

# 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: Citizen participation and co-management for health in Chile

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## Executive Summary

By law, citizen participation is mandated at all levels of Chile's decentralised public health system and supported by Ministry of Health norms, guidelines and performance incentives. The approach, established in the biopsychosocial model of municipal primary healthcare (PHC), envisions communities as co-participants in decision-making and action. It is part of the national democratisation and rights agenda and deepening policy measures since the 1990s, with established rights and mechanisms for access to information, public accounts, participatory public administration, and non-discrimination measures, backed by the 2011 Citizen Participation Law (Law 20.500). The public National Health Fund (*Fondo Nacional de Salud*, FONASA) covers 75% of the population. Supported by the Ministry of Health and co-ordinated by subregional health services, the integrated public healthcare system's strategic governance model has four integrated axes: citizen participation and user satisfaction; health team strengthening; efficient and effective healthcare; and intersectoral action.

The deep scan case study of Chile explores participatory practices at different levels of the public health system, ranging from local primary healthcare (PHC) centres (CESFAM), subregional health services, municipal health promotion, and an autonomous community initiative. This case 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.

The six experiences documented in the case study were identified by national authorities and experts as illustrative of practices, progress and challenges of citizen participation in health in Chile, and potentially relevant for global learning.

- i. The Adelaida in Biobío experience features empowered formal citizen councils, organised at local and provincial levels of the health system, capable of leveraging intersectoral and private sector resources for action on social determinants of health affecting people with disabilities.
- ii. A primary health centre (CESFAM), Madre Teresa de Calcuta, in the Santiago metropolitan region, addressed challenges developing a citizen participation plan with community representatives in a neighbourhood with little social cohesion, weak public infrastructure and disperse community resources.
- iii. In Santiago Sano, an adolescent committee of student leaders, organised in 10 municipal high schools, had decision-making control in development and publication of a sexuality manual.
- iv. Psircutopia, an initiative in a deprived neighbourhood of the northern city of Ovalle, engaged socially vulnerable youth in performance art, aiming to expand their self-esteem and capacities to express needs and connect with available services.
- v. Another Santiago CESFAM, Juan Pablo II, developed a receptive environment for exercise of health rights by immigrants, through culturally appropriate information and support for inclusion in local health councils, public accounts and citizen dialogues.
- vi. In contrast, Grupo Llaretta is an example of autonomous community-led work, generating resources and supportive networks over 30 years in a historically mobilised neighbourhood of Santiago, independent of government organisations.

The health system model of co-participation in decision-making describes community leaders, citizens and immigrants and their organisations as 'users' of public services, together with health or government professionals and workers. A priority focus, exemplified in the documented practices, is the engagement of vulnerable and marginal groups. The practices discussed adhere to national statutory and policy guidelines that seek to promote the exercise of active citizenship in the protection of health rights, in social control over public administration, and in the design, implementation and evaluation of public policies. Community participation at all levels of the health system is supported and enabled through norms, guidelines, performance goals, incentives and

financial inputs, set by the Ministry of Health. Territorial networks and partnerships with civil society and the private sector are key components, with NGOs playing an important role in reaching marginalised groups.

The participatory governance model in Chile is still in transition from more passive, information sharing and consultation-driven approaches towards more deliberative, empowering practices of participation. Despite policy attention to participation, processes are generally poorly documented and not evaluated. Yet, KI and other external sources reported general progress in citizen participation and perceived positive social and health results, particularly in understanding that participation is not just a means but an objective in its own right. The experiences documented provide concrete examples of how national policies promoting rights of all people and more comprehensive primary health care (PHC) have played a role in implementing health-sector driven mechanisms and spaces for participation. Participants in these formal spaces are increasingly claiming greater autonomy and forming networks. Civil society organisations are providing critical input in driving greater decision-making power and influence and demanding more empowering commitments and support by government. This highlights the relevance of Grupo Llaretá's vision of 'ceded' top-down spaces, echoed in a 2017 report of the National Council on Citizen Participation.

A key insight from the case study is the importance of defining the social roles, objectives and results of participatory practice. Even basic practices at the level of informing, such as information and complaints offices and public accounts, are meaningful if people are truly involved before, during and after. Some space of power to decide on specific issues prioritised by the community, with concrete interventions, financing and measured results are seen to be critical for achieving change, particularly from the perspective of social actors.

Another important feature is the territorial approach to participatory governance, which means engaging people and communities where they live, study and work, particularly socially vulnerable groups who are not accessing health and social services, in transforming environments and the health system. Especially notable is the link to economic activities, including the eco-orchards in Biobío, which use recycled organic materials, and the network of healthy food carts/kiosks in Santiago. Eco-garden initiatives in schools in Biobío contribute to healthy eating environments. Healthy Spaces in Santiago uses participatory diagnosis and budget proposals to remodel public spaces. The explicit inclusion of people with disabilities, immigrants and other marginalised groups in councils, committees and diagnosis and planning processes is a requirement of participatory governance. One specific practice, the co-design and production of health materials with communities (adolescents and immigrants), is underscored. Citizen health councils can also be adapted elsewhere. In Chile these are not elite boards, but composed of users, community and health worker representatives, providing unique, valued knowledge on needs, expectations and 'common sense' solutions. Many of the methods and tools applied in Chile are well established in other contexts. Participatory diagnosis with citizens and social organisations applies various options (brainstorming, sociograms, problem trees, flowcharts, and problem/solution matrices), many as visual methods, and there is online guidance with links to additional sources.

Chile's efforts towards transformative citizen co-management for health and wellbeing continue, with an emphasis on empowering spaces and support for communities. Valuing different types of knowledge and building horizontal spaces for joint learning and action with health workers, the health system is increasingly integrating intersectoral action and involving community actors as the basis for authentic participation. This has long been championed by institutions such as [Fundación EPES](#), and autonomous community initiatives, such as Grupo Llaretá and the diversity of civil society actors that form the National Council on Citizen Participation. This national body's 2017 report proposes constitutional, legislative, institutional and national budgetary provisions to advance empowering participation in public decisions, within continuing efforts to shape social power in Chile.

## 1. The site

By law, citizen participation is mandated at all levels of Chile's decentralised public health system and supported by Ministry of Health norms, guidelines and performance incentives (Subsecretaría de Redes Asistenciales, 2017). The approach, established in the biopsychosocial model of municipal primary healthcare (PHC), envisions communities as co-participants in decision-making and action:

*The community and health teams identify and analyse problems, formulate and negotiate proposals and actively satisfy the prioritised needs of the population in a purposive, democratic and concerted way* (Subsecretaría de Redes Asistenciales, 2013b:85).

This deep scan case study on Chile examines six experiences, which illustrate participatory practice at different levels of the integrated public health system, including local PHC centres (Centro de Salud Familiar, CESFAM) a sub-regional health service, municipal health promotion, and an autonomous community initiative.

**Figure 1: Map of Chile with sites**



Source: Adapted from <http://chiletraveltours.com/images/>

Four of the experiences are from low- and middle-income municipalities in the Santiago Metropolitan Region. The Biobío site explores practices in a high-poverty southern province, where 29% of the 396,041 inhabitants are rural, 32.1% live in poverty, and 24% present some level of disability, particularly women (INE, 2016). Another is located in Media Hacienda, a marginal, high-poverty neighbourhood confronting drug use in the northern municipality of Ovalle (Figure 1).

The experiences focus on an array of issues, including empowered citizen councils within an intersectoral network to improve health and wellbeing of people with disabilities (Adelaida), participatory planning (CESFAM Teresa de Calcuta),

engagement of marginal adolescents (Santiago Sano and Psircutopia), rights of immigrants (CESFAM Juan Pablo II), and community-based action on gender violence (Grupo Llareta). (See summary description in *Appendix 1*.)

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 selected high-, middle- and low-income countries, with support from the Robert Wood Johnson Foundation Global Ideas Fund at CAF America.

## 2. The context

Chile is a democratic country of 17.5 million inhabitants, with a centralised government. President Michelle Bachelet is in her second term of office, 2014-2018. The country is organised into 15 administrative regions and 346 municipalities with elected mayors. Sustained economic growth in the free market economy has led to improved wellbeing and dramatic reduction in poverty. Annual per capita income (GNI, Atlas method) is US\$14,100 (2015), around 25% that of the United States (World Bank, 2016). Social inequalities are profound, exemplified by a highly unequal income distribution with a Gini index of 0.465 (OECD, 2016) despite a slight decline in recent years.

Average life expectancy at birth is the second highest in the Americas after Canada at 80.5 years (83.4 years for women and 77.4 years for men) (WHO, 2016). The demographic transition is advanced, with growth under 1% and a population structure with 20.6% children (0-14 years) and 14.5% elderly (60 years or more), and the latter projected to reach 18% by 2020 (INE, 2014). Promising economic prospects have led to increased migration to Chile, particularly from Latin America and the Caribbean, doubling the immigrant population between 2002 and 2014, reaching 2.3% of the total population (OECD, 2014; Rojas Pedemonte and Silva Dittborn, 2016). Like many middle- and high-income countries, Chile is facing changes in health risks associated with population aging and consumer economies, including environmental pollution, stress, social isolation, substance abuse and unhealthy behaviours. Non-communicable diseases account for 83% of total disability-adjusted life-years and injuries for 12%, with only 4% due to communicable diseases, maternal, perinatal and nutritional deficiencies (Ministerio de Salud, 2007).

The notion of state responsibility in health insurance and provision, particularly for vulnerable groups, is longstanding, first manifest in the 1952 National Health Service and enduring through neoliberal privatisation and decentralisation in the National Health Fund (Fondo Nacional de Salud, FONASA) (Mardones-Restat and de Azevedo, 2006). Recent health and social policy reforms, which have generated global interest, emphasise fulfilling citizens' rights and improving equity, moving from targeted to progressive universalist approaches (Contreras and French-Davis, 2012). For 80 priority health problems, the [AUGE](#) (FONASA, no date) plan (acronym for Acceso Universal con Garantías Explícitas) entitles affiliates of both public and private health systems to guarantees of access to quality care in accordance with clinical guidelines, maximum wait times for diagnosis and treatment, and financial protection (caps on out-of-pocket payments) (Gilbert, 2012; Bossert and Leisewitz, 2016). Intersectoral approaches to integral social protection are evolving from a focus on indigent families in Chile Solidario (2002) to progressive universalism across the life course, particularly early child development in [Chile Crece Contigo](#) (Gobierno de Chile, 2017a) (2008), established during President Bachelet's first term in office (ECOSOC, 2008; Gobierno de Chile, 2017a).

Chile has nearly universal health coverage through its two-tiered insurance system, in which all dependent and independent workers make mandatory 7% salary (or reported income) contributions to the public fund, FONASA, or pay more (averaging 10%) for private insurance (Instituciones de Salud Previsional, ISAPRE) (Ministerio Secretaría General de la Presidencia, 2005). Over 75% of the population is covered by FONASA, overwhelmingly poorer, elderly and sicker people, priced-out of or excluded from private insurance due to risk or pre-existing conditions. FONASA provides access to healthcare services mainly through the National System of Health Services (Sistema Nacional de Servicios de Salud), co-ordinated by the Ministry of Health's Undersecretary of Health Care Networks (Subsecretaría de Redes Asistenciales). It allows access to registered private providers with the purchase of 'free-choice' vouchers. This public health system includes 29 Health Services (Servicios de Salud), integrated territorial healthcare networks of public hospitals and free municipal PHC. PHC centres, including attached urgent care services, are the main entry points, aiming to resolve 90% of the assigned population's health needs with appropriate referral to hospitals (Subsecretaría de Redes Asistenciales, 2013a).

