gráficos; and Prestes Maia and implemented 27 on-site, semi-structured interviews with councilors, health professionals and public officials on the routine process of the health facility, councils, and their interaction with local communities. We observed five council meetings and reviewed documents of previous meetings.

The monthly meetings of the LC and LFC are the participatory practices that structure community participation in the SUS. In these meetings, citizens, health professionals and public officials come together to discuss their daily problems concerning health issues in the region. As enabling factors we found:

- a. the formal institutionalisation of health councils;
- b. the presence of social mobilisation and popular organisations in the region that promote leadership and participation; and
- c. the personal profile of the councilors - more proactive councilors were able to guarantee improvements in health units' conditions even in disabling environments.

One of the main challenges faced by health councils is that health professionals and public officials often have a bureaucratic relationship with the councils, seeing them as one more obligation to be fulfilled.

As indicated earlier, the published literature on the performance of the health councils suggests that they have contributed to modest improvements in incorporating the demands of civil society in health policy making; in social control and citizen oversight over policy; and in generating favourable contexts for including those in more vulnerable conditions in decision-making. In the case study site, the participatory practices described included: a wide range of actors defending the SUS and a mental health service against closure; improved measures to tackle violence and to support service access for people with disabilities; and actions to support pharmacists and access to medicines. There is also some evidence that service coverage increased and local health funding improved, however many factors may have affected this.

Key findings of this study that could potentially inform practices elsewhere include:

- Promoting, through the councils and other forms of participation, alliances between civil society organisations and health professionals to support a universal health system;
- The importance of a process of institutional building of spaces and health programmes, as the Family Health Strategy, that creates space for citizen engagement and for health professionals updating their links with the community;
- Fostering teamwork and capacity building in health personnel to facilitate their connection to communities;
- Supporting the role of community health workers in mediating the relations between citizens and health professionals, promoting healthy behaviour and facilitating access to healthcare for vulnerable groups;
- Organising meetings that bring civil society, health workers and public officials together to promote and protect social rights in the public debate.

# 1. The case study site

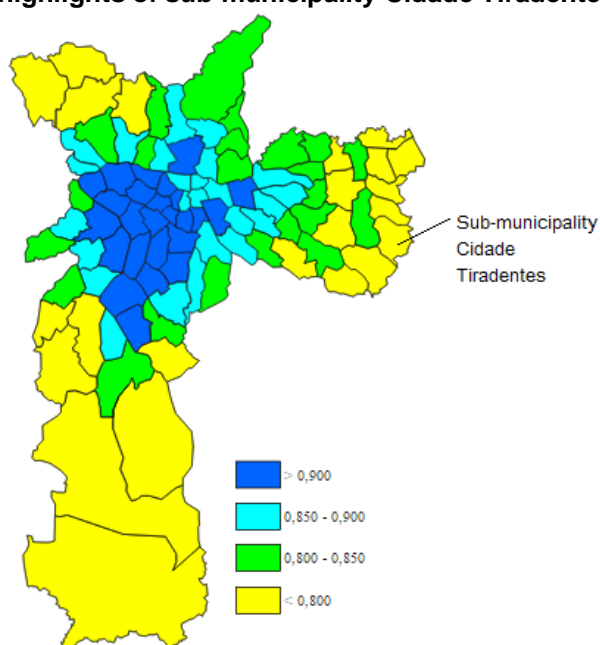
This case study presents how and to what extent institutionalised social participation has been shaped at the micro-local level in the sub-municipality of Cidade Tiradentes, Brazil, through a specific type of participatory institution: the local facility health councils (LFC) operating along primary care health units (*Unidade Básica de Saúde*, UBS). It also discusses other channels for citizen participation taking place alongside the institutionalised spaces (i.e. the councils) through the work of community health workers and non-institutionalised forms of social participation, such as protests. It examines how far a more two-way dynamic, connecting community participation inside the UBS with health professional participation inside the community, may help the health bureaucracy and local politicians hear the communities' voice and translate that into effective health policies that better serve the citizens living in poor peripheries.

The case study was implemented within the Shaping Health project led by Training and Research Support Centre (TARSC) entitled 'Learning from international experience on approaches to community power, participation and decision-making in health' that includes five sites in the USA and case studies from in twelve sites in twelve selected high-, middle- and low-income countries, with support from the Robert Wood Johnson Foundation Global Ideas Fund at CAF America.

Brazil is the largest country in Latin America, world's fifth largest country in territorial extension and the ninth largest economy, with a population of more than 200 million inhabitants. It is a federal republic divided into three levels: federal, state and municipal. The country has 26 states, plus the Federal District, and 5,570 municipalities. Each subnational unit is autonomous with full self-government and self-regulation powers.

Home to 40 million people, the São Paulo state holds 20% of Brazil's total population and has the largest public healthcare system in the country. The municipality of São Paulo has a population of nearly 12 million inhabitants and is the state's capital. The municipality is administratively divided in 32 submunicipalities and 96 districts and is conspicuous for sharp social inequality and unequal access to public services. Cidade Tiradentes, one of these submunicipalities (consisting of one sole district also named Cidade Tiradentes). It has over 220,000 inhabitants living in an area of 15km that, until 50 years ago, was occupied only by the Atlantic Forest. By the 1980s it had become a commuter town with over 40,000 housing units (the biggest complex in Latin America). Its fast and unorganised occupation has divided Cidade Tiradentes' inhabitants into two vulnerable clusters: a formal one, of 160,000 people living in housing units; and an informal one, in the so-called *favelas* (Brazilian term for slums), with more than 60,000 inhabitants (Figure 1).

**Figure 1: Municipality of São Paulo, Human Development Index by submunicipalities with highlights of sub-municipality Cidade Tiradentes**



Source: Atlas Municipal da Cidade de São Paulo (2007)

Living 35km away from the city centre, its local inhabitants are the poorest and most marginalised in the city, with high rates of unemployment, little access to cultural and entertainment public services, and poor connection to public transportation (Indicators for Cidade Tiradentes and São Paulo, 2015). Nonetheless, the historical disregard of municipal governments in the region, combined with the insufficient public policies to revert this scenario, have led to the emergence of social movements in Cidade Tiradentes. These movements seek to raise public pressure and link people through participatory councils to seek solutions to their problems (Coelho, 2010).

