

shaping health



Exchanging on social power in health

Experiences of social power and participation in local health systems

Volume 2: Key features of the deep scan case studies

Rene Loewenson

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August 2017

Training and Research
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With support from a grant
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The project on “Learning from international experience on approaches to community power, participation and decision-making in health”, co-ordinated by the Training and Research Support Centre, aims to gather evidence and build learning on promising practices in and models of authentic community participation, power and decision-making in health systems in high-, middle- and low-income countries. It aims to build dialogue and networking for peer-to-peer exchange and support on approaches and practices that can be adapted locally, in the USA and in other countries. Support for this research was provided by a grant awarded by Charities Aid Foundation of America from the Robert Wood Johnson Foundation Donor-advised Fund. The views expressed here do not necessarily reflect the views of CAF America or the Robert Wood Johnson Foundation.

For further information email TARSC admin@tarsc.org.

1. Background

Health systems face challenges: in ensuring universal access, in reaching and appropriately caring for socioeconomically and culturally diverse communities, in engaging other sectors around the social determinants of health (SDH) and in tapping opportunities for and meeting emergent challenges to health. These challenges include changes in society and people's exposure to a wide range of social media. International evidence indicates that meeting these challenges and addressing health disparities call, in part, for a health system, particularly at primary-care level, that is proactive, oriented to communities, families and individuals, comprehensive, participatory and linked with other services and activities that improve population health.

'People-centred' health systems and 'a culture of health' involve people as members of communities not only as individual, passive patients seeking treatment for ill health in services shaped by others, but as citizens with rights, deciding, acting on and contributing to improvements in health and wellbeing, and in the public information, relationships, leadership and capacities to support this. People participate from individual to social levels, as service users/consumers and as citizens and social groups claiming rights to health and to conditions that promote health and wellbeing. Participation arises in different ways; it ranges from manipulation to co-determination and control. It is motivated by different interests in communities and health systems. It takes place within formal and informal, invited or claimed spaces. It may be transient or sustained, occurring within different health system functions. Across these different motivations, forms and spaces, the processes used for participation reflect and transform relationships of power and trust existing within and between communities, health systems and other actors that affect how resources are used for health.

The *Shaping health* project in 2016-17 has explored and shared experiences of building social power and participation in health. We have focused on people living and interacting in particular geographical locations or with common or shared

interests and their interaction with local-level health systems, to promote population health. We gave particular attention to forms of participation that build autonomous and self-determined social power, confidence, capacities and understanding in communities to identify needs, set priorities for and engage in decision-making on the conditions, resources, services and governance arrangements that promote population health. The project is led by Training and Research Support Centre (TARSC) and implemented with partners from the USA and from twelve countries internationally, with a grant awarded by Charities Aid Foundation of America from the Robert Wood Johnson Foundation Donor-advised Fund. A community of practice involving five sites in the USA and sites of work in Australia, Brazil, Canada, Chile, Ecuador, India, Kenya, New Zealand, Scotland, Slovenia, Vanuatu and Zambia over a year shared experiences, analysis and learning on social power and participation in local health systems, including in a Shaping Health web platform.

A number of separate reports have been produced that: present a conceptual framework on social power and participation in health; compile an annotated bibliography of published literature on social power and participation in health; outline site features and discussions on management of change for the five sites in the USA, present short case study reports from six international sites and deeper case study reports from a further six countries internationally.

This document compiles in one volume a summary of key features of the six deeper scan case studies on social participation and power in local health systems in Brazil, Chile, Kenya, New Zealand, Scotland and Slovenia. It draws on the full case study reports, referenced and separately presented.

A separate document (Volume 1) presents the [summaries of the six short case studies](#) in the project, while a separate synthesis report integrates the learning and insights from the combined body of work and discussions in the *Shaping health* project.