The PHC biopsychosocial family and community health model, applied in most Family Health Centres (Centro de Salud Familiar, CESFAM) throughout Chile, has a life-course preventive approach, including maternal-child care, cardiovascular and mental health control programmes with AUGE guarantees. According to a Ministry of Health key informant, in 2016 around 50% of PHC facilities were certified as applying the model, including a majority of larger CESFAM, serving most of the national population, such as those in the study sites. Smaller centres, community hospitals, rural stations and outposts are still developing the model's requirements. The model encourages a strong social role for families and community organisations with specific mechanisms, tools and incentives, in line with broader national legislation for participation (Subsecretaría de Redes Asistenciales, 2015b). Several factors constrain the intent to move teams out of centres to work with

families and communities. Overwhelming demand for medical care, arising from the accumulated disease burden, has shifted resources towards PHC urgent care. Scarce resources are skewed towards biomedical AUGE guarantees, further aggravated by difficulties to attract and retain physicians and family medicine specialists in PHC, related to salary, working conditions, perception of low professional challenges and prestige (Goyenechea and Bass, 2013). Intersectoral health promotion policies for healthy diet and exercise, using community and settings approaches, began in the late 1990s with the 'Vida Chile' programme. Now the 'Choose Healthy Living in Community' intersectoral system ([Elegir Vivir Sano en Comunidad](#)) is under the Ministry of Social Development (Ministerio de Desarrollo Social), which co-ordinates integral social protection policies (Ministerio de Desarrollo Social, 2017).

Citizen participation in health in Chile has a long history: Mobilisation of popular classes had a central role in the creation and development of the health system and policies prior to the 1973 military coup. The memory of this, in which disadvantaged communities collaborated in health system-building and in social responses to public health problems, continues to shape – but also somewhat overshadow – current participatory practice (Hadjez-Berrios, 2014). After the return to democracy in 1990, the notion of participatory administration in health was re-established in a new context of decentralisation and a free-market economy (Torri, 2012). Over the last decade efforts to create more robust spaces/mechanisms and to renew a culture of meaningful participation include [Law 20.500](#) (Gobierno de Chile, 2012), which establishes citizens' rights to public information, participatory public administration, civil society strengthening, and non-discrimination and respect for diversity (Gobierno de Chile, 2012). Recently, the National Council for Citizen Participation and Strengthening of Civil Society, established in 2016, after a year of work and regional dialogues, presented in January 2017 a report to the President, calling for a constitutional right to participation, strengthening of Law 20.500, a permanent autonomous national council, and other institutional, legal and policy changes (Consejo Nacional de Participación Ciudadana, 2017).

Within this framework, Ministry of Health norms (2015) define community participation in government and health as:

*...a process of co-operation in which the State and citizens jointly identify and deliberate on public problems and their solutions with methodologies and tools that promote creation of spaces for reflexion and collective dialogue, aimed at the active inclusion of citizenry in the design and making of public decisions.*

*...the capacity to influence decisions on health, in relation to the design, implementation, evaluation of policies, plans, programmes, and projects linked to recovery, rehabilitation and prevention of disease and health promotion, as well as decisions related to use and investment of public resources. (Ministerio de Salud, 2015:1)*

Community participation and user satisfaction, health team strengthening, efficient/effective health services and intersectoral action, are key governance and strategic axes of Chile's integrated public health networks model (OPS, 2010; Subsecretaría de Redes Asistenciales, 2013b). The specific mechanisms and tools to channel citizen demands/inputs and to enable participatory decision-making and action, in this co-management perspective, include:

- a. **Accountability** and social control through annual public accounts, whose contents and mechanisms of reporting on policies, plans, programmes, and budgets are jointly decided with community members. The [public account](#) process is mandatory for the Ministry of Health, Health Services and some hospitals and widely adopted by PHC (inetchile, 2017). It includes reports, formal presentations and dialogue with the community on all management decisions, including measures to strengthen access to public information, participatory public management, civil society action and non-discrimination and respect for diversity.
- b. **Physical and online offices** of information, complaints and suggestions, called **OIRS**, whose acronym means 'listen' in Spanish, are mandatory in all public services and facilities. They are direct mechanisms of participation, enabling individuals to receive information,

make suggestions, complaints and pay compliments. Standard procedures are in place to respond to all [complaints](#) (Superintendencia de Salud, 2014) within 15 days, together with periodic reviews by facilities and healthcare networks to incorporate appropriate management and programme improvements and redress measures, as for example, in relation to more dignified, respectful treatment, waiting times and deft administrative procedures.

- c. **Non-discrimination and inclusion** practices to increase socio-culturally appropriate services and exercise of rights. Examples include concrete measures related to [friendly hospitals](#) (Hospital San Juan de Dios, 2017). Intercultural programmes and approaches developed with [indigenous communities](#) (Ministerio de Salud, 2016b), immigrant groups and [gender](#) perspectives (Servicio de Salud Talcahuano, no date).
- d. **Civil society and citizen councils** are formal participatory bodies with advisory, control and increasingly deliberative roles, which are an integral part of the public health system's institutional and management framework at all levels. Local development councils of PHC centres work in tandem with health teams and are represented in Health Service level civil society councils (COSOC). Twenty-two of 29 Health Services include community members in their Integrated Health Network Councils (Consejo Integrado de Red Asistencia, CIRA), joint decision-making bodies of health directors from different levels (Artaza-Barrios et al., 2013).
- e. **Citizen consultation and dialogue** meetings and activities are generally convened by Health Services, Regional Health Authorities and PHC centres, but organised by the community. They aim to involve individuals and community and social organisations in defining priorities and providing inputs for design, implementation and evaluation of health policies and programmes, related to emerging problems, changes in laws and regulations, new technologies and other issues affecting population health.
- f. **Community health workers and other resources** for outreach and implementation of health plans and programmes.
- g. **Participatory budget** mechanisms were implemented in eight Health Services in 2016-2017 to jointly decide public spending on health prevention and promotion activities, improvements in service quality and other policy priorities. While still marginal in terms of the total public budget, the option of competitive funds, administered by health and other government sectors, to finance projects presented by social organisations. Is growing (Subsecretaría de Redes Asistenciales, 2013a, 2015b; Ministerio de Salud, 2015). In addition, the majority of infrastructure projects and investment plans consult citizen councils and the community in their design and monitoring, including site visits.

### 3. The case study

The Chile case study aimed to understand practices of meaningful participation, power and decision-making in health, drawing on six municipal/local and subregional experiences within the national model of citizen participation. It inquired about the facilitators and barriers to and processes for wider application, following the framework provided by Training and Research Support Centre (TARSC) and prioritised areas identified with US sites (Loewenson, 2016; TARSC, 2016).

The specific experiences were selected in consultation with participation departments of the Ministry of Health, Health Services and other experts to display innovative applications and identify challenges. An initial selection was discussed with TARSC and the sites in the USA at the 2016 convening meeting, and further refined in consultation with TARSC (*Appendix 1*). Ethics approval was obtained from the Faculty of Medicine, University of Chile review committee. A document review was carried out (*Appendix 2*). Additional data was supplied by key informants and group interviews with health sector and community actors (*Appendix 3*). Interviews were audio-recorded and transcribed.

The focus of the data analysis was on the mechanisms, resources, methods, and tools for community participation and decision making; the improvement in health and the health system they

seek to bring; actual practice and functioning; the enabling factors and the challenges faced in implementing approaches for community participation, power and decision-making; the inclusion, voice and agency of those most at risk of poor health; and national and local health service measures and mechanisms that facilitate or block these arrangements.

This report combines findings from the document review and interviews in describing, analysing and discussing the participation practices, processes and mechanisms; their contribution to the changes sought; the supporting and disabling factors affecting these outcomes; and on what may be useful for wider application in other contexts, including in the USA.

## 4. The participatory work

The six experiences of participatory work examined in the case study were selected to illustrate practices and challenges of community participation in different areas and levels of the health system:

- i. **Biobío Health Service's Adelaida and health council experiences** feature empowered formal citizen councils, organised at local and provincial levels of the health system, capable of mobilising intersectoral and private sector resources for action on the social determinants of health affecting people living with disabilities and other marginalised groups.
- ii. **CESFAM Madre Teresa de Calcuta's roadmap to strengthen participation** illustrates the challenges of developing a citizen participation plan with community representatives in a neighbourhood of Santiago with little social cohesion, disperse community resources and weak public infrastructure.
- iii. **The Santiago Sano adolescent committee** of student leaders, organised in ten municipal high schools, had decision-making control in the development and publication of a sexuality manual for adolescents.
- iv. **Psircutopia**, in the northern municipality of Ovalle, engages deprived and socially vulnerable youth in performance art to expand their capacities to express needs and effectively obtain available services.
- v. **CESFAM Juan Pablo II's work with Haitian immigrants**, in the Santiago metropolitan region (MR), developed an intercultural approach to create a receptive environment for exercise of health rights by the immigrant population, providing culturally appropriate information and supporting inclusion in local health councils, public accounts and citizen dialogues.
- vi. **Grupo Llareta** has over 30 years of autonomous community-led work on human rights and social determinants of health with a gender focus, maintaining independence from the health system and government. The group of community leaders has generated resources and supportive networks in a historically mobilised neighbourhood of Santiago.

These experiences share a common vision and aim to improve health through community participation, based on empowerment and exercise of rights. Yet, they also display differences in scope and stages in the ongoing efforts to transition from paternalistic, informative approaches to participation towards more deliberative, empowering models, in which individuals and communities share power in making decisions and taking action for health.

Collectively, they involve a range of actors:

- **State and citizen co-participants.** In the PHC model of co-participation in decision-making and action, the main actors are 'users,' a term used to describe community leaders, citizens and immigrants who use public services and their organisations, as well as 'internal' users or health or government professionals and workers. Community resources aim to supplement professional and technical teams and resources for health. Nevertheless, the level of co-management and empowering participation achieved varies in different localities. The involvement of state institutional actors also varies among the experiences, minimum in Grupo Llareta, supportive in Biobío and Santiago Sano and leading processes in other

experiences. Other community actors include academia, non-government organisations (NGOs) and the private sector.

- **Vulnerable and marginal groups** are a focus of participatory practice to build awareness and support exercise of rights. The six areas of practice described in the next subsection all cover specific disadvantaged groups:
  - i. In Adelaida, people with disabilities, their families and organisations in provincial and municipal Community Disability Councils (Consejo Comunal de Discapacidad, CCD).
  - ii. In CESFAM Madre Teresa de Calcuta, schools, church groups, senior clubs and other social organisations in a low resource community.
  - iii. The Santiago Sano and Psircutopia experiences focus on adolescents in general and specifically those at risk for drug and alcohol abuse, respectively.
  - iv. In CESFAM Juan Pablo II immigrant families from Peru, Bolivia and Haiti.
  - v. In Grupo Llareta, the whole community, particularly women.
- **Professionals, workers and institutions** in the health sector, given the state commitment to [participatory governance](#). Each PHC CESFAM has a team dedicated to facilitating social participation activities, with at least half-time of a professional, usually a social worker, psychologist or social scientist with expertise in qualitative and participatory methods, supported by other staff. These professionals usually take part in regular training activities on topics such as human rights, gender, intercultural approaches, popular education, community psychology, social action-investigation techniques, social education, social and community anthropology and public management. Additional resources and guidelines are provided by Health Service participation units and the Ministry of Health. The type of professional involved in the participation activities also depends on the issue in focus. For example, Santiago Sano included communication and sexual health experts to support adolescents, and Psircutopia involved actors and other artists to implement workshops. A common cross-cutting feature was the strong commitment to community and participatory work. In part, it was motivated by Ministry of Health policy priorities, performance goals and incentives, including professional advancement for completion of training activities. However, professional gratification was also an impetus, according to several KIs.
- **Other actors**, including NGOs, universities and the private sector, trained by Fundación EPES in participatory strategies with Group Llareta and in Adelaida inclusion of the private business community and industrial unions. Academic personnel also gave support to surveys, studies, qualitative and participatory action approaches and training.

#### 4.1 Biobío Health Service: Empowered councils in the Adelaida strategy

The Adelaida in Biobío strategy, inspired by public health policy recommendations from the 1988 global health promotion conference in Australia (WHO, 2010), is a community and intersectoral, territorial strategic plan for health. The province's health system and its citizen councils play pivotal roles. Co-ordinated by the [Citizen Participation](#) (Servicio de Salud Biobío, 2017) unit of the Biobío Health Service, it responds to a Ministry of Health performance goal on intersectoral, participatory work (N°14) (Gobierno de Chile, 2016; Servicio de Salud Biobío, 2017). Adelaida prioritised the population living with disabilities in the province, seeking to mobilise intersectoral, community and private sector resources to enhance social inclusion and improve wellbeing, through exercise of rights, capacity building, creation of job opportunities and compliance with non-discrimination laws.