According to a 2015 survey by the Municipal Secretariat of Racial Equality, 55.4% of Cidade Tiradentes inhabitants are black. This figure is comparatively higher than the percentages for the whole city, of which 37% of the population is self-declared black. In 2010, the per capita revenue of 32.6% of households in the district was lower than half the minimum wage, and 13.6% of these families lived in extreme poverty (against 8.5% for the city of São Paulo) (Seade, 2010). Unemployment rates are equally high at 11.6%, largely above the city's rate of 8.8%, according to the [website of Rede Social de Cidades](#) (Rede Sociais de Cidades, 2012). In 2015, the per capita income for Cidade Tiradentes inhabitants was approximately US\$124.15, less than half the city's average income of \$343.75 (Seade, 2016).

In terms of health, Cidade Tiradente residents suffer not only from problems related to early pregnancy, chronic conditions, infectious diseases (such as dengue fever, syphilis and tuberculosis) and mental health, but also from the stigma of social violence that results in its poor health profile relative to São Paulo, shown in *Table 1*.

**Table 1: Key social indicators: Cidade Tiradentes and São Paulo, 2014/2015**

Indicator (2015)	Cidade Tiradentes	São Paulo
Teenage pregnancy (mothers under 19 years of age)	19.12%	12.73%
Life expectancy	53.85	75.4
Infant Mortality rate per 1000 birth	13.2	10.8
External mortality rate (violence and accidents)	45.76/100,000 inhabitants	47.97/100,000 inhabitants
Mortality rate due to circulatory diseases (CVA and cardiovascular diseases)	12.81/10,000 inhabitants	20.53/10,000 inhabitants
Homicide rates (data from 2014)	1.84/10,000 inhabitants	1.45/10,000 inhabitants
Juvenile homicides – young people between 15 and 29 years of age (data from 2014)	7.43/10,000 inhabitants	4.92/10,000 inhabitants
Homicide rates	1.84/10,000 inhabitants	1.44/10,000 inhabitants

Source: Rede Nossa São Paulo 2016

The local network of public health facilities in Cidade Tiradentes includes twelve primary care health units (UBS), one hospital, two outpatient clinics and one emergency room. Each of those facilities holds a local facility council (LFC).

## 2. Context for the case study

The Brazilian Universal Health System (*Sistema Único de Saúde*, SUS) has a long social history. Social mobilisation was one of its keystones, particularly during the 1964 -1985 dictatorship.



## 2.1 Historical background

The country was colonised by Portugal in 1500 and became independent only in 1822. Marked by large regional and social disparities, Brazil experienced high rates of economic growth in the 20<sup>th</sup> century. At the same time it underwent a vertiginous process of urbanisation. In 1940, only 30% of the population lived in urban centres. According to the census in 2000, 81.4% of the population lived in cities (IBGE, 2000). This demographic change was not accompanied by an adequate expansion of public healthcare facilities, and the same could be said about education, housing and other social services. The cities grew in a disorderly way and expelled the lower income population to the margins, in places with little or no social infrastructure. With time, Brazilian urban centres have witnessed countless social movements demanding from successive governments better access to social services and the right to participate in policy making and implementation, in almost all sectors of social life (Houlston, 2007).

Another important factor for the emergence and expansion of several Brazilian social movements was the military dictatorship, which lasted 21 years (1964-1985). The Sanitary Movement, a social movement also known as 'health movement,' was one of them. Consisting of healthcare professionals – unionised doctors, academics and the medical student movement – the Sanitary Movement's trajectory has a lot in common with other popular movements organised to bring democracy back, as the faith-based communities (namely the *Comunidades Eclesiais de Base*), Mothers' Associations, popular education groups, and movements against poverty (Singer and Brant, 1983; Sacardo and Castro, 2002), and also the Workers' Party (*Partido dos Trabalhadores, PT*) (Bógus, 1998; Machado, 1995; Dowbor, 2008; Escorel et al., 2005; Barros, 2002; Coelho 2013). They all brought together progressive professionals, intellectuals and residents of the poor peripheries to struggle for social justice.

Professionals identified with the principles of the Sanitary Movement advocated for the effective universalisation of the health system and the institutionalisation of citizens' participation in the formulation, management and monitoring of health policy (Neder, 2001). The movement continued to grow during the democratic transition government that succeeded the military regime in 1985.

In this phase, representatives from the Sanitary Movement took on key positions in the national Health Ministry and state Health Secretariats, reinforcing principles of change: decentralisation; universal and equal access to health services; comprehensive care, organisation in regions of health (where smaller cities reference their patients to more specialised care centres in bigger cities, forming an integrated network of health services in the same region); and the development of participatory institutions (Dowbor, 2008; Lima et al., 2005; Noronha and Levcovitz, 1994).

Equally noteworthy was the role played by civil society associations. These associations were engaged in a number of local initiatives, such as the creation of HIV/AIDS programmes, and also helped to disseminate the notion of health as a citizen's right (Nunn, 2009).

In 1988, when the Federal Constitution - called the Citizen Constitution - granting universal and free healthcare to all Brazilians - was enacted, the Brazilian health sector had already undergone a long path of reforms (Govt of Brazil, 1988). Considered a historical landmark, this constitution sought to connect citizens and the state through health councils and conferences, also referred to as 'participatory institutions' (Avritzer, 2007). As reflected in a [short video on participation in National Health Conference](#), participatory institutions in Brazil are found in a range of policy areas and take on various forms as institutionalised spaces for incorporating citizens and civil society associations into policy processes (Avritzer, 2007; Cornwall et al., 2008).



In 1990, a provision in the constitution was implemented through Federal Law 8142/90 (Govt of Brazil, 1990a). It defines as participatory bodies the Health Conference and the Health Councils at all three levels - national, state and municipality - bringing together citizens, government representatives, service providers and health professionals. The law does not specify what social groups should be represented. However, in several councils, internal rules specify the number of councilors that should represent neighbourhoods, people with disabilities or minorities. This law also binds the transfer of federal financial resources from the health ministry to states and municipalities to the existence of state, municipal and local health councils (Coelho, 2012).

## 2.2 SUS: The Brazilian public health system

The health sector in Brazil represents 6.6% of its gross domestic product (GDP). There is, however, an important dichotomy between the public and the private sector. While the public sector takes care of 70% of the population for 47% of the total national health expenditure, the private sector encompasses 53% of the total health expenditure but covers only 30% of the population (Coelho and Dias, 2015).

The Ministry of Health formulates national public health policies and the states and municipalities implement. States and municipalities deliver services directly and hire both private and non-for-profit organisations for service delivery. The federal government is responsible for nearly 50% of SUS financial resources. States are required to invest at least 12% of their revenues in the SUS, while municipalities must invest at least 15% of their revenues. Another important feature of the Brazilian health system is its decentralised nature. Municipalities have the main responsibility for healthcare provision, with autonomy to apply resources as to respond to the specific needs of populations given the differing characteristics of the cities (Ministry of Health, 2002; Govt of Brazil 1990b; 2006).