2. Methods

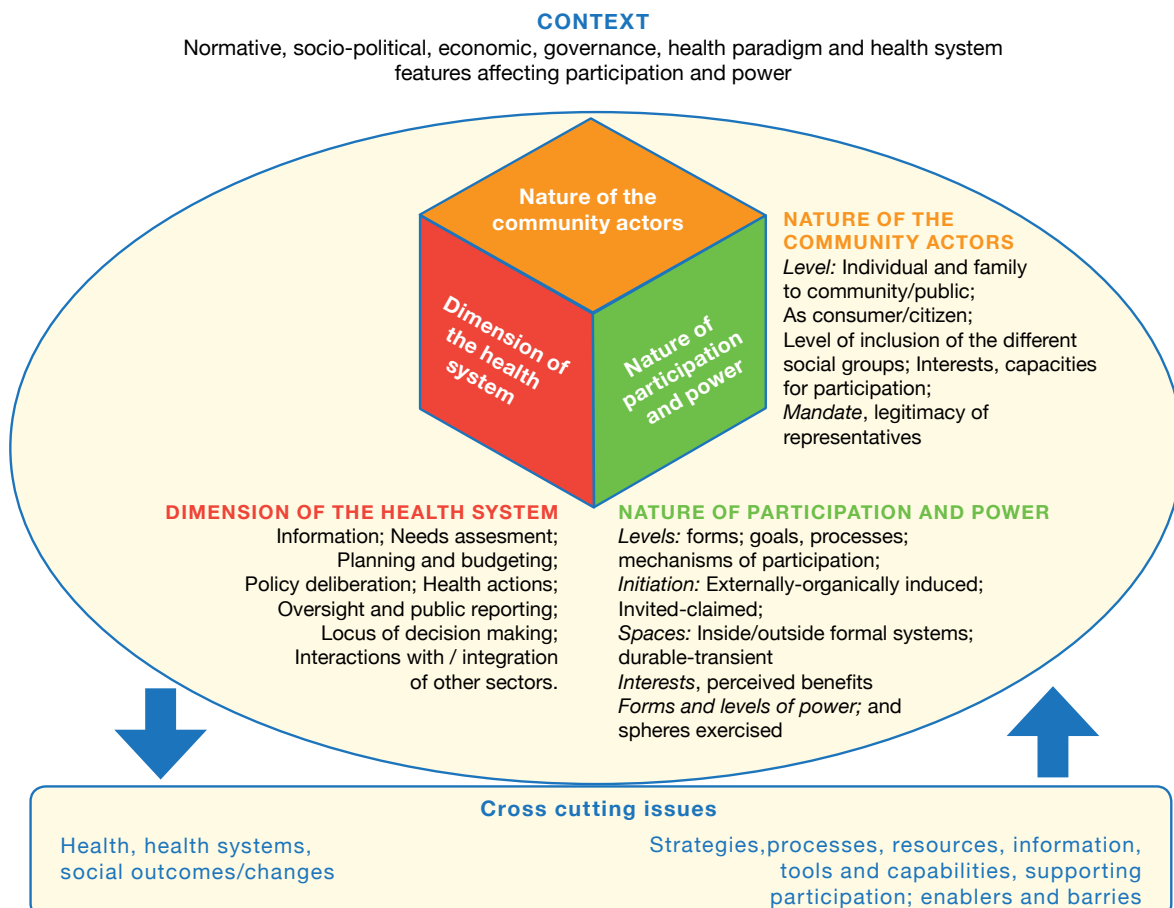
In the six selected countries, the deep scan case studies gathered and reported evidence on promising practices in and models of meaningful community participation, power and decision-making in local-level health systems, including a focus on marginalised communities. They include innovative municipal/local level models, even if not countrywide. The case studies followed a framework provided by TARSC in Loewenson (2016), covering elements summarised in *Figure 1*, taking into account prioritised areas of interest identified by sites in the USA.

The six case studies thus:

- Focused on areas of social participation and power in health, and in arrangements and measures for intersectoral co-ordination between health and other sectors relevant to improving health and the social determinants of health (SDH).
- Presented evidence from document review, key informant interviews with relevant stakeholders and observation of and capture of visual evidence from key processes in the site on the context for and purpose of the work; the practices and the mechanisms, tools and resources used; the enabling factors and the challenges faced and the meso-level measures facilitated or blocking these arrangements, and the health and other outcomes from the work.
- Presented learning from the work that may be useful for wider adaptation, including in the US sites.

The deep scan case study reports were drafted and, after internal and external peer review, finalised in July 2017. Each case study is separately reported and the full reports are available online.

Figure 1: Multidimensional framework for organising evidence on experiences of how social power is being organised at the community and primary level of the health system



3. The deep scan case studies: key features

This section presents key features of the deep scan case studies, drawing from the case study reports, with hyperlinks to further information, resources and video material. The full case study reports referenced in each summary

provide more detailed information and source references. An appendix includes tools referred to in the case studies, while information on other tools and resources is provided through hyperlinks in the text or in the references.