The Biobío Health Service has around 30 formal citizen councils, including PHC local development councils, hospital councils and municipal health and social department bodies. The members of the councils are users of public health facilities or representatives of civil society, social or functional organisations, and health workers, who are elected every two years by the community and health teams. The PHC councils have historic origins in 1970s councils, which were revitalised after the return to democracy, strengthened in 2000s in the context of the AUGE health reform, and further

reinforced in the last decade. Now they are constituted as legal entities, which enable them to present projects for public funding from health and other government sectors.

*In 1996, the Ministry began to ask health centres to constitute Development Councils or Consultative Councils, as they are also called, or Health Committees in the rural stations (postas). In theostas, the Health Committees are years old. They never ceased to exist, because they support the work of health technicians who are in charge. We had fiveostas then, so we started to think about expanding participation and working with the health teams. We started to think about generating a new network of organisations, to finally have effective participation, not just on paper -- KI CESFAM Biobío, 2017*

Their role is considered integral to the participatory management approach of the family health biopsychosocial and the integrated health services models (Subsecretaría de Redes Asistenciales, 2013b; Servicio de Salud Biobío, 2017).

*I once included a performance goal for PHC directors, as part of their evaluation that was to be evaluated by the President of the Development Council [CDL]. Why? Because I do not care if [the Director] tells me, 'Listen to this, we did this and that' if the community is not involved and doesn't know what they are doing, I am not interested -- KI, Health Service, 2017.*

A provincial network of councils was established to identify and address common challenges and needs, share local experiences and best practices in effective participation (see photo). In Biobío, councils work with CESFAM, hospital and health service teams in various activities to involve individuals, families and social organisations in the design, implementation and evaluation of territorial plans and programmes to improve population health and healthcare services, using social determinants of health perspectives. One of the main lines of action of Adelaida was capacity building of civil society leaders to advance intersectoral and private sector action.

According to key informants, Adelaida works because of the strong social and organisational base at local and provincial levels. People with disabilities, their families and organisations participate in Municipal Community Disability Councils (Consejo Comunal de Discapacidad, CCD). The councils function as local support networks for the design and implementation of policies, programmes and projects benefitting this subpopulation. The local councils work directly with the Biobío Health Service Participation Unit, but also form part of the Provincial Disability Network together with other government sectors and the private sector, established in 2015, building on prior work that began in 2009. The private business community and industrial unions are represented in the provincial network by an industry association, the Sociedad de Fomento Fabril (SOFOFA) (SOFOFA, no date).



5th Annual meeting of Local Health Councils, Biobío Province © M Mazzei, 2016

*I am the leader of the Municipal Disability Council. We work with support networks, which include the Health Service of Biobío and all public entities; and through them, we bring benefits to each municipality where there are these councils; work together with them, set territorial goals, and analyse shortcomings, strengths, weaknesses. We carry out projects that benefit the entire province. -- KI community Biobío, 2017*



Rights march Adelaida, Los Angeles, Chile ©Biobío Health Service, 2016

The municipal councils define an annual work plan around priority issues to improve living and working conditions of people with disabilities, facilitate access to services, and inclusion in social networks. They elect an executive board, which represents the members before governmental and non-governmental entities, manages the annual plan, develops projects to obtain financial resources and mobilises the community. The provincial council meets every month to review progress and challenges

presented by working group commissions, organised to manage solutions to priority issues, such as accessible infrastructure, housing, health, training and employment. In addition, members organise activities to engage their base organisations. Leadership training of community, health and sectoral participants through courses and workshops was and continues to be a key aspect of local and provincial plans. Currently the Health Service is implementing 'Schools for Leaders' to strengthen organisational capacities, for example to present and manage project proposals for public funds. Various participatory mechanisms and tools, including information offices, direct consultation through webpages, dialogue events and support to form social organisations, are used to engage people with disabilities and their families in activities. Social media tools, such as Facebook ([CCDMulchen](#)) (CCD Mulchen, 2017), [Red provincial de la discapacidad](#) (Red Provincial de la Discapacidad Biobío, 2017), [participación ciudadana SSBB](#) (Servicio de Salud Biobío, no date)) are widely used by the community. WhatsApp groups facilitate co-ordination and dissemination of council activities with members, wider working groups, and the community. KIs indicate that several Biobío PHC Local Development Councils have implemented communication mechanisms to reach communities, especially those in more isolated areas. These mechanisms include magazines and radio programmes, considered to be especially useful for promoting activities and providing information on access to health services.

The local councils participate in healthcare management activities, such as review of waiting lists, allocation of medical visits, home visits, and support to users. Representatives are integral participants in the technical, Health Service-level councils for healthcare network integration (CIRA) to provide pragmatic, user perspectives. They are also actively involved in health promotion actions, such as neighbourhood improvement and environmental risk control projects, community training and health education activities and campaigns related to issues such as nutrition, exercise, and access to preventive services. For example, according to KIs during 2016, the CESFAM Norte Council in Los Angeles, Chile, advocated for reactivation of a construction project for a new CESFAM, Nuevo Horizonte. It also carried out mini-health promotion activities in CESFAM waiting rooms, schools and other community settings, related to healthy eating, smoke-free environments, environmental protection and responsible ownership of animals, participated in community health fairs and health campaigns.

*We worked hard on promotion, disease prevention with the users, handing out brochures, we hold Olympics, micro-events in the CESFAM, we work with schools -- KI CDL, CESFAM Norte, 2017.*

The CESFAM Norte Council supported self-help organisations for people with disabilities, elderly people, and rural organisation leaders and users. It advocated before the Biobío Health Service for funds to pay transportation costs of rural community leaders to facilitate their participation in different activities. In 2014, 2015, and 2016 they were awarded participatory budget projects by the Health Service to train community health monitors and to generate a network of eco-orchards, which uses

recycled organic material, in the five rural health stations associated with CESFAM Norte. In 2017, the project was expanded to include two rural educational establishments. Other local health council initiatives enhance community green spaces and healthy eating through creation and maintenance of eco-gardens (Servicio de Salud Biobío, 2017).

## 4.2. CESFAM Madre Teresa de Calcuta: Participation in a context of low social cohesion

In 2016, the Ministry of Health set a new PHC performance goal for community participation to strengthen territorial, sociocultural and rights-based participatory approaches. PHC centres were required to develop and implement a participation plan in conjunction with the community and its organisations, following the biopsychosocial model (Subsecretaría de Redes Asistenciales, 2015a; Servicio de Salud Metropolitano SurOriente, 2015). According to ministry and community KIs, council members and other civil society actors from different parts of the country suggested the change, aiming for more effective participation in the health system. CESFAM Madre Teresa de Calcuta saw the new mandate as an opportunity to build a network for participation that involved users and health teams in a community that was not demanding participation. The community it served in Puente Alto, on the outskirts of the Santiago RM, was a new neighbourhood created from public housing programmes with low social cohesion and poor public infrastructure.

A CESFAM social worker in charge of community participation dedicated 15 hours weekly to develop the participation plan, with support of another health worker for two hours weekly.

*We said: well, let's take advantage of a chance to do something more interesting to re-link with the community. Let's also take advantage of the schools. And our design was that, a little broader, maybe a bit too ambitious... and that was what we did in December 2015, January 2016, when we decided to establish bonds with all these local actors... The first thing was a first broad call and invitation to participate. Then we decided to involve specific actors. Anyway we had to go to them and give them the invitation... finally we got three schools and a kindergarten involved during the year and other representatives of community organisations... We managed to include several senior clubs and the collaboration of parishes here in the sector. And the others are representatives of the neighbourhood council, a housing committee. But there was no [spontaneous] demand from the community. We went, we called on them, we invited them and they agreed to join this participation plan -- KI CESFAM2, 2017.*

The stages of the participatory activities to develop the plan, included (CESFAM Madre Teresa de Calcuta, 2016b):

1. *Visits and public call:* During the CESFAM public account in April 2016, the planning process was launched with a public invitation for the community, municipal and health workers. In April and May 2016, the two-member participation team visited schools, senior clubs, neighbourhood territorial organisations, parish groups, a community housing committee formed around a municipal neighbourhood improvement project in Villa Porvenir, the CESFAM council and other social organisations to invite them to participate. A logo was designed to identify the planning activities that were posted on the CESFAM [blogspot](#) and other communications (CESFAM Madre Teresa de Calcuta, 2016a).

2. *Participatory diagnosis:* At the beginning of the process, a diagnosis of the situation and type of participation in the community was carried out, using focus groups and a survey questionnaire. Fourteen focus groups, four with health teams and ten community groups, were convened around strategic groups in the CESFAM territory, including schools, seniors, and





community is still not really empowered or even motivated to participate. Interest was primarily focused on expanding medical and dental appointments, which mainly depends on the CESFAM budget. In addition, after the planning stage, budgeted CESFAM staff time for implementation of participatory activities has decreased. Thus, KIs aim to sustain engagement of the groups that had participated in the planning.

### 4.3. Santiago Sano: Adolescent sexuality manual

[Santiago Sano](#) (Dirección de Salud de la Municipalidad de Santiago, 2014b) is a health promotion strategy of the Municipality of Santiago, based on health in all policies and population health approaches, which began in 2012 with Mayor Carolina Tohá and continues under the new administration, elected in 2016. It aims to improve the health and wellbeing and reduce the risk of non-communicable diseases of the 1.8 million people who reside, study, work or transit in the city centre. It seeks to do this through interventions in neighbourhoods and work with community groups to promote healthy eating, physical activity, reduction of alcohol and tobacco consumption (Dirección de Salud de la Municipalidad de Santiago, 2014b). The community participation strategies range from participatory diagnosis, definition of priorities, design and content of initiatives, participatory budgeting, joint implementation and evaluation. The initiatives implemented include [a network of healthy food carts/kiosks](#) (Dirección de Salud de la Municipalidad de Santiago, 2016), which unify distribution of food trucks and stands to increase availability of healthy products; [Healthy Spaces in Santiago](#) (Dirección de Salud de la Municipalidad de Santiago, 2014a) based on participatory diagnosis and budget proposals to remodel public spaces; and the campaign '[Let's make a deal for good treatment](#)' (Municipalidad de Santiago, 2016b), a communication strategy to promote recognition of children as subjects of rights (Dirección de Salud de la Municipalidad de Santiago, 2014b).

One innovative participatory experience was the co-design and elaboration of a sexual health manual with adolescents: 'Building Healthy Environments in Santiago: 100 Questions on Adolescent Sexuality' (*100 preguntas sobre Sexualidad Adolescente*) (Municipalidad de Santiago, 2016a). The municipality had set up adolescent friendly spaces for individual and collective health interventions in six municipal high schools in August 2014 (Dirección de Salud Santiago, 2017).

*...friendly spaces inside the high schools with a psychologist, who would carry out brief interventions to address problems of substance consumption, and also a midwife, who would liaison with the community and deliver sexual and reproductive health counselling services -- Santiago Sano, group interview, 2017.*

The adolescent friendly teams held sexual health workshops, which ended with an opportunity for participants to raise questions anonymously, express concerns and make suggestions to design and improve future activities.

*At the end of those workshops, a box was passed to receive any questions they had for evaluation. There came a time when we had so many questions and there was no space to address them during the workshops -- Santiago Sano, group interview 2017.*

Given the large number and range of concerns raised by the adolescents, Santiago Sano decided to systematise the questions and answers in a published manual. Santiago Sano obtained financing for an advisory panel of experts, design and publication costs, but ceded leadership to an adolescent committee, in order to effectively address their concerns.