The SUS is currently organised into three levels of care: primary care, medium complexity and high complexity. For example, in the state of São Paulo around 25% of the total public health expenditures (municipal, state and federal) finances basic care services, while 55% is spent in medium- and high- complex services. Each category has its own facilities' network for service delivery and for social participation. Our case studies focus on primary care and health councils placed at primary care health units (Unidades Básicas de Saúde, UBS). Primary care is structured around the Family Health Strategy (*Estratégia Saúde da Família*, ESF), which works with multidisciplinary teams. The ESF focuses on health promotion and preventive medicine. Teams work at the UBS and make periodic visits to families that live within spatial boundaries covered by the strategy.

In São Paulo municipality, in accordance with national guidelines set by the Health Ministry for urban areas, ESF teams include a physician, a nurse, two nursing assistants, a dentist and six community health workers. Each community health worker (*agente comunitário de saúde*, ACS) is responsible for the follow-up of around 200 families. By interacting with the local community, these workers play key mediating roles, bridging between the population and the local public health team. Besides referring patients to consultations with doctors and nurses, these workers are responsible for health promotion, prevention and education. On the other way round, they bring back to the local health facility team citizens' perspectives. *Table 2* summarises SUS levels of care and service delivery networks.

Citizen participation is mandatory in all these networks (Govt of Brazil 1990a; 2003; 2007). For this to happen, the federal, states and municipal governments constitute their respective health councils with representatives of citizens, health managers, service providers and health professionals. In all councils, citizen council members are elected by citizens while public officials are appointed by their peers and service providers by their associations. The election process is always publicised, and the results are made public through official government gazettes. The landscape of health councils in the country is described in *Table 3*.

**Table 2: Health system levels of care, SUS, Brazil, 2017**

	<b>Facilities characteristics</b>	<b>Role</b>	<b>Social representation</b>
<b>Primary care network</b>	The UBS (the primary care units) counts on generalist health workers. The core of this network is the Family Health Strategy (FHS)	This level is responsible for the preventive healthcare and referring patients requiring specialised care to the remaining networks	Local Facilities Councils  Local Health Councils  Municipal Health Council
<b>Medium-complexity network</b>	Health facilities count on professionals with specialisation in cardiology, endocrinology, nephrology, and orthopedics, among others	This level is responsible for specialised treatment and some minor surgery procedures	Local Facilities Councils  Local Health Councils  Municipal Health Council
<b>High-complexity network</b>	Hospital Centres count on a team of professionals with a higher degree of specialisation such as neurosurgery or pediatric oncology, for example	This level is responsible for most complex health cases that need invasive surgery procedures and face life risk	Local Facilities Councils  Local Health Councils  Municipal Health Council

Source: Authors' elaboration

**Table 3: Mechanism for social participation, municipal to SUS levels, Brazil, 2017**

	<b>Role</b>	<b>Composition</b>
<a href="#"><u>The National Health Council</u></a>	To monitor and deliberate on public health policies. It is responsible for approving the national health budget and monitoring its execution, as well as approving the National Health Plan every 4 years	48 <a href="#"><u>elected members</u></a> . 50% are representatives of citizens, the other 50% of health professionals, municipal health secretaries, state health secretaries and the private sector
<a href="#"><u>State-level health councils</u></a>	To co-ordinate the health strategy and goals at the state-level. To approve and monitor the state health budget and plans	<a href="#"><u>In the state of São Paulo</u></a> , State Law No 8.983 (1994) defines the composition of the State Health Council, which has 30 full-time members with the same proportional representation of the National Council
<a href="#"><u>Municipal-level health councils</u></a>	To deliberate and monitor municipal health policies. To approve and monitor the municipal health budget and plans	<a href="#"><u>In the municipality of São Paulo</u></a> , Municipal Decree No. 38.576 (1999) regulates the councils' composition with 32 representatives of civil society (16), health workers (8), government institutions (6), service providers and material suppliers (2). In total, the São Paulo Municipal
<a href="#"><u>Local facility councils</u></a>	To strengthen the ties between each facility and the community it serves, with a better understanding of local needs and characteristics	<a href="#"><u>These councils</u></a> are composed of a minimum of four and a maximum of 16 members (and the same number of alternates) with two-year terms. The number of councilors is determined by the complexity of each health facility

Source: Authors' elaboration

In the next section, we discuss the contribution of the councils of local facilities to democratising social policy making at the micro-level, where public services are delivered to vulnerable fringes of Brazilian society.

### 3. Methods

Within the larger Shaping Health project on how participation practices, processes and mechanisms are contributing to community empowerment and health promotion, this case study in Cidade Tiradentes explores how, in a highly deprived and violent setting, the links between the community, the local health councils - which are part of a national infrastructure for citizen participation - and community health workers with the Family Health Strategy (ESF) are promoting health and better health services in the region. To do so we explore the following assumption:

A more two-way dynamic connects community participation inside the primary care health units (UBS) through the facility health council and health professionals' participation inside the community through the CHW as part of the health team. This enables the community voice to be heard by the health bureaucracy and local political power and be translated into effective health policies that better serve the citizens that inhabit the poor peripheries.

The study began in November 2016 with a literature review and discussion of the USA case and other cases that are part of the wider project. In January and February 2017, we visited four UBS out of the sixteen public health facilities currently operating in Cidade Tiradentes; attended four facility councils' monthly meetings; and visited neighbourhoods and informal settlements in the region. From March to June 2017, we analysed collected evidence and produced the final report.

The selection of the four facilities was based on inputs from municipal health managers working in Cidade Tiradentes: two UBS that had more active participation from local communities and another two, which had less active participation. We would caution that the classifications of the UBS by the municipal health managers be checked in future studies. In addition, one UBS in each group hosts the Family Health Strategy (ESF). Those lacking the ESF are called 'traditional UBS' and are organised in lines with a pre-ESF model, thus more specialist/doctor-centred (pediatrician, gynecologist and general practitioners), which does not include community health workers or family health teams. This mix reflects a variation between a new UBS type, structured around the ESF teams, and the more traditional model above.



UBS GRÁFICOS, the researchers, Vera and Alexandre, and the UBS manager pointing to the informal settlement on the map © Alexandre Calandrini /2017

The sample was too small and internally variable to make rigorous comparisons on the participatory and ESF dynamics. Even so, we moved forward as the case study is an exploratory study aimed at documenting experiences and practices of participation. Our analysis of the results points out plausible relations in the features described, but does not assume causality. Twenty-seven semi-structured interviews were carried out in addition to the follow-up and observation of: a) four council meetings; b) one protest by UBS pharmacists; and c) two on-site visits to the communities of Jardim Maravilha and Ferraz, two informal settlement communities in Cidade Tiradentes. The features of the UBS selected are shown in *Table 4*.

The material was analysed in two steps. First, all the interviews were recorded and partially transcribed. Field diaries were organised. Second, the information was organised into categories allowing for comparisons between the participatory dynamics found in the four UBS. The information was documented and shared for feedback and discussion within the Shaping Health project. Based on these results, we also tested the plausibility of our hypothesis and noted the relevant contributing features, described in the remaining sessions.



Overview of the Jardim Maravilha © Alexandre Calandrini 2017

**Table 4: Features of the 4 selected UBS, Cidade Tiradentes, São Paulo, Brazil, 2017**

UBS Name	Features	Research activity
UBS Carlos Gentile	Active council Family Health Strategy teams	<ul style="list-style-type: none"> <li>7 interviews: 2 community health workers; 1 nurse; 2 councilors, 2 citizens</li> <li>One health facility council meeting attended</li> <li>Protest of pharmacists against closing the UBS pharmacies attended</li> <li>On-site visit to the Jardim Maravilha informal settlement with a community leader</li> </ul>
UBS Fazenda do Carmo	Active council	<ul style="list-style-type: none"> <li>5 interviews: 1 pharmacist, 1 nurse, 2 citizens, 1 psychologist</li> </ul>
UBS Gráficos	Not active council Family Health Strategy teams	<ul style="list-style-type: none"> <li>8 interviews: 2 community health workers, 1 nurse assistant; 1 nurse, 3 citizens, 1 councilor</li> <li>One health facility council attended</li> <li>On-site visit to the community of Ferraz</li> </ul>
UBS Prestes Maia	Council not active	<ul style="list-style-type: none"> <li>6 interviews: 1 social worker, 2 councilors, 2 nurses, 1 SUS citizen</li> </ul>



## 4. The participatory work

This section explores the nature of community and professional actors, the nature of the health programmes and participatory practices and the territorial specificities found in the four facilities visited in Cidade Tiradentes. When we speak about participation practices inside the UBS we have two dimensions of participation in mind: institutionalised forms of participation and non-institutionalised forms. Institutionalised participation happens within formally recognised ‘participatory institutions’ (Avritzer, 2007), in this case the health councils. While non-institutionalised participation includes citizens’ political mobilisation through protests and complementary forms of participation channeled through alternative mechanisms. Examples of this include the Family Health Strategy, not always originally designed to serve as participatory spaces, yet serving as entry doors for citizens to engage the state. These are described below.

### 4.1 Institutionalised participation in health in Cidade Tiradentes

As mentioned earlier, LFC play oversight, monitoring and planning roles in regards to local health service delivery, following the needs and profile of the local population. The participatory practices vary from council to council. Some have mandatory regular monthly meetings, while others also engage in health promotion and other activities.

The regular meetings last for nearly two hours and are organised by the councils’ executive secretary, who can be a health professional or citizen representative. The agenda is discussed collectively and, while anyone can attend these meetings, only elected councilors can vote. Decisions are often made by consensus and majority rule is avoided. A short video [on participation in Cidade Tiradentes](#), done by CEBRAP’s Citizenship, Health and Development Group, in 2006, depicts these dynamics.

The way the electoral process is organised varies from council to council, but elections are always publicised and results are made public in the municipality Official Gazette. Nevertheless, the issue of representativeness remains a challenge. Few people are involved in council elections and some councilors have been elected with only 10-16 votes, in areas of a potential electorate of more than 20,000. The number of citizens involved in LFC elections varies between municipal health districts, based on the degree of social mobilisation in the area, the local health authority profile and the level of political involvement in local health policy. Elected councilors are sometimes invited to participate in short capacity building courses on citizens’ rights, SUS structure and policies, financing rules and the policy process. For example, the OSS Santa Marcelina, a non-for-profit organisation that manages all the UBS and the hospital in Cidade Tiradentes, provides a course about the role of health councilors, although not all interviewees participate in such courses.

Every UBS has a box in the reception area where service users can deposit comments or complaints. The content of these boxes is discussed during health council meetings. For other specific problems, professionals might be invited, such as pharmacists to discuss the shortage of medicines in the pharmacy. The main complaints discussed in the LFC involve delays in specialty consultations or medical exams, the need for medicines and criticism regarding the way some attending physicians or other health professionals deal with patients. Equally important, local councils discuss and act upon issues beyond health policies, such as those related to local social issues like violence and drug abuse. When directly questioned about health policies, our interviewees were often simple and straightforward: “We have shortages of medicines,” “We have shortages of doctors,” “We have year-long waiting lists for medical exams or specialty consultations,” not to mention the constant fear in a context of rampant social violence, whose perpetrators oscillate between police or organised crime, or it’s internalised in family relations, where domestic violence and drug abuse produce major disturbances in social life.

The local councils do their best to address such complaints. Some try to gather signatures from the whole community to officially request a solution for the shortage of medicines. Others less active showed a feeling of resignation and thus powerlessness to change reality. The most active councils not only pursued official collective requests, but also encouraged street demonstrations - not always embraced by actions from their peers. Though the diversity of actions and actors is critical to the participation process, a councilor's proactive profile appeared as an important feature in promoting its effectiveness.

There are also more unusual situations, as the one that happened in the final months of 2016, when one nurse was assaulted in a facility parking lot and her car was stolen. Months later, a doctor had her car stolen after being beaten by criminals, leading the doctor to abandon her post. To respond to this 'wave of violence', as the interviewees called it, health professionals and LFC organised themselves to close the service for three days, as a sign of protest, demanding police enforcement and the need to close the service an hour earlier, as it gets more dangerous late at night. Both goals were achieved. Interviews also revealed councilors performing mediating roles, including negotiating with local organised crime leaders, in order to protect the UBS.