*Using money from the Integral Health Care Model fund of the Ministry [of Health], we allocated resources to hire an illustrator, and the rest of the things, and to print the book in paper format. At that moment, we began to think about how to disseminate the book, so we set up an Editorial Committee with staff from Santiago Sano. But we realised that we did not know very well what adolescents were like, how they communicated, what things were of interest. We had lots of questions that we had to choose from, which ones should go in, how to design the book? So we decided to create a committee of adolescents, letting them make*

*those decisions; essentially all the editorial decisions of the book. That's what we did --*  
Santiago Sano, group interview 2017.

Once the decision was made to establish the Adolescent Committee, it had autonomy to develop the process of choosing the questions that the text would answer.

*The committee was formed in six schools where we had friendly spaces and in four other national schools of excellence, so it represented the diversity of public high schools in the municipality. Adolescent leaders were chosen by the schools; we had no say in that --*  
Santiago Sano, group interview, 2017.



Santiago Sano Adolescent Committee at work ©  
Santiago Sano. 2016

The adolescents worked with the experts to make sure that the responses were accessible in language and tone.

*Later, in the following sessions they asked illustrators for test illustrations with one of the questions, which was how to put on a condom. Then, from those illustrations, the teenagers voted for the illustrator they liked best, and that was the illustrator we hired --*  
Santiago Sano, group interview, 2017.

The book was printed and launched in September 2016. The uncensored text was criticised by conservatives, generating a public controversy that was fueled by the municipal election (Rehbein, 2016). The

mayor and the executive committee had to defend the initiative. Many parents and adolescents openly voiced support for the process in mass and social media (Cooperativa, 2016). However, the debate limited the widespread distribution of the printed copies, especially after the mayor-elect announced it would not be republished. Yet, to some extent, the controversy also enhanced its impact. Other municipalities copied the initiative. Printed copies are available upon request and the [digital version](#) was made available on various external websites (Municipalidad de Santiago, 2016a).

#### 4.4. Psircutopia: Engaging adolescents through performing arts

Psircutopia was started in 2012 by the Department of Health and Environmental Hygiene of the Municipality of Ovalle, deriving from the need to provide specialised prevention and treatment of drug and alcohol abuse for youth under-20 years of age, in compliance with AUGE guarantees. The department was aware that older children and adolescents, especially those with substance abuse problems or at high risk, were not engaging with the PHC centres, but were often referred from family and criminal courts. The aim was “to contribute to the development and promotion of social inclusion of children and young people with transgressive and/or risky behaviour, which increases the probability of delinquency, interpersonal violence and perception of insecurity in excluded and social vulnerable sectors in urban radius of the Municipality of Ovalle” by providing opportunities to engage in performing arts workshops and events (Ilustre Municipalidad de Ovalle, 2017:1). The goal was to increase the adolescents’ self-esteem and capacities to express needs and obtain available services through performance, self-help groups and community activities (Ilustre Municipalidad de Ovalle, 2017).

In 2011, the health team began offering treatment for problematic consumption of substances by children and adolescents in schools, outside health centres. A full-time psychologist would go to municipal schools to diagnosis and treat adolescents, admitting them to the AUGE programme. Afterward, a social worker was hired to handle adolescents’ social problems. This psychosocial team provided individual and family group psychotherapy, mental health consultations, home visits and group psychosocial interventions. In 2012, the health department implemented a physical space in a marginalised neighbourhood with a large number of people who had migrated from Santiago in

previous decades with weak community ties, little social cohesion and high levels of insecurity, crime and drug trafficking. The municipal health team sought to develop activities with adolescents “fostering the sense of belonging and identity of users and their families” (Varela and Regodeceves, 2013:4). At that time, a theatre director was added to the psychosocial team to carry out workshops in theatre, circus and music, creating Psircutopia.

Psircutopia is open to all adolescents who ask to participate or are referred from schools and family courts. They are required to be in school, have some family bond and not more than moderate drug consumption. These requirements may exclude the most marginalised youth, but they are considered necessary by the team for programme success. Annually, approximately 30 adolescents are enrolled for the 18-month treatment programme, but many who have completed the course keep coming to Psircutopia. The wider community participates in some activities, such as performances and presentations by the adolescents.



Adolescent performers, Psircutopia, ©Monitor Arturo Varela, 2013

Today, with the support of four performing arts experts, Psircutopia offers a diversity of activities, including courses and workshops on circus (juggling is one of the most popular), cinema (how to work in groups to make short films), theatre, art therapy, and music (including construction of musical instruments). The workshops are planned annually with varying numbers of sessions according to the area, up to three a week, and from two to twenty participants. The types of workshops are defined by the skills of the expert monitors, but adolescents choose the workshop of interest and are able to change if they desire. Adolescents are active participants in the workshops, defining the rules of conduct that guide the sessions -- for example, respecting and not talking about peers who are absent. KI participants valued having a space in their neighbourhood where they could concentrate, learn new skills and share experiences with peers. Engagement of adolescents in performing arts builds self-esteem and capacity to work in teams of youth, who face discrimination because of their history of drug abuse and marginality and empowers them before the community. During training sessions, they learn to trust the staff and participate in self-help groups, contributing to a sense of belonging to a community, which these adolescents lacked, and lead to greater adherence to drug treatment and prevention programmes. An adolescent KI observed, however, that this takes time and not all feel confident enough to communicate their views and to participate in councils.

In addition, the Psircutopia team developed first-level school initiatives, funded by the Health Service as a good PHC practice, co-ordinating with education and the governmental drug prevention programme to train community workers to support self-help groups (Colaboración Pública, 2013; Servicio de Salud Coquimbo, 2016). These training schools have weekly sessions on issues such as prevention of drug consumption and domestic violence. When community workers graduate, they form self-help groups of twelve people, which aim to be supportive, totally confidential conversation groups (Equipo OvalleHoy, 2015). Psircutopia has carried out four first-level schools with community groups and in prisons with incarcerated youth and their families.

*When you convene one, there are twelve people who can share your life experience, you can tell them about your week. How it was, and if something bad happens to you, for example... the group is about trust... with people who share your problem, any pain they have... -- KI Ovalle, 2017.*

## 4.5. CESFAM Juan Pablo II: Health rights of immigrants

In the last decade, Chile has become a pole for international migration, mainly from South America (Rojas Pedemonte and Dittborn, 2016). Beginning in 2003, the Ministry of Health began to provide access for immigrants to basic and emergency healthcare, specifically for pregnant women. With the increase in vulnerable, undocumented migrants, the Ministry of Health adapted its regulatory framework to promote and improve access to healthcare, regardless of ability to pay or immigration status, in alignment with World Health Assembly resolutions (Subsecretaría de Redes Asistenciales, 2016, and Presidencia de la República, 2015). Although average income-based poverty is lower for immigrants than Chileans (9.7% versus 11.7%) multidimensional poverty – which considers education, health, employment and social security, housing, and social cohesion – is higher (23% versus 20.6%) (CASEN, 2015). Immigrants face barriers to access health services, such as lack of information, cultural and linguistic differences, compliance with administrative requirements and other difficulties, especially for the undocumented (Subsecretaria de Redes Asistenciales, 2016).

CESFAM Juan Pablo II provides PHC for 15,500 people, in Villa La Reina, a neighbourhood in the Santiago MR with high social deprivation, unemployment, poor living conditions and overcrowding, drug addiction and security, among other vulnerabilities. In 2009 the CESFAM health teams began to detect a growing migrant population, many undocumented, socially isolated without strong social networks or knowledge of how to access to health and social services.

*We began to realise that foreign populations began to arrive in our sector (...)...People in general do not know that in this municipality there is an area with people who have economic, social problems, who sell drugs, the same scourges that occur in slums that you know are vulnerable -- KI CESFAM, 2017.*

In this context, CESFAM teams developed an intercultural CESFAM project to create a receptive environment for the immigrant population to exercise their health rights, by receiving funding from the municipality and the Ministry of Health.

*The CESFAM health team, complying with its commitment to the community, has tried to organise internal units to respond more efficiently to this [immigrant] population, who are vulnerable due to the absence of networks, social isolation, fear because of irregular legal status, ignorance of services and discriminatory treatment -- KI CESFAM, 2017.*

The CESFAM social worker and participation staff set up internal administrative mechanisms to respond to the needs of immigrants, many of them undocumented.

*Then, we entered them manually when they required an appointment, we spoke with the statistics staff and we invented a system so that they could attend people without RUT [an identity card]. It was very difficult, but (...) we managed to give them health service -- KI CESFAM, 2017.*

Some of these local innovations to provide services to undocumented migrants preceded national instructions by the Ministry of Health and FONASA, including administrative registration processes, which were not yet in force at the time. In addition, KIs indicated that they had to overcome resistance from some members of the PHC team, who did not know how to attend the immigrant population, especially the Haitians because of significant cultural and language differences.

*We did a lot of sensitisation with [local health] officers about the issue of care for immigrants, because in the beginning, in those years..., it was very difficult to incorporate them because internal users [health teams] refused (...), they did not want to accept them -- KI CESFAM, 2017.*

The first stage was a process of consultation and dialogue with members of the immigrant community, NGOs, PHC teams and other municipal sectors to better understand health and social needs, determinants, and access barriers faced by immigrants. This led to giving priority to Haitians, due to the rapid increase of this group and their special language, social and cultural circumstances.

[Immigrant families were reached](#) through the Chilean [Catholic Immigrant Institute](#), an NGO working with immigrants, and through the municipality and kindergartens, with 400 immigrant families registered. Immigrants, including Haitians, were elected to the CESFAM local development council and formed several groups.



Mapping family health problems with Haitian users © Isabel Riquelme, CESFAM JPIL, 2016

The next step was intercultural sensitivity training for all health centre personnel. Materials on how to access services were translated into Creole, disseminated to community members and available in OIRS. A Haitian community facilitator was hired for outreach and to support translation, if necessary. *We have a Creole teacher for support and we are holding Spanish workshops for Haitians. So, it happened naturally, in the sense that people began to feel part of and can access the health centre and all its services* -- KI CESFAM, 2017.

While the main focus was facilitating access to, and use of, PHC services by immigrants and their families, it also sought their inclusion in participatory mechanisms. Around 400 families from Peru, Bolivia and Haiti, of different ages, are involved in CESFAM programmes.

*We have representatives in the Local Health Council. We have an immigrant population that participates in the diagnoses. In all the instances and mechanisms we have for health participation, immigrants are present. They are now organising themselves [in social organisations than can participate for funds]* -- KI CESFAM, 2017.

The programme has been featured among the best practices to address immigrant health needs by the Health Service and NGOs. Health teams and the community perceive positive benefits and satisfaction (Red Salud Oriente, 2016). An annual 'No Discrimination Day' was also instituted (Municipalidad de La Reina, 2016). This community activity proposes to highlight and understand the growing migratory reality of contemporary Chile and to facilitate greater inclusion of the immigrant population through awareness of their customs and culture.

#### 4.6. Grupo Llaretta: Empowered, autonomous community action

'Health and life and dignity' is the motto of Grupo Llaretta from La Bandera, a low-income neighbourhood in the municipality of San Ramón in the Santiago MR. This experience is an example of social empowerment in which "people take the initiative independently of external organisations, developing contacts for resources and technical assistance, but retaining control over these resources" (Cornwall, 2008). Autonomous social action is historic in the La Bandera *población* (informal settlement), which originated from the occupation of an *hacienda* (agricultural estate) in 1969 (CEME, 2005).

In the early 1980s, members of the group participated in training workshops for community health workers, *monitoras*, organised by Fundación EPES, a non-governmental foundation, whose mission is to improve health of vulnerable people and communities through participatory strategies of education, promotion, advocacy and social mobilisation, with a gender and rights perspective, respect for diversity and the environment (Fundación Educación Popular en Salud, EPES, no date).

*We started in '83, with a nutrition workshop and then, from year '84, the health group began training for a full year, and were accompanied for three years by EPES, which is a foundation that works in popular education. And after that they [EPES] told us they were leaving, but they disengaged slowly, because detachment is super healthy. But first we felt that they were abandoning us. Those things that many people who had not participated said 'Well (pucha),*

*now they go, what are we going to do.’ But they gave us all the tools to keep going alone. And indeed, it was so, and until now we haven’t broken the link. Today, our relationship is of partnership, of companions (compañeros), horizontal. The process has been interesting. We have 32 years organising – KI Llaleta, 2017.*

The role of EPES in furthering active participation is recognised in the literature (Maldonado, 2011) and by several KIs. “I have a connection with EPES, I’ve been to their training. I believe I am a daughter of EPES.”

In the first period marked by the dictatorship, Llaleta was active in defence of human rights, as well as addressing health and quality of life issues with *pobladores* (residents of informal settlements) and linking with other social movements in Chile and Latin America (Grupo de Salud Llaleta, 2000). After return to democracy in the late 1990s, the group focused on addressing social determinants of health.

*Our vision of health opened a broad spectrum of action. Because we understand that health is not just illness, which is limited, but if we understand health as a vision of the world, of life, a concern that has to do with human rights, decent housing, free spaces, healthy environment, freedom from violence...work, health, education... we have a work for some time, it opens the world – KI Llaleta, 2017.*

The approach to participation is of empowered collective action and ideological.



Mural on awareness of violence against women © Fundación EPES, 2016

*Well, we understand participation from the perspective of commitment to the community. We don’t need money – obviously some but we generate it ourselves. Nor do we believe that participation has to do with giving, with making people dependent. We believe in relationships of equality. So, we build the understanding of problems together, with collective diagnosis and to find solutions. From a position of horizontality we participate in making diagnosis, solving, analysing, obtaining results; results to put before the community to see what was done – KI Llaleta, 2017.*

They have deployed different methods to raise community awareness and build collective capacity to address problems, including murals, theatre, workshops, campaigns and counselling. Recently, in 2016, the group painted a mural in commemoration of the international day for the elimination of the violence against the women, raising money themselves by preparing and selling food in the local street market (Fundación Educación Popular en Salud EPES, 2016c). The mural’s message (adjacent photo) was: “Today he left me flowers for the last time. Yesterday he killed me. If only I had asked for help. I wouldn’t have received flowers for the last time.”

The group is continually renewing -- several generations have been involved over the years, maintaining a core of 11 members, who are embedded in the community, with a broader network of collaborators that connect around specific issues. They use Facebook and WhatsApp to arrange meetings and communicate with their wider network.

*We live here; living here we worked based on our own needs, most of us had lived through violence....” We have to work, so we can’t put in that much time. But when we take on a problem we have all these partners around us, when the time comes they are there – KI Llaleta, 2017.*

The group is mostly self-sustained but received financial support of a church group from Texas, USA. They were able to buy a plot and with volunteers build [Casa Llaretta](#) (Grupo de Salud Llaretta, 2014).

*It's been good. We can choose who we receive, politicians... We have a nice room, a beautiful space that is used by the community, different organisation - KI Llaretta, 2017.*

Llaretta has developed community workshops and training on quality of life and health issues, some linked to EPES Foundation. Llaretta is critical of the scope of activities and spaces for participation driven by the health system, which are often narrowly focused and underestimate community capacities.

*We had an experience where they asked to participate in one stage, not the whole process...The [CESFAM] here in the community wanted us to participate in collecting samples because there was an outbreak of tuberculosis... so we participated, but first we asked what the problem was, what sector, how we could do more about the causes. We were only asked to bring in the [sample] jar, not what would happen with the results, only that, so we weren't interested...it's not enough to collect a sample if you don't know what is going to happen. For us participation is having all the elements to be protagonists not just observe from the bench -- KI Llaretta, 2017.*

Nevertheless, this viewpoint appears to be evolving, partly because of EPES's involvement in implementation of training activities and development of terms of reference for community health workers, who will be paid members of the PHC team (Fundación Educación Popular en Salud EPES and División de Atención Primaria, 2017). Llaretta members have facilitated and presented in EPES training workshops with the health sector, for example one recent activity with the Metropolitan North Health Service on 'participatory and community health strategies'.

## 5. Support and input from other levels and actors

The practices discussed adhere to national statutory and policy guidelines that seek to promote active citizenship in the protection of health rights, social control over public administration, and design, implementation and evaluation of public policies, with aims of contributing to health, health equity and improved quality of life in all sectors (Gobierno de Chile, 2012).

**Public health system participation structure.** Chile's integrated territorial health service networks contemplate community participation at all levels. The priority is reflected in specific performance goals, incentives and financial inputs to develop participation, set by the Ministry of Health: at health service level several performance goals relate to community participation, encompassing OIRS and user management committees; communication to staff and users on good use of healthcare networks; development of participation plans to monitor territorial, local plans; hospital participatory plans to improve user satisfaction, and intersectoral health plans. Self-managed hospitals have goals for participation in the balanced score card, including participatory public accountability, a functioning user council that meets regularly (usually monthly) and at least four times a year with the hospital director, and appropriate, timely replies to complaints. In primary care centres, financial bonuses for staff are associated with the health goal to develop a participation plan, documented in the CESFAM MT Calcuta experience. A PHC activity indicator measures timeliness of responses to complaints. In addition, participation is part of the biopsychosocial family and community health model certification. The practices discussed in Biobío Health Service, Santiago CESFAMs, and the Ovalle Health Department illustrate the importance of guidelines, direct support and financing from other levels of the health system. Specifically, in Biobío, the Health Service director and its Participation Unit advocated and provided institutional support for public-private partnerships, provided technical guidance for health councils, financing and co-ordinated provincial meetings to collectively evaluate, exchange experiences and address challenges. Ministry of Health prioritisation

of certain issues, including immigrant and adolescent health and AUGE problems led to additional support, input and financing, leveraged by health and community alliances in these areas.

**Financial inputs.** Within the public financing noted earlier, programmes and activities that support participation compete with other health priorities, especially direct healthcare, for limited resources. Thus, while the CESFAM model includes an ‘officer in charge of social participation,’ at least half-time (22 hours a week), KIs acknowledge that this is not enough time to really co-ordinate outreach and intervention activities with community actors. Often half-time dedication is even less, because the same professional also has direct healthcare responsibilities (Servicio de Salud Metropolitano SurOriente, 2015). Progressively, participatory budget mechanisms are used to finance projects prioritised by the community, defined in seminars or other deliberative mechanisms. While still marginal in terms of total government spending, increasingly **competitive funds** of health and other public institutions are being established, in which local government and social organisations, including health and community councils, present projects for financing. Recent examples include a [Tarapacá](#) (Gobierno Regional de Tarapacá, 2017) regional government fund for health promotion, physical activity, sport and cultural initiatives, and the [Talcahuano](#) (Servicio de Salud Talcahuano, no date) Health Service fund for activities to promote lesbian and gay women’s right to access inclusive and sensitive healthcare. Nevertheless, some organisations, like Grupo Llareta generate their own financial resources, through members’ efforts or support from non-governmental networks rather than public funding. The group affirms that this gives them freedom to define their work plans and autonomy since their role as social actors does not depend on government priorities: “We don’t dance to anyone’s music. We choose the music and we dance” -- KI Llareta 2017. **International financing** also plays a role in some sites.

**Territorial networks and partnerships** with civil society, government sectors and the private sector are key components of the health governance model based on rights and social determinants of health. The health sector has a co-ordinating and facilitating role, as exemplified by the Adelaida in Biobío experience, where the provincial government provided administrative support for the intersectoral network, integration of government services, and access to different funding sources for Municipal Disability Council projects. Inclusion of SOFOFA, the business association, facilitated dialogue between organisations of people with disabilities and businessmen of the province for improvement of job training initiatives. **Community resources** such as social and functional local organisations and trained community health workers are important actors. One of the key activities of Adelaida was an intersectoral forum on citizen participation held in 2015, convening community actors and professionals from governmental institutions, such as the regional disability service and others involved with issues of labour, poverty, employment, education, housing, sports, children, adolescents, the elderly and other social sectors. In the opening, the Health Service director said, “We understand governance [in health and other sectors] as a process of collective action around organised interactions of actors, the dynamics and rules – formal and informal - with which society makes and implements decisions and determines conduct” (Lajino, 2015). On the one hand, the forum aimed to build common understanding of social roles, share experiences, review mechanisms, methods and tools and to integrate diverse efforts to enhance community participation through intersectoral action. On the other hand, outside government networks, Grupo Llareta maintains links with local and national NGOs, social and functional organisations, and international organisations, focussing on La Bandera neighbourhood, but also supporting the emerging vision of more empowering social participation demanded by civil society organisations.

**NGO support** is important in reaching communities, especially marginalised groups with special needs, and building capacities for meaningful participatory decision-making and action by these groups in conjunction with health teams. Standing out in the Chilean site is Fundación EPES, which shaped Grupo Llareta’s approach and trained many community leaders, who are active in councils.

*We were convinced that the biggest problems have to do with how society is organised ... the proposal was to form health groups that, inserted in different organisations and their communities, could generate proposals of educational action towards the community, as opposed to the visions that had mostly developed since Alma-Ata, in which the community*

*participated as a support to primary care services. We started in a context of rupture between civil society and State [during the dictatorship] -- KI EPES, 2017*

KIs also point out the role of academics and students in supporting implementation of participatory methods, seeing the triad of academia, community and health teams as a critical alliance, today and historically in Chile, exemplified in the Biobío and CESFAM MT Calcuta experiences.

**Social media and information technology** are widely used by the health system and mentioned in all the experiences. The public health system – from the Ministry of Health to municipal CESFAMs – has invested in websites and social media, and some sites use WhatsApp to communicate.

## 6. Enabling conditions, challenges and how these were addressed

The enabling conditions and factors that support participatory practices in our case study derive from legal and policy frameworks for social inclusion and citizen participation at national, regional, provincial and local levels, driven by civil society demands. The main challenges relate to the translation into action in local contexts with resource constraints and varying degrees of political will.

Statutory commitment to associations and community participation (Law 20.500, 2011) (Gobierno de Chile, 2012) aimed to deepen participatory democracy by including principles and adequate mechanisms for participation in public administration decision-making in policies, plans, programmes and actions, guaranteed and promoted by the State. Numerous mass demonstrations, led by students, pensioners, and health users, among other groups, and increasingly lower voter turnout in elections, suggested growing disaffection between citizens and institutions, situations the law sought to address.

Central-level KIs perceive that “citizenry and civil society are very demanding of rights” and are “not as complicit” with the strategy to channel and moderate demands through mechanisms that are administered and regulated by the government. Thus, even though implementation of the citizen participation law strengthened development of participatory mechanisms within the integrated health system governance model, their meaningfulness and issues of whether citizens want to participate in these spaces and have capacity to fully engage are still challenges (Ministerio de Salud, 2015).

Awareness of inequities affecting all aspects of society is driving demands for better access and quality of education, health and other public services and greater voice and decision-making power in policy reforms. The emblematic reforms currently underway to overcome inequities include free education from pre-school to university and a participatory process of Constitutional Reform (Gobierno de Chile, 2017b). Yet, time and capacity to fully engage are also unequal, requiring additional support for marginalised and deprived groups. In terms of evaluation, individuals and groups may be consulted, but examples of strong social control are scant. One example is the Observatory for Gender and Equity ([Observatorio](#) de Género y Equidad) (Observatorio Género y Equidad, 2016), which promotes debate, evaluation and deliberation on gender rights policies.

Other policy commitments have facilitated participatory practices. National immigration policies and specific [health sector](#) (Ministerio de Salud, 2016b) initiatives provide access to healthcare in the public system for all people, independent of their immigration status (Presidencia de Chile, 2015). National policies to promote health with local funding opportunities from the ministries of health and social development have strengthened meaningful community responses to public health challenges.

Nevertheless, the transition towards more empowering participation is still a work in progress, with heterogeneity across sectors and territories, dependent on the will of political and administrative authorities. In many cases, the mechanisms implemented are more consultative or informative rather

than deliberative or empowering, demotivating community leaders and citizens. Financing is still insufficient to guarantee adequate functioning of participatory mechanisms. Thus, despite the statutory rights, in many places civil society is unaware of their existence or has a negative impression (Consejo Nacional de Participación Ciudadana, 2017).