Inside a UBS in Cidade Tiradentes © A Calandrini 2017

The fieldwork was not able to identify any other structural policy action taken - either by one council or by all of them together - to tackle the violence and drug abuse issues. From the community perspective, councilors participated in various associations: church-related groups, women's social movements, associations supporting addicts (such as the association *Movimento Amor Exigente*), and neighbourhood associations, some with over 450 members. Among the main concerns voiced by those participating in these organisations are the need to protect children and women from violence and sexual abuse, to protect young people from drugs and crime, and to organise the community to confront organised crime. As they put: "the territory is theirs [controlled by the organised crime], they are an armed power." This set of grassroots organisations, independent citizens, health professionals and health managers taking part in council meetings expect to contribute toward a more effective health system and the ability of the community to tackle organised crime.

## 4.2 Non-institutionalised forms of citizen participation in health

Through our research, we observed the importance of non-institutionalised forms of participation, complementary to the institutionalised ones, in responding to problems that the procedures of institutionalised participation failed to solve. Examples of social participation taking place outside formal participatory institutions observed during the field research were street protests and the mediation work of community health workers.

The protest episode observed was a political mobilisation related the frequent issue of shortages of medicines in SUS facilities. The context for this particular episode in Cidade Tiradentes dates back to February 2017, when the newly elected mayor, from a



Street demonstration against the new policy of distributing medicines, São Paulo downtown, © A Calandrini Feb. 2017

center-right-wing party, decided to shut down the UBS internal pharmacies that prescribe and give out a range of free medicines to patients. The mayor indicated the City Hall would instead opt for partnerships with private pharmacies to give out those same medicines to SUS patients, and that the shortages of medicines would be solved with donations by the pharmaceutical industry. As an immediate response to those announcements, some councilors - alongside UBS pharmacists - went to the streets to demonstrate against such measures in front of the Health Secretary, in the city centre, 35km away from Cidade Tiradentes.

A second example of non-institutionalised participation occurs through the work of community health workers. These are non-degree health professionals, whose main requirement is being a resident for at least 2 years in the area covered by the Family Health Strategy (ESF). They are probably the keystone of the ESF, as they work as 'extended arms' of the health service in the communities where they live and serve. We consider this to be a form of non-institutionalised participation because these workers' primary function is related to the formal care structure, rather than to the formal participation structure (i.e. health councils). Nonetheless, during our field research, community health workers were also seen in council meetings, either performing the role of note takers or actively taking part in discussions, showing that both forms of participation can be mutually reinforcing.

Importantly, two UBS in our research were, as discussed earlier, traditional ones. That is they do not count with the ESF teams. When nurses from these facilities were asked what they needed most in their service, they frequently mentioned community health workers. They recognised that community workers know who is in need and have the capacity to: a) bring patients to the UBS, and b) mediate between the health system and the population. When health professionals cannot count on these workers they feel uncertainty about who is being left behind:

*I know I have 50 patients in diaper use, 249 patients who use insulin, but if I had a community worker to do these monthly visits in people's homes, I could have more information. ... Patients may be in great need and if nobody comes from their house saying: 'Look at Mr. John, he needs someone to visit him, or Mrs. Maria is in bed', I will not know. So I feel a bit distressed. There are a lot of people out there, and if they do not come here in the unit, we will never know they might be in need.*

*"There are patients lost out there and we don't know what is happening to them! If they do not come here, we'll never know ... And it happens! It happens! I've seen a patient with a leg's mummification here. With a member putrefied and unable to get out of the house ... Just here! And if a neighbour does not come and say: 'Look, he lives alone, he smokes, he had a stroke, his leg is rotten' we will not know ... The community workers really help a lot."* - Health worker KI 2017

Although participation is not the primary focus of the community health workers, the patients often see them as channels to express their claims and have their voices heard. One worker interviewed for this study stated that is not uncommon for the community health worker to mediate between the patients and the local government, even for issues beyond health, such as the ones related to children's learning disabilities in local schools.

Also important are the activities among health professionals and between health professionals and the population that help bridge the gap between the health system and the community. In this vein, looking at the ESF teams we found daily routine meetings promoting integration of community health workers, nurses and doctors. There are also meetings among health professionals - for example, nurses, pharmacists, psychologists - who work in different services in the Cidade Tiradentes region. Several professionals cited capacity building programmes that aim to keep professionals up to date. These activities help to keep alive the communication and exchange of experiences among health professionals concerning their work in the community. These professionals also engage in preventive work by organising health promotion activities in schools and seeking alternatives to motivate the younger population to believe in their future.



In short, the interplay between these institutionalised, non-institutionalised forms of citizen participation and joint professional activities help create dialogue, negotiation and mediation between two quite different realities: one experienced by the professional staff and the other by the local community. Hence, despite not formally granting decision-making powers to citizens, as councils do, those non-institutionalised participatory dynamics can be considered channels for citizen participation as they mediate between citizens and the state institutions, fostering health institutions' responsiveness to community's needs.

### 4.3 Overview of the UBS and councils visited

In this section we present a brief overview about how institutionalised and non-institutionalised practices are coming together daily in the visited primary care health facilities in Cidade Tiradentes. We also provide an account of one meeting of the Local Health Council, which oversees the whole sub-municipality.

The UBS Carlos Gentile is located close to Jardim Maravilha, a large slum. There are seven ESF teams attending 8,400 families in the area. Community health workers visit these families at least once a month. During these visits, the workers develop a close relationship with the families and also collect data concerning the families' health profile. Every month, the ESF team revises the collected data and discusses it with other health professionals to decide the actions to be taken and prioritised.



UBS Carlos Gentile used under creative commons license from Google Maps May 2017

At the time we visited this UBS, 260 pregnant women had been assisted in the area, eight of them with syphilis and 20% adolescents. Each ESF team takes care of nearly 20 women, but in the Jardim Maravilha slum this number increases to 60. Last year ten tuberculosis patients were identified in the area. The UBS delivers preventive and curative care as, for example, vaccinations, papanicolaou (pap) tests, care for diabetes and hypertension. The main deficiencies related to SUS presence in the region identified in the interviews were the lack of mental health services and ineffective prevention of abuse of alcohol and other drugs.

This UBS has the most active and dynamic councilors, many of whom are former elected councilors who still participate in all of the meetings. In the meeting held in February 2017, twenty people were present - a high number for a health council of just one facility. Some of the most active members have links with social movements, such as the landless workers movement (*Movimento dos Trabalhadores Sem Terra*, MTST), or affiliation with the Workers' Party (*Partido dos Trabalhadores*, PT). The UBS managers, CHWs, councilors and former councilors and citizens that use UBS services attended the meeting. They started by reading the complaints and praise from the suggestion box. The TV interview reported earlier was discussed, where the newly elected mayor said he would take the UBS pharmacies out of the UBS to private pharmacies. Some councilors supported the ideas, while others suggested that they should not be so naive as to believe the effectiveness of

such measure and proposed going to the streets to protest. On the same day, a street demonstration in front of the Health Secretary, in the city centre, included both councilors. These two councilors also encouraged the participation of others. For example, one of the councilors interviewed mentioned being encouraged by more active councilors to participate in the health council. During the site visit, this councilor also walked with us into the narrow pathways of the Jardim Maravilha *favela* to show us one of the houses where he helped to solve a conflict between its residents and the UBS. At the end of the meeting, they committed to participate and engage in a health promotion event on prevention of cervical cancer. There was an emotional moment, when the UBS dentist reported he was leaving for another job and was there to say goodbye, receiving back a warm farewell.