Part of the resistance of organisations such as Grupo Llaretà to engage in participatory spaces offered by the health sector had to do with past experiences. The group emphasised their own collective identity and continuous, shared learning and experiences as enabling factors, building resilience and capacities to develop strategies and use methodologies based on the knowledge of the group, the community and broader networks. According to KIs, constant self-assessment and identification of weaknesses and areas for improvement are also important. Yet, adjusting work plans to their own capacities to generate resources and support may constrain the potential for impact. Bypassing opportunities for public financing and integration with intersectoral territorial networks may limit the scope of real transformative change in the increasingly complex social landscape. However, the perception of the possibility of authentic, empowering participation within spaces for participation in the health system may be changing.

*Today at the national level we see a change in the health system, which is trying to implement programmes in popular education, with a more participatory approach and more authentic participation. From the health centres, an agreement with EPES that applies this model will be implemented with health teams in the whole country. This is the model we live -*  
- KI Health Council, 2017.

Health Service performance goals are set for four years. Nevertheless, the logic of annual planning at facility level prevails, often leading to a proliferation of activities, projects and workshops rather than sustaining transformative processes. Even supposedly transformative approaches such as participatory budgets may derive in tokenism and new competitive funding may even hamper integration and empowerment of community groups, as one ministry KI noted:

*It generates competition among organisations...and the process dies a natural death when the resources are spent. So I believe that the process can only be sustainable when capacities are installed at the local level –* KI Ministry of Health, 2017.

The intersectoral network that operates Adelaida at the provincial level includes institutional representatives to support collaborative, integrated work. However, according to KIs, its effectiveness really depends on the capacities of local disability councils to integrate people with disabilities, their families, caregivers and the interested community living in the municipal territory with intersectoral actors. The main challenges for sustainability are in developing autonomous capacities and representativeness of the array of councils. Broadening the base of councils to include other age groups and ethnicities is a permanent challenge for health councils, which tend to be composed of mainly older women.

*The majority of council members are adults and seniors; I believe that a big challenge is how we capture participation with other age groups: with young people, with adolescents. But on the other hand, we should also take advantage of the potential that older adults give us, from the point of view of demographics, the importance that older adults already have as the majority population; and we also see this as an opportunity to link not only with the development councils, but also to link them to institutions connected to older adults -- for example, with the National Service of the Elderly and also with the Older Adult Community Councils, with Municipal Associations of the Elderly, representatives of territorial organisations (neighbourhood councils, senior adult clubs, for example) --* KI Health Service, 2017.

According to KIs, lack of interest in participation can be overcome if people and organisations have a say in proposing issues and the modes and dynamics of participation are meaningful. “We have said in various meetings and congresses that we do not want to be a performance goal, we want to be actors in health” -- KI community leader, 2017.

The 2016 change in the PHC participation performance goal to develop a biannual community participation plan aimed to tackle these challenges (Subsecretaría de Redes Asistenciales, 2015a). Nevertheless, informants affirm that there continues to be “permanent tension” with other health performance goals, which overwhelmingly focus on morbidity care, given the available resources.

*I know that other professionals would like to work on this. I know that my doctors would like to be involved. We have many family doctors who would like to work on this because they were trained for this, but I cannot... Because I have to safeguard urgency of covering medical care in the morning. So, I would like the Ministry of Health when they give us these tasks to accompany with financing for this. We have the same person doing fifteen hundred things, like an octopus... The teams are super pressured trying to meet health targets, activity rates and we have to spend time on this. Many, many members of this team are giving their personal time to move this forward -- KI Ministry of Health, 2017.*

Yet, it is acknowledged that the proliferation of mechanisms and the number of activities does not necessarily advance the objective of meaningful participation. “When I saw the first plans, I realised that some plans were a sequence of activities and mechanisms: public accounts, dialogues, encounters, the more the better, but for what purpose?” -- KI Ministry of Health, 2017. KIs from Grupo Llaretta and EPES affirm that community participation from the level of the state is still in development and not yet a reality in Chile. They perceive that the state maintains a vision of the community as ‘patients’ and ‘sufferers’ more than as co-agents, basically focused on information-sharing and instrumental roles.

*The difference with popular education is how the other is perceived, as passive or ignorant, and whether all people are validated and recognised as subjects. There is no single way of knowing. People know and their ways of knowing are a valuable resource for themselves and for social functioning -- KI EPES, 2017.*

To some degree, this view was echoed by the National Council on Social Participation January 2017 Report (*Appendix 7*). They highlighted the limited spaces for citizen expression, unacceptable inequalities in decision-making power and influence, advocating for more direct empowering commitments and support. They argued that public administration should strengthen and better coordinate existing mechanisms towards deliberative power and with adequate resources for meaningful functioning. Enforcement and sanctions for non-compliance need to be established. To strengthen civil society organisations, they proposed increases in public financing, beyond competitive funding of social projects, and a national, regionalised system of capacitation and training for social leaders and public functionaries. Specifically, they proposed to the President a constitutional amendment and reforms of the legal framework for empowered citizen and civil society agency in public decisions (Consejo Nacional de Participación Ciudadana, 2017). In spite of the overall critical view, they acknowledged health sector advances in driving and sustaining community participation.

Among the different sites, enabling factors of social cohesion and collective principles, such as solidarity, were stronger in older communities, including La Bandera where Grupo Llaretta operates or Biobío. Processes in newer settlements such as Puente Alto, Villa La Reina and Media Hacienda in Ovalle depended more on health sector motivation and incentives, reflected in the origins and stages of participation.

Finally, it should be noted that the Chilean participatory model focuses mainly on public services, FONASA users, public schools and not private insurance affiliates or private institutions. Yet, recent social mobilisations for health to cover high-cost treatments (not included in AUGE) have been led by the middle-class, whose focus is more on expanding individual entitlements rather than solidarity and advancement of collective social rights.

## 7. Outcomes

In general, processes are poorly documented, focusing on activities with little attention to evaluation of outcomes, despite the policy attention on participation. In part this is explained by lack of time and resources for evaluation, including feasible methods.

Nevertheless, key informant and external sources, including other levels of the health system, cited press and NGO webpages, perceived positive progress towards both community health aims and participation objectives, even when there was uncertainty about the outcomes related to population health and wellbeing and empowerment. A better understanding of social processes and social determinants of health strategies was perceived.

Progress is acknowledged – generally from narrative claims and not documented or evaluated – but still tends to focus on types of activities and participants rather than the extent to which processes are transformative and reach meaningful levels of joint decision-making and collaborative action. This reflects to some extent what is asked for from higher levels of the health system in guidelines and performance goals.

*In our guidelines to the health services we ask for a baseline...They have to analyse their territorial context considering sanitary and socioeconomic indicators and social movements related to health. Based on that analysis, they have to present their annual planning. It is mandatory to include in that plan participatory public accounts, training for the participation worker in the health centres, reports on [council] meetings and activities... and to plan activities to improve health of vulnerable groups in the territory -- KI central level, 2017.*

*So, here we talked about changing... to focus on the objective. The objective is to strengthen citizen participation, with territorial relevance, with a social determinants [of health] approach -- KI central level, 2017.*

A Ministry of Health KI suggested that the indicators could be more significant, for example “[existence] of networks and strategic alliances, which is a more structural indicator.”

*Sometimes, when we review plans, we still observe ‘workshopism’, or focusing too much on activities rather than focusing on the objectives, transformation processes, better health, impact on quality of life, social integration and reduction of equity gaps -- KI central level, 2017.*

Yet, to some extent KIs from Adelaida in Biobío perceived positive changes in terms of access and opportunities for people with disabilities in the province, affirming that local citizen councils were playing a leading role in leveraging multisectoral partnerships. The dynamics of intersectoral collaboration were seen to have facilitated integration and greater synergy of existing resources but also generation of new financing and support, which were perceived to have enabled greater exercise of rights, improved living conditions, and increased educational and employment opportunities for people with disabilities. Consolidation of the strategic alliance with the business association SOFAFA, which views the initiative as part of their social responsibility commitment, resulted in private businesses hiring more people with disabilities, according to KIs.

Moreover, increasingly participants of formal spaces, such as councils, are claiming greater autonomy and forming their own networks, an expected consequence of the community participation-intersectoral-health network governance model of the public health system. A KI from a local PHC council expressed this change:

*When one projects the health that Chile should have, we believe that it is necessary to have community health, preventive health, as well as better healthcare management. It’s clear, then, what we have said in several meetings and congresses. We do not want to be a health [system] target, we want to be actors in health. That is our objective.*

*Why do we want legal status? Because we believe that we have reasons... and the strength to do this. Councils are distributed throughout the country, in 345 municipalities, each one has a number of CESFAM.(2017).*

In Santiago Sano, despite setbacks in the original plan to distribute the manual in municipal schools as a tool for sexuality education due to political pressure to downplay its priority, innovation in participatory processes based on school committees and local expertise to develop public health solutions continues. A recent example is the award of a grant from Bloomberg Philanthropies, 'Galvanising school committees to reduce childhood obesity'. The project utilises a games and competitions approach to mobilise school committees of students, parents, teachers and local NGOs to adopt evidence-based healthy behaviours, such as walking and packing nutritious lunches. Points earned through participation in these activities can be traded into rewards for the school and the community, such as new playgrounds, other infrastructure or equipment (Bloomberg Philanthropies, 2016).

According to KIs of CESFAM Juan Pablo II, the initiative changed the identity of this centre, which became intercultural, dignifying immigrants as rights-holders and agents of change that enriched the local fabric by adding and valuing cultural and idiomatic diversity: "We are an intercultural centre, it is our seal (...). Although what we were doing was not otherworldly, it has to do with the fulfillment of [rights], which is what corresponds to public health" -- KI CESFAM, 2017.

CESFAM Juan Pablo II was able to develop a participatory intervention, engaging and maintaining commitment of community organisations, which had not participated previously, and electing a new PHC council. Implementation during 2017 and 2018 will test the ability to establish strong informative, participatory mechanisms and maintain in a context with limited health system, public infrastructure and community assets.

Psircutopia reported increases in numbers of adolescents registered and adhering to drug treatment and prevention programmes that they attributed to their activities, reaching over 500 youth and their families (Servicio de Salud Coquimbo, 2017). Adolescent participants valued the opportunity to learn new skills, interact with peers and with therapists, who focused on them not only as individuals but as a group, which they claim contributed to reduction of consumption and increased school attendance. However, in terms of empowerment and active roles in citizen councils and other participatory events, adolescents felt unprepared and not confident of their capacities to contribute: "I think if they asked me questions, I'd answer nonsense. I think my opinion is super-childish." Another said, "One lacks the vocabulary to express oneself" -- KI group interview, 2017.

The experiences documented in this case study should be understood as part of a process to advance community participation for health within a broader agenda of democracy and rights in Chile. Deepening efforts led by the Ministry of Health were especially significant in 2016- 2017, in anticipation of the 40<sup>th</sup> anniversary of the Alma-Ata Declaration and the importance of health in the 2030 Sustainable Development Agenda. A year-long massive participatory process related to PHC, called "Building Social Value" (*Construyendo valor social*), involved 387 self-organised local 'conversations' and over 10,000 individual contributions from actors throughout the country, replicating the methodology of the constitutional reform process. Users, health professionals, workers, community organisations, unions, students, academics and political and government authorities participated to share their visions and to make contributions to strengthen PHC as the centre of the health system and to further community participation and citizen responsibility. More than a thousand participants gathered to discuss proposals to strengthen equity, efficiency and effectiveness of PHC at the 2017 Primary Health Care Congress ([Congreso de Atención Primaria](#)) (Servicio de Salud Aconcagua, 2017), which will guide strategic plans over the next years.

## 8. Discussion

### 8.1 Key insights/learnings shared from the work

**Participatory governance in health: A model in development.** Health is considered a fundamental social right in Chile. Its realisation has been a social and government priority for decades in a context of a free market economy, motivating a series of adjustments, but without structural transformation of its inherently inequitable dual health system. Rather, Chile's path has centred on establishing enforceable guarantees for health priorities and strengthening free, public PHC in pursuit of greater health equity and public health-system effectiveness and efficiency. Strengthening participation has been an integral part of these efforts with concrete spaces, guidance and incentives, taking multiple forms, serving different interests from legitimisation, efficiency, and sustainability, ranging from information mechanisms, public accounts, representative bodies, and increasingly greater social control and more deliberative decision-making.

An important feature is the territorial not centre-based approach to participatory governance, which aims to engage people where they live, study and work, particularly socially vulnerable groups with inadequate living conditions, who are not accessing health and social services. This has meant constructing and sustaining networks of community participants and organisations, health and other sectoral teams over time to enhance combined capacities for action, acknowledging the specific expertise and contributions. Both Biobío (more top-down) and Grupo Llaleta (bottom-up or horizontal) emphasise networks.

The case study experiences provide concrete examples of how national policies and a more comprehensive PHC model have played a role in implementing top-down approaches to participation. These have enabled all immigrants to access healthcare, enabled more participatory approaches that reach and encourage necessary uptake and given youth and other social groups specific voice. New statutory rights to participatory co-management attempt to further empower participation, sustained by strong social organisations. This is a process of transition, co-habiting heterogeneous basic and innovative practices, with multiple beliefs, values and practices in the health sector and the community in different local contexts.

While participation is still largely driven or conceded by the health sector, opening spaces inevitably leads to questioning and demands. Efforts to contain or channel demands in ways that are always comfortable inevitably leads to distancing and demotivation. This affirms the value of critical questioning and innovative approaches by non-governmental, community and academic actors. Partnerships of health sector, PHC clinics, community, NGOs and university were considered to be pivotal in the perceived positive outcomes of the case study experiences and critical for the transition towards fuller forms of participation and social power.

One of the key insights from the Chile case study is the importance of defining social roles, objectives and the results of participatory practice. Even basic practices at the level of informing, such as information and complaints offices and public accounts, are significant if people are truly involved before, during and after. Some space of power to decide in meaningful ways on specific issues –even if narrow in scope– which have been prioritised by the community, with concrete interventions, financing and measured results are understood to be fundamental for achieving change, particularly by social actors. Valuing different types of knowledge and building horizontal spaces for joint learning and action with health workers, intersectoral and community actors are increasingly acknowledged by the health system as the basis for authentic participation.

## 8.2 Practices, measures and tools that may be adapted/adopted

The experiences discussed are cited as good practice by Health Services, Ministry of Health and, in some cases, academia and NGOs. They have been disseminated and to some measure taken up by other territories and levels of the health system in Chile. The question is whether elements can be adapted or adopted in other countries without a centralised, integrated public health system.

Chile has embraced a model of integrated health services, promoted by the Pan American Health Organisation, around axes of participation of users and health workers, efficient and effective healthcare, and intersectoral action on social determinants and equity. In other contexts, Chile's territorial focus might be built around the needs of the community attended by a PHC centre. Elements of the model can be emulated, such as community work around improving communication, user satisfaction and integrating multisectoral action on social determinants with a network of community partners.

Citizen health councils can also be adapted elsewhere. In Chile these are not elite boards, but composed of users, community and health worker representatives, who provide unique knowledge on needs, expectations and common sense solutions.

Specific concrete measures that might be useful for other countries to consider and adapt, as contextually relevant, include:

- Explicit inclusion of people with disabilities, immigrants and other marginalised groups in participatory councils, committees and diagnosis and planning processes;
- The link to economic activities, such as eco-orchards that use recycled organic materials and eco-gardens in schools in Biobío and the network of healthy food carts/kiosks in Santiago;
- Participatory diagnosis and budget proposals, such as Healthy Spaces in Santiago, to remodel public spaces;
- The co-design and production of health materials with communities (adolescents and immigrants); and
- Horizontal health team and community capacity-building approaches and participatory practices, based on popular education approaches that acknowledge and value different forms of knowledge and expertise.

Many of the methods and tools applied in Chile are well established in other contexts. Guidance for participatory diagnosis with citizens and social organisations include options (brainstorming, sociograms, problem trees, flowcharts, and problem/solution matrices) with links to sources with further information, specifically identified in guidelines and orientation documents (*Appendix 5*). Some resources on participatory mechanisms are targeted towards the community (*Appendix 6*). In practice, health teams have adjusted these methods to resources, population and context, particularly in engaging socially vulnerable groups. Notably, visual mapping through drawings and pictures of problems and solutions, located territorially and in time (roadmaps from initial to desired situation) are techniques often used.

## 8.3 What the site is interested to learn from the other sites

In general, key informants expressed interest in learning from other sites, particularly practices for motivating, enabling and sustaining meaningful participation by excluded and marginalised groups, in ways that are empowering but do not shift responsibility for health.

Evaluation is a specific area of interest identified by key informants at all levels. Chile has performance goals that generally measure products or processes but not outcomes. In addition, good practices are identified and shared, yet not really evaluated. Informants discussed the importance of practical ways to generate relevant evidence on the impacts of participatory interventions, which are not overly complex or resource-intensive. Of particular interest are participatory evaluation methods.

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## Acronyms

AUGE	Universal Access with Explicit Guarantees plan (Acceso Universal con Garantías Explícitas)
CCD	Consejo Comunal de Discapacidad (Municipal Disability Council)
CCU	Consejo Consultivo de Usuarios (Hospital advisory user council)
CDL	Consejo de Desarrollo Local (Local Development Council, CESFAM)
CESFAM	Centro de Salud Familiar (Family Health Center)
CIRA	Consejo de Integración de la Red Asistencial (Integrated Health Network Council)
COSOC	Consejo de la Sociedad Civil (Civil Society Council)
EPES	Fundación Educación Popular en Salud (Popular Health Education Foundation)
FONASA	Fondo Nacional de Salud (National Health Fund)
ISAPRE	Institución de Salud Previsional (Private Health Insurance Institution)
OIRS	Oficina de Información y Reclamos y Sugerencias (information/complaints/suggestions office)
PHC	Primary health care
SOFOFA	Sociedad de Fomento Fabril (Association to Promote Industry and Business)
SNSS	Sistema Nacional de Servicios de Salud (national public health care network)
TARSC	Training and Research Support Centre

## Appendices

### Appendix 1: Summary description of participatory experiences

Practice/health system level/social groups	Location	Intended changes (aim)	Origin/motivations
Formal citizen councils at local (municipal and CESFAM) and health service levels of the public health system	Biobío Province (Health Service) and local PH levels	To enable and facilitate participation in the family and community health model through elected, representative councils.	Health system participatory mechanism for Co-determination of the community in decisions and actions. Representatives seek influence. Historic roots in 1970s local health councils. Linked at local and provincial levels with the “Adelaida” initiative.
Health in All Policies (HiAP) territorial approaches for prioritised populations and settings.	Biobío Province (Health Service), “Adelaida” Initiative	To improve health and well-being of disabled people through integration of sectoral programmes and participation.	Health Service origin, motivated by HiAP and participation approaches (Adelaide), Sectors interested in effectiveness and efficiency. Community organisations and local councils (see above) are part of the integral support networks at municipal and provincial levels.
	Santiago Sano (Sexual health manual for adolescents)	To identify and address the sexual health concerns and needs of adolescents as part of a wider intersectoral approach, using HiAP, SP and life-course perspectives to improve health and well-being in neighborhoods, schools and other settings.	Established by the mayor’s office, the Santiago Sano team convenes municipal departments, citizens and civil society. Community: influence and participatory budgets. Adolescents: opportunity to express needs and receive information and services.
PHC Social Participation plan	Madre Teresa de Calcuta CESFAM, Puente Alto, Santiago MR.	To strengthen SP with a territorial, sociocultural and rights approach for the biopsychosocial model through a plan developed with community organisations, families and individuals.	Ministry of Health’s new PHC SP performance goal, originating from local health councils and civil society organisations. Community: information, influence, social control, input and action on Social determinants of health
Engagement/non-discrimination of immigrants in health services and representation in local councils	Juan Pablo II CESFAM, La Reina, Santiago MR	To create a receptive environment for the exercise of health rights by immigrants and refugees living in Villa La Reina.	CESFAM initiated to increase responsiveness and non-discrimination. Immigrants: interest in better health services and treatment.
Community-based social participation movement (empowered community health workers)	Grupo Llaretta in La Bandera, San Ramón Municipality, Santiago MR	To build autonomous, collective responses to health issues, articulating community and government resources, beyond channeled health system spaces	Bottom-up, starting with trained community health workers (EPES) and building capacity for autonomous action with networks of support, focusing on gender violence and health rights issues
Engagement of adolescents in drug prevention initiatives through performance	Psircutopia, Ovalle Municipality, Coquimbo Region	To reach vulnerable adolescents and engage them in drug prevention programmes through participation in circus art	Municipal health department: to meet AUGE guarantees for adolescents with drug problems. Adolescents: opportunity to engage in creative, interactive activities.

## Appendix 2: Document review

The **document review** included published and grey literature, including documents, videos and photographs from the experiences described.

The inclusion criteria for published literature:

- Documents related to social participation in the health system, particularly in Chile.
- Regardless of the date of publication, but preferring documents published after 2000.
- Documents in English and Spanish.

Searches were conducting using in PubMed and Scielo databases, using the following search terms in Spanish and English with no restrictions of date or article type or text availability. The search terms used were selected from the original project protocol:

"community networks" OR "citizen participation" OR "social participation" OR "community health workers" OR "community health centers" OR "community health services" OR "intersectoral action" OR planning OR "healthcare financing" OR "financing, government" OR "Primary Health Care" OR "Health Service" OR "social networking" AND "Chile" [Mesh]

Descriptors in English and Spanish were obtained from the website Health Sciences Descriptors of the Virtual Health Library of BIREME (available from: <http://decs.bvs.br/E/homepagee.htm>). Concepts not found on BIREME were translated to Spanish by the team.

Eight articles published in scientific journals were retrieved:

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8. Torri, M.C., 2012. Multicultural social policy and community participation in health: new opportunities and challenges for indigenous people. *International Journal of Health Planning and Management*, 27, pp.e18–e40.

Grey literature. Searches were done of national institutional websites of Health Services and regional health authorities, using the search term “participación” or reviewing the “participación” section to obtain key government/policy guideline documents. Additional searches were carried out for specific experiences in Google and municipal websites of sites, including social media. Key informants also provided additional reports, videos and photographs of the participation experiences.

Full texts and links of the documents retrieved were organised using Mendeley reference manager.

All the documents reviewed are listed in section 7. References of this report.

## Appendix 3: Key informants (KI) and group interviews

### Biobío Health Service

1. Director and Participation Unit (group interview)
2. Local health council (CDL) members from provincial network (group interview)
3. Rural CDL member (KI)
4. Rural CDL member (KI)
5. “Adelaida” community leader (KI)

### Santiago Sano

6. Santiago Sano team (group interview)

### CESFAM Juan Pablo II, La Reina

7. CESFAM participation professional (KI)
8. Community facilitator (KI)

### CESFAM Madre Teresa de Calcuta, Puente Alto

9. CESFAM participation professionals (KI)

### Grupo Llaretta – La Bandera

10. Community leader (KI)
11. EPES (KI)
12. CDL and national citizen council member (KI)

### Psicutopia

13. Psicutopia team (KIs)
14. Adolescent participants (group interview)

### Ministry of Health

15. Participation advisor, Minister’s Cabinet (KI)
16. Primary Care Department Participation Unit head (KI)

## Appendix 4: Creole pamphlet. CESFAM Juan Pablo II

Inite	Sèvis nou bay
Famasi	Bay medikamans premye swen yo.
Depo Lèt	Bay aliman konplèt yo (fanm ansent, ti gason ak ti fi ki gen pi piti ke 6 lane epi granmoun ki gen plis ke 70 lane) ki toujou sou kontwèl doktè.
Sevis Enfimiyè	Egzamen, koud, anestezi (pwogram vaksen), podolog pou moun dyabetik. Sevis nan kay pou moun ki pa ka deplase.
Pwen enpotan	
sant pou dan	Sèvis dantal pou moun ki afilye a CESFAM, Cordillera N° 25, Villa La Reina. Telefon: 224 81 81 88, <a href="mailto:cecfamodon@corp-lareina.cl">cecfamodon@corp-lareina.cl</a>
Sant dereyabilitasyon kominal.	Bay sèvis terapet ak reyabilitasyon a kelke maladi ki soti nan CESFAM ou lopital Dragones de La Reina N° 616. Telefon: 224 81 58 81, <a href="mailto:cor@corp-lareina.cl">cor@corp-lareina.cl</a>
SAPU	Sant djians, 24 trè sou 24. Echeftique N° 8419. Telefon: 226517291, <a href="mailto:cecfarmossandon@corp-lareina.cl">cecfarmossandon@corp-lareina.cl</a>
COSAM	Sèvis espesyal nan sante mantal. Selman moun ki asosye a CESFAM ou lopital ki nan sistèm lan. Quillagua N° 480, Villa La Reina. telefon 22481 75 94, <a href="mailto:cosam@corp-lareina.cl">cosam@corp-lareina.cl</a>
Salud responde	Se yon sant sèvis minis la mete pou bay enfomasyon de sistèm sante chilyen. Telefon 600 360 77 77

\*siw bezwen orè chak sant sa yo, ou prale nan OIRS.