UBS Fazenda do Carmo is located in a more central and better off area of Cidade Tirandentes. This is a traditional UBS with no ESF, and it shares the building with an outpatient health unit. At the time we visited the UBS, 300 pregnant women were in the UBS area, 50% of them adolescent. There is also a huge problem with drugs, especially crack. A growing number of tuberculosis and syphilis cases were reported. Elderly people are seen as a further vulnerable group and one difficult to reach given the absence of ESF teams in this UBS. This UBS has an active council, with four elected councilors. The councilors are invited to take part in the four monthly meetings with the facility's health professionals. They are also involved in mediating the relationship between the UBS and the local community, as the facility cannot count on community health workers. According to our interviewees, one of the main problems in the region is violence, which is an issue often discussed in the council. The council also wrote a petition to the judiciary system to demand the presence of pediatricians in the outpatient service.



UBS Fazenda do Carmo used under creative commons license from Google Maps May 2017

UBS Graficos is located near the border of the municipality of São Paulo and close to environmental protected areas, which are being occupied by informal settlements. It harbours three ESF teams, covering 3,600 families.



UBS Gráficos used under creative commons license from Google Maps May 2017

The observed council meeting happened in January 2017. Four people attended the meeting: the UBS manager, one UBS councilor as the other was absent, a CHW, and a councilor from the Cidade Tiradentes sub-municipality council. They started the meeting reading the feedback from the suggestion box. They discussed the shortage of medicines and proposed to write a document to formally state the council's position. They mentioned the difficulties in serving the people not formally registered in the UBS, with about 1,000 families living in an illegal settlement right in front of the UBS, albeit within the boundary of another municipality. The UBS does not receive a budget to cover this community and has raised this issue with higher level government authorities with little response. In the meeting a health worker noted the need for a family health team to be dedicated to this area, given the high level of violence, extreme poverty, drugs, infectious diseases and adolescent pregnant women. The challenge was discussed, but with reference to this population in "they versus us" terms. In a later interview one councilor observed that the community had little interest in getting involved in or even knowing about council activities. This councilor was particularly interested in representing people with disabilities, based on a perception of the humiliations they suffer in health services, and had identified changes to the UBS structure to facilitate their access to services, such as moving the cervical cancer screening room from the first to the ground floor given that the UBS does not have a lift.

The UBS Prestes Maia is located in a more central and urbanised area of Cidade Tiradentes. This facility has no ESF teams. In the same building there is a mental referral center, which would be closed by now if the council, together with the local community and health professionals, had not actively defended it.



UBS Prestes Maia used under creative commons license from Google Maps May 2017

Nonetheless, the LFC is not seen as a very active one. It has only two health councilors representing the community. One of them is highly political, with links to different politicians from different political parties. This councilor was able to obtain approval for changes in the UBS physical structure, in transportation and in food for integrative mental health activities. The councilor also receives visits from different community members, asking for help in reducing their long waiting times for medical exams or specialty consultations. While this is a concerning issue, since councilors have no such power to interfere on waiting lists, it also reveals the different kinds of mediating roles they play between their communities and service providers. The other health councilor presents a completely different profile, an older person already retired, who regularly attends all monthly councils meetings, and has a much more conciliatory profile. When asked about his role, he responded that he felt powerless to change things in the health service, as not many people identify him as a councilor.

When asked about their role as councilors at UBS Prestes Maia, key informants mentioned their role in supporting the UBS by communicating with the community and assessing the



UBS performance. They criticised the absence of more influential professionals, such as the facility senior management, in council meetings. Councilors interviewed believe having the senior management engaged would improve the chances of making citizens' demands heard. The UBS manager pointed out the role of the council in mediating his communication with the community, such as in helping to solve problems with users being aggressive with health personnel.

Finally, in addition to the local facility councils, Cidade Tiradentes also has a Local Health Council, overseeing the whole sub-municipality that meets monthly. This council gathers representatives from the twelve Cidade Tiradentes' UBS (elected councilors, health professionals and managers) and representatives from the Health Technical Supervision, which represents the Municipal Health Secretary at the sub-municipality level. More than 50 people attended the January 2017 monthly meeting. This meeting had a more formal structure than the meetings of the HFC did. The facilitator presented the agenda, followed by a lecture by an epidemiologist on yellow fever, given the report of cases in the region. After that, councilors representing different UBS gave an overview of the health-related problems experienced in their areas. In this meeting, the combative tone was more apparent. The complaints common to all UBS created a momentum pushing for more official actions, such as the voting process to approve a collective declaration against the withdrawal of pharmacies from the UBS and an official request to find a solution for the current shortage of medicines in the area.



Local health council meeting in Cidade Tiradentes © Alexandre Calandrin Jan 2017

## 5. Enabling conditions and challenges

The case study compared four UBS: Carlos Gentile and Fazenda do Carmo, considered as having more participative councils with Gráficos and Prestes Maia, deemed as counting on fewer formal participatory institutions. It also looked at UBS hosting the Family Health Strategy, Gentile and Gráficos vis-à-vis Fazenda do Carmo and Prestes Maia, which do not reply on the strategy. The aim was to explore the assumption that a more two-way dynamic, one connecting community participation inside the UBS (active health councils) and health professionals' participation inside the community (presence of ESF), would enable the community's voice to be heard by the health bureaucracy and local political power and translated into policy changes more responsive to the needs of citizens living in the poor peripheries (achievements described in the interviews). To do so we compared, on one hand, councils' profile (more or less active) and the presence of the Family Health Strategy (yes or no), on the other hand, the achievements described in the interviews as a result of the local facility council work, which includes agenda-setting gains, institutional behaviour changes, daily routine problem-solving and policy changes.

We expected that UBS Carlos Gentile, which has both an active council and the ESF, would better articulate citizens' participation and reach a more comprehensive set of achievements. UBS Fazenda do Carmo and Gráficos should follow, albeit with less positive results, and Prestes Maia, would appear with more modest outcomes. If our expectations were confirmed we could take this a sign of the plausibility of our assumption.

The results of the study only partially confirmed our initial expectations concerning the enabling factors. In fact, UBS Carlos Gentile, based in one of the poorest visited areas,

displayed a comprehensive set of achievements in terms of institutional behaviour changes, mediation, monitoring and conflict resolution. UBS Fazenda do Carmo also performed as expected, displaying important, yet less comprehensive, achievements, which included mediation and engagement with other state mechanisms, such as the Judiciary. Nevertheless, UBS Gráficos and UBS Prestes Maia presented unexpected results. UBS Prestes Maia, which has neither an active council nor the ESF, displayed many achievements in relation to mobilisation, mediation and daily routine problem-solving (i.e. facility building improvement), while UBS Gráficos, which counts on the ESF, presented only modest achievements.

To understand these results we revisited the narrative presented in the earlier section and concluded that a third variable should be taken into account: the councilors' profile. That is to say: their personal characteristics and political connections. As such, this third dimension adds another layer into the analysis of institutionalised participation, inserting the dimension of individual agency into the explanatory model. *Table 3* compares the enabling conditions with the reported achievements (including agenda-setting gains, institutional behaviour changes, daily routine problem-solving and policy changes) in all four UBS.

**Table 3: Comparing community participation in four basic health units – Cidade Tiradentes, São Paulo, 2017**

UBS	LFC is active?	FHS is present?	Proactive Councilor	Achievements
<b>Carlos Gentile</b>	+	+	+	<ul style="list-style-type: none"> <li>• Mobilisation to stop the mayor's decision to shut down the UBS internal pharmacies</li> <li>• Strong links between councilors and local community</li> <li>• The council helped to address problems with violence that affected the UBS routine</li> <li>• Councilors help in mediating relations with the community</li> <li>• To monitor UBS conditions</li> <li>• To inform the UBS team about citizens complaints</li> </ul>
<b>Fazenda do Carmo</b>	+	-	-	<ul style="list-style-type: none"> <li>• Petition to the Judiciary to demand the presence of pediatricians in the outpatient service</li> <li>• Councilors are invited to take part in the UBS internal meetings</li> <li>• Councilors are asked by UBS professionals to help in mediating relations with the community</li> </ul>
<b>Gráficos</b>	-	+	-	<ul style="list-style-type: none"> <li>• Structural changes in the UBS building to facilitate the access for users with disabilities</li> </ul>
<b>Prestes Maia</b>	-	-	+	<ul style="list-style-type: none"> <li>• Structural changes in the UBS building</li> <li>• Support for SUS users to participate in outdoor activities</li> <li>• Mobilisation to support the continuity of mental health services in the UBS area</li> <li>• Councilors are called by the UBS professionals to mediate relations with the community</li> </ul>

Source: Authors' elaboration

These results that include a number of different and positive outcomes help to preserve and improve the SUS locally. They range from monitoring UBS conditions, addressing problems with violence that affect the UBS routine and successfully pressing for structural changes in the UBS building. These enabling factors are:

- a. the presence of an active health council
- b. the health councilor's profile, meaning his/her personality and level of political involvement in local politics and engagement with social movements
- c. the presence of the Family Health Strategy (ESF).

In terms of challenges, a limiting factor is the voluntary nature of this work. In a site where most people have, on average, 4-5 hours per day round trip commute to work in the expanded city centre, being a health councilor and earning no extra wage for that is a challenging task. The role of councilor is manageable only for those either living or working locally - such as small business owners who have some social bond to the communities - or already retired who have time or involved with social movements or engaged in local partisan politics. We believe this contributes to a more socially conservative profile of the councils and reinforces the exclusion of marginalised groups, such as inhabitants of new 'land occupations' (new *favelas*), which are not present there. Another challenge is how councils and councilors can learn to use social media to promote and communicate their activities to the community, as only one councilor confirmed using social media to comment on public issues.

## 6. Outcomes of the work

An issue that has gained prominence in the Brazilian literature concerning institutionalised participation is how to assess its effectiveness. After all, participation matters? How and when? (Pires, 2011). In one of the studies in this vein, Coelho and Waisbich (2016) point out the importance of councils' advocacy for access to health, infrastructure and security as constitutional rights as being key to implementation of the Brazilian universal health system during the 1990s, when the tendency was to reduce social policies. In the last 20 years, councils pushed to secure and expand financing and access to public health services, and the councils have defended those rights not only within the local and municipal councils, but also in state and federal councils and national health conferences.

The authors recognise the health councils' role in monitoring activities, overseeing the daily routine of health services, especially in poor and remote areas of Brazilian cities, including São Paulo, resulting in a more inclusive and dialog-oriented decision-making process. Nonetheless, according to Coelho and Waisbich, greater participation could not guarantee more equal relations among managers and councilors. For instance, public managers have their own agenda and the necessary means to make it happen, even when it implies ignoring opposing civil society voices.

For this present study, we have seen that participatory practices have resulted in a wide range of actors defending the SUS and working for its improvement. The outcomes of this work can be seen, for instance, in successful negotiations for improving health facility buildings, achieving greater accessibility for disabled patients, preserving the mental health support unit at UBS Prestes Maia and mobilising to ensure the continuity of pharmacists at UBS Carlos Gentile. The cases studies also suggests, as can be seen in *Table 3* (see *section 5*), that when community health workers are present and councilors are politically committed to mobilising and organising their community, a more comprehensive set of achievements could be reached, as it was the case in UBS Carlos Gentile.

It should also be highlighted that in the pharmacies episode, where councilors' position conflicted with the official position of the Health Secretariat, civil society succeeded, or at least influenced decision-making. This was a different result to what previous studies, such as the one by Coelho and Waisbich (2016), would have predicted.

The councilors fought inside and outside the councils, articulating institutionalised and non-institutionalised forms of participation, in a clear demonstration of how they combine them. They mobilised their communities to protest and influence policy guidelines and, together with other the forces that opposed the Health Secretariat, succeed, forcing the mayor to give up closing the UBS's pharmacies.

## 7. Discussion

This case study explored the assumption that a more two-way dynamic, one connecting community participation inside the UBS and health professionals participation inside the community, would be an enabling factor, helping the communities' voice to be heard by the health bureaucracy and local political power and enabling its translation into policy changes more responsive to the needs of citizens that inhabit the poor peripheries.