\*Agradecemos la traducción a Creole realizada por el Sr. Jemps Aloute, migrante Haitiano de Villa La Reina.

### SANT DE SANTE POU FANMI JUAN PABLO II



BYENVINI

VWAZEN AK VWAZIN MIGRANS NOU  
YO KI NAN VILLA LA REINA

Parinacota # 440 – nan kwen Mamiña  
Fè demand lè pouw wè ak doktè  
Telefon 22-4816389- 22-3609800

Informa Municipalidad de **La Reina**

Source: CESFAM Juan Pablo II, 2016

## Appendix 5: Resources for development of social participation for health teams

Level	Resource
Health Services	<p><b>Regulatory framework for participation:</b></p> <p>Transparency. Resolución exenta n°31  <a href="http://transparencia.redsalud.gob.cl/transparencia/public/ssp/2015/res31.pdf">http://transparencia.redsalud.gob.cl/transparencia/public/ssp/2015/res31.pdf</a>            (Ministerio de Salud, 2015)</p> <p>Resolución exenta n°712  <a href="http://www.ssvsatransparencia.com/2012/Participacion%20Ciudadana/Norma%20Participaci%F3n%20Ciudadana.pdf">http://www.ssvsatransparencia.com/2012/Participacion%20Ciudadana/Norma%20Participaci%F3n%20Ciudadana.pdf</a> (Ministerio de Salud, 2011)</p> <p><b>Technical documents:</b></p> <p>Orientaciones técnicas Metas Sanitarias 2017  <a href="http://www.araucanianorte.cl/images/PDF-WORD/OT_METAS_sanitarias_2017-31-09-2016.pdf">http://www.araucanianorte.cl/images/PDF-WORD/OT_METAS_sanitarias_2017-31-09-2016.pdf</a> ((Ministerio de Salud, 2016a)</p> <p>Orientaciones técnicas y metodológicas compromisos de gestión en el marco de las redes integradas 2016 (Gobierno de Chile, 2016)</p> <p>Guía metodológica diálogos participativos  <a href="http://participacionciudadana.subdere.gov.cl/sites/default/files/Gu%C3%ADa%20Metodologica%20Di%C3%A1logos%20Participativos_0.pdf">http://participacionciudadana.subdere.gov.cl/sites/default/files/Gu%C3%ADa%20Metodologica%20Di%C3%A1logos%20Participativos_0.pdf</a> (Subsecretaría de Desarrollo Regional y Administrativo Ministerio del Interior y Seguridad Pública - División de Organizaciones Sociales Ministerio Secretaría General de Gobierno, 2015)</p> <p>Guía metodológica cuentas públicas participativas  <a href="http://participemos.gob.cl/wp-content/uploads/2016/03/Gu%C3%ADa-Metodol%C3%B3gica.pdf">http://participemos.gob.cl/wp-content/uploads/2016/03/Gu%C3%ADa-Metodol%C3%B3gica.pdf</a> (División de Organizaciones Sociales Ministerio Secretaría Regional de Gobierno, 2014)</p>
Primary Health Care	<p><b>Regulatory framework:</b>  <a href="http://www.leychile.cl/Navegar?idNorma=1081568">http://www.leychile.cl/Navegar?idNorma=1081568</a> (Subsecretaría de Redes Asistenciales, 2015a)</p> <p><b>Technical documents:</b></p> <p>Orientaciones para la implementación del Modelo de Atención Integral de Salud Familiar y Comunitaria  <a href="http://web.minsal.cl/portal/url/item/e7b24eef3e5cb5d1e0400101650128e9.pdf">http://web.minsal.cl/portal/url/item/e7b24eef3e5cb5d1e0400101650128e9.pdf</a>            (Subsecretaría de Redes Asistenciales, 2013a)</p> <p>Participación Ciudadana en Atención Primaria  <a href="http://web.minsal.cl/wp-content/uploads/2016/09/2_PARTICIPACIÓN-CIUDADANA-APS.pdf">http://web.minsal.cl/wp-content/uploads/2016/09/2_PARTICIPACIÓN-CIUDADANA-APS.pdf</a> (Subsecretaría de Redes Asistenciales, 2015b)</p> <p>Elaboración Diagnóstico Participativo. Serie: Participación ciudadana para una mejor democracia  <a href="http://www.gobiernoabierto.gob.cl/sites/default/files/biblioteca/Serie_5.pdf">http://www.gobiernoabierto.gob.cl/sites/default/files/biblioteca/Serie_5.pdf</a>            (Subsecretaría General de Gobierno, no date)</p>

## Appendix 6: Resources for the community to develop social participation

Resource	Link
Law 20.500 on citizen participation	<a href="https://www.youtube.com/watch?v=K4S8_UeWBXY">https://www.youtube.com/watch?v=K4S8_UeWBXY</a> (Gobierno de Chile, 2012)
OIRS Oficina de Informaciones, Reclamos y Sugerencias	<a href="https://www.youtube.com/watch?v=Vlbr96a3ME">https://www.youtube.com/watch?v=Vlbr96a3ME</a> (Servicios de Salud Osorno, 2016)
Participatory Public Accounts, Ministry of Health 2016	<a href="http://web.minsal.cl/cuenta-publica-2016/">http://web.minsal.cl/cuenta-publica-2016/</a> (Ministerio de Salud, 2017)
Participation and Consultation of Indigenous People	<a href="http://web.minsal.cl/participacion-y-consulta-a-los-pueblos-indigenas-2/">http://web.minsal.cl/participacion-y-consulta-a-los-pueblos-indigenas-2/</a> (Ministerio de Salud, 2016b)
Public Accounts SSMO 2016	<a href="https://docs.google.com/forms/d/e/1FAIpQLScs95vsvVjvZHYIA6ZA2CDtEB7NlrLuPps9bGhMoG2kd-ketA/viewform">https://docs.google.com/forms/d/e/1FAIpQLScs95vsvVjvZHYIA6ZA2CDtEB7NlrLuPps9bGhMoG2kd-ketA/viewform</a> (Servicio de Salud Metropolitano Oriente, no date)
National Council on Citizen Participation and Civil Society Strengthening	<a href="http://consejoparticipacion.cl/">http://consejoparticipacion.cl/</a> (Gobierno de Chile, no date) <a href="http://consejoparticipacion.cl/envia-tu-opinion/">http://consejoparticipacion.cl/envia-tu-opinion/</a>
Citizen councils	<a href="http://www.consejosciudadanos.cl/formacion.html">http://www.consejosciudadanos.cl/formacion.html</a> (Consejos Ciudadanos, 2011)
Participatory diagnosis and proposals	Self-organised dialogues <a href="http://www.ciudademergente.org/es/">http://www.ciudademergente.org/es/</a> Diagnostic games and techniques <a href="http://www.epes.cl/wp/wp-content/uploads/2016/03/Catálogo_EPES_2015_rev-septiembre-2.pdf">http://www.epes.cl/wp/wp-content/uploads/2016/03/Catálogo_EPES_2015_rev-septiembre-2.pdf</a>
Community health workers	Manual for community health workers <a href="http://web.minsal.cl/wp-content/uploads/2017/01/Manual-Apoyo-incorporación-ACS-en-Cecosf.pdf">http://web.minsal.cl/wp-content/uploads/2017/01/Manual-Apoyo-incorporación-ACS-en-Cecosf.pdf</a>
Community mental health circles	Chile, Recoleta: <a href="http://www.recoleta.cl/circulos-comunitarios/">http://www.recoleta.cl/circulos-comunitarios/</a> Minnesota: <a href="http://aquimn.blogspot.cl/2010/01/circulos-comunitarios-de-salud-mental.html">http://aquimn.blogspot.cl/2010/01/circulos-comunitarios-de-salud-mental.html</a>
Popular education methods and tools, EPES	<a href="http://www.epes.cl/2016/04/centro-de-recursos/">http://www.epes.cl/2016/04/centro-de-recursos/</a> (Fundación Educación Popular en Salud EPES, 2016a) <a href="http://www.epes.cl/2016/03/materiales-educativos/">http://www.epes.cl/2016/03/materiales-educativos/</a> (Fundación Educación Popular en Salud EPES, 2016b) <a href="http://www.popednews.org/resources.html">http://www.popednews.org/resources.html</a>

## Appendix 7: Recommendations of the National Council on Citizen Participation and Strengthening of Civil Society

The National Council on Citizen Participation and Civil Society Strengthening was created by decree in 2016 to advise the President about institutionalising citizen participation and strengthening civil society in Chile, in a national debate on these issues. In particular, the 24 member council of civil society and academic leaders (6 from regions and 9 women) were charged with elaborating a report on the situation in Chile and a proposal to reform Law 20.500 on Citizen Participation and Associations. One year later, in January 2017, they delivered their report and proposals to President Michelle Bachelet, with 12 immediate recommendations (Consejo Nacional de Participación Ciudadana, 2017):

1. The government should present before the end of its administrative term legislative bills for the legal reforms required to address the proposals of the Council.
2. Strengthen the role of the Undersecretary General of Government, as coordinator of citizen participation in public administration, to articulate and guarantee compliance and complete implementation of Law 20.500.
3. Reinforce the National Registry of non-profit legal entities through the incorporation of standards of transparency and sincronisation of procedures with the Internal Revenue Service and interconnection with FONASA and other services, inscription at the municipal level and others.
4. Establish a Model Regulation of Citizen Participation for state organisms, which includes standards for each mechanism and modes of financing, in order to guarantee compliance with Law 20.500. This should consider a head of citizen participation in public services and municipalities and incorporation of observations and responses of Civil Society Councils (COSOC) in public accounts.
5. Enhance implementation of a regional policy on citizen participation, including in this standard or regulation spaces to form capacities of work teams and institutional mechanisms for social influence in the administrative policies of Regional Government in all regions of the country.
6. Facilitate access, accounting and transfers from public funds, standardising modalities for presenting proposals and financial reporting through a single application form and guidelines for all state organisms on the different types of bank accounts that social organisations can choose for deposit of funds.
7. Promote strategies and mechanisms to advance implementation of a policy on volunteers in Chile.
8. Modify the Regulation on Federations and Confederations, eliminating requirements on notary public documentation, quorums and electoral bodies, to facilitate its applicability.
9. Elaborate a National Policy on Citizen Participation and an Index of Citizen Participation.
10. Substantively reform Law 19.418 on Neighbourhood Territorial and Community Organisations to address serious problems of their functioning.
11. Elaborate a policy for strengthening civil society that contemplates at least: baseline financing, capacitation, technical assistance, visibilisation and recognition as social actors.
12. Democratise relevant and useful information for civil society organisations, eliminating barriers to access to information, and creating a single web portal for these organisations.



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

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