This assumption is rooted in a set of premises assuming that investing in social participation can improve (and has improved) the Brazilian SUS, making it more responsive to citizen's needs. To do so the case study looked at the local health councils (sub-municipality level) and the local facility councils (primary care health units level), in place for more than 15 years and part of a larger and older national structure for public participation. These mechanisms resisted the party political alternation during all these years and are still active from national to local levels. In their routine, they tackled the divide in public health systems between citizens, on one hand, and health professionals and public managers, on the other hand. This routine is expected to promote community empowerment and a better SUS. How? Empowering communities' capacity to identify problems and be part of the solution. As a note of caution, this capacity can change across the councils (and also in time), ranging from more instrumental and modest forms to more transformative and radical ones. The outcomes of the Brazilian health councils are recognised in the existing literature on citizen participation in health policies, and also present in the evidence gathered through this study, modest, yet transformative as they contribute to maintain and ameliorate a universal health system (Cortes, 2011; Wampler, 2011; Holcman et al., 2004; Garcia and Santana, 2011). In this sense, the SUS helped to promote health and tackle health inequalities (Coelho and Dias, 2015).

The findings presented throughout this study draw attention to the potential and also to the challenges involved in building participatory practices for health promotion in localities such as Cidade Tiradentes. First, this case indicates the role of an alliance between civil society groups, health professionals and public managers to implement and maintain a universal health system in violent and poverty-torn settings. When the state alone was not able to protect health personnel from assaults and violence, an alliance between the local health council and the UBS was needed to secure the presence of health professionals in these units.

Second, this case also shows that in marginalised neighbourhoods – such as Cidade Tiradentes – various civil society organisations are resisting the area's degradation and seeking to empower its inhabitants. Those actors have been able to make strategic use of the limited state institutions available on-site, including health councils, to deal with daily life problems affecting the community, including framing interactions away from a purely health perspective. The Carlos Gentile's HFC achievements show how important the coming together is of social mobilisation and institutionalised and non-institutionalised forms of participation.

Third, the daily work of the community health workers in mediating between the local community and other health professionals is an enabling factor for empowering citizens, less from a decision-making perspective than from their ability to make public services more aware and responsive to local community needs.

In the fourth place, health professionals in their daily routine are developing a collective work. Through peer-to-peer exchanges and capacity-building trainings received, those professionals are constantly striving to better understand and connect with the local reality.

Fifth, this study shows that the health councilor's profile matters. In other words, the councilor's personality and level of political involvement in local politics, as well as



engagement with either more local or city-level social movements, were at the core in energising the council's work. Those spaces would also benefit from a change of the socially conservative profile of the councilors, incorporating the representation of marginalised groups, such as inhabitants of new 'land occupations'. Democratising access to councils is an important frontier to be overcome to make them more accessible to the local, poorest citizens.

In sum, this study suggests that empowering citizens and their capacity to take part in the decision-making of issues affecting their daily lives can be achieved through active participatory institutions, working communitarian health practices, and vocal councilors. When reflecting on how to guarantee those enabling conditions, in our study it seems clear that power dynamics and political mobilisation are important factors. Active councils are those performing with experienced and well-connected councillors. Power and political mobilisation also help to explain why, and where, City Hall decides to expand the family health strategy in its local facilities. In sum, there is a virtuous cycle whereby more active councils and councillors are able to mobilize more active actors to play a role within the broader local political scenario.

## **7.1 Practices, measures and tools that may be adapted**

An important experience reported in the study is the building of institutionalised spaces, which lower the costs of political mobilisation and participation and help bring state and society actors closer. It is about mobilising, participating and sharing views and work. It is also about building institutional spaces – the councils, the Family Health Strategy, the capacity-building trainings and forums for exchange for health professional – that facilitate learning about both local realities and healthy behaviours. In this sense, we believe that these spaces are important because they facilitate the recognition and pursuit of shared goals.

Equally important is the presence of proactive councilors with political experience at all local councils. They help initiate beginners into the processes of participation, empowering other councilors in participating more fruitfully.

This study also reveals a series of key findings on community power, participation and social change in health that could inform policy debate in other similar contexts, such as:

- Promoting institutionalised alliances through health councils and conferences and other forms of non-institutionalised participation between civil society organisations and health professionals to support a universal health system;
- The importance of a process of building institutional spaces and programmes that open space for citizen engagement and for health professionals updating their links with the community;
- Organising meetings that bring civil society, health workers and public officials together to promote and protect social rights in the public debate;
- Fostering the role of community health councilors in bringing citizens'/users' demands, perceptions and suggestions to health managers and professionals;
- Fostering teamwork and capacity building in health personnel to enable their social connection;
- Supporting the work of community health workers in mediating the relationship between citizens/users and health professionals and in promoting healthy behaviour and facilitating access to healthcare for pregnant women, people with chronic diseases, mental health issues and the elderly.

## **7.2 What the site is interested to learn from other sites**

The participatory practices described in this case study demanded that political agency and social energy be built. This agency and energy were present during the re-democratisation process, when a coalition of people from different social and professional backgrounds came together to fight against the dictatorship. Nowadays, this structure plays a role in

generating policies and practices that contribute to sustaining a universal health system that strives to be more accountable to poor and marginalised populations.

The problem is that the challenge of inclusion and inequality persists as new groups arrive at urban peripheries, violence grows and poverty deepens with the economic crisis. In this situation we are interested, for example, in learning more about the conditions that allow organisations and individuals to mobilise and bring inhabitants of new informal settlements (new *favelas*) to participate in the institutionalised channels described in this case study.

We are also interested in learning more about how this institution building works to open spaces for dialogue and collaboration between state and society, in ways that could be stimulated by greater involvement of younger residents and promoted by more dynamic and creative forms of citizen participation through the use of social media and other innovative tools.

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Changing socio-political and economic conditions and social inequalities in wellbeing within and across countries affect health in ways that call for strategic collective leadership and action.

Health services need to craft approaches that successfully prevent and care for complex co-morbidities and promote health in populations that are diverse, literate and socially connected. Participation in health and in decisions on services is increasingly viewed not simply as a means to better health, but claimed as a democratic right.

How are local health systems organising social participation and power to meet these opportunities and challenges?

**There are many innovative, practical experiences and insights from those involved that we can learn from.**

Shaping Health, an international project, is gathering and sharing evidence and learning on how community members are participating in decisions on and actions in local health systems across a range of high, middle and low income countries. It aims to build peer to peer dialogue and exchange on approaches and practices that can be adapted in the USA and in other countries.

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Exchanging on social power in health

CEBRAP and TARSC 2017