3.1: Cidade Tiradentes, São Paulo, Brazil

For the full report see: Coelho VS, Calandrini A, Waisbich LT (2017) 'Case study: Voices from Cidade Tiradentes, São Paulo, Brazil,' in the Shaping Health programme on Learning from international experience on approaches to community power, participation and decision-making in health. CEBRAP, TARSC: July 2017. <http://tinyurl.com/yaddlr74>



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Key features

Citizen participation in health in Brazil is mandated by law and effected through participatory councils with members elected by citizens and through other direct forms, such as meetings and petitions and through community health workers and councillors. Non-institutionalised forms of participation, ranging from joint actions to protests, complement institutionalised forms, creating a zone of dialogue that has facilitated public action on the provision and uptake of local public services. While not without challenges, participation has been enabled by active health councils, capable and politically and socially connected councillors and by a Family Health Strategy that engages people through multidisciplinary teams.

Key findings that could inform practices elsewhere include:

1. Promoting an alliance and organising meetings between civil society organisations, health professionals and managers to support a universal, rights-based health system;
2. Investing in local institution building (local councils and processes) to open spaces for citizen engagement and health professional links with the community;
3. Fostering elected community health councillors in bringing citizens demands, perceptions and suggestions to health services; community health workers to mediate between families, including disadvantaged groups and services; and teamwork and health personnel competencies in services to enable their connection to communities.

The country and local context

Brazil is a federal republic divided into three levels: federal, state and municipal. The country has 26 states, plus the Federal District, and 5,570 municipalities, each with full self-government and self-regulation powers. Home to 40 million people, São Paulo state has wide social inequalities, including access to public services. Cidade Tiradentes, a sub-municipality 30km from the city centre, has a mix of formal and informal slum (*favela*) settlements with over 220,000 inhabitants. Its local inhabitants are the poorest and most marginalised in the city, with high rates of unemployment, little access to social facilities, public services and public transport.

Cidade Tiradentes residents have poorer health status than the city average, with common risks of early pregnancy, chronic conditions, infectious diseases and social violence. Its residents have formed social movements to raise public pressure for solutions to their problems.

The national public health sector, the Sistema Único de Saúde (SUS), is a public health system based on the constitutional right to health and organised into three levels of care: primary care, medium- and high-level complexity. The public sector SUS takes care of 70% of the population for 47% of total health expenditure, while the private sector spends

53% of total health expenditure to cover only 30% of people. The health system is decentralised and municipalities have the main responsibility for allocating resources and for provision of basic care. Primary care units, Unidade Básica de Saúde (UBS), are the main primary care level facilities and the entry to the SUS, with a key role in prevention, basic care, screening for specialised care and referral. A Family Health strategy engages citizens directly on health promotion and care through visits by multidisciplinary teams covering 1,000 families. The teams include a physician, a nurse, two nursing assistants, a dentist and six community health workers (CHWs), with the latter being the intermediaries between the community and local services.

Citizen participation is a key feature of the SUS and mandated by law, through participatory councils, with half the members elected by citizens and the other half representing government, health workers and service providers. The councils closest to communities are local councils at municipal level and local facility councils within SUS primary care and hospital facilities. They contribute to policies and plans in line with local population needs and monitoring services. The local councils in São Paulo have been in place since 2002, but vary in their participatory practices from council to council.

The site and its practices

This case study explores institutionalised and non-institutionalised forms of citizen participation in the local facility councils (LFCs) based in the UBS primary care health units in Cidade Tiradentes. The experience of LFCs was examined in four different UBS: Fazenda do Carmo, Carlos Gentile, Gráficos and Prestes Maia. We explored the two-way dynamic in participation, from the community to local health facilities through the LFCs as institutionalised and from facilities to the community through non-institutionalised channels and entry points for citizens to have a voice in the health system. (See the [CEBRAP video](#)).

As **formal mechanisms for institutionalised participation** the LFCs represent citizens, health workers and health managers. They hold regular meetings, with a collectively agreed agenda. Although anyone can attend these meetings, only the elected councillors can vote. Decisions are usually made by consensus. While elections for councillors are always publicised and the results are made public, the turnout for these elections is often low, and few councillors come from highly marginalised groups, potentially weakening their representativeness. Elected councillors may be included in short



Local health council meeting in Cidade Tiradentes © A Calandrini 2017

capacity building courses on citizens' rights, SUS structure and policies, financing rules and the policy process. Beyond councillors' direct interaction with community members, communities have other ways of making input to the LFCs, by putting suggestions in boxes at the UBS, discussing content during council meetings or inviting specific professionals or community members for input on agenda items, such as medicine shortfalls in the pharmacy or social violence. One local council gathered signatures from the whole community to officially request a solution for shortages of medicines. Active councils pursue official collective requests, but also encourage street demonstrations. The councillor role appears to be critical for how far more proactive strategies are pursued, how far the community is mobilised, and how effective the mediation is between communities and authorities. LFC councillor links with community members are also built through their participation in various associations of community members, including church-related groups, women's social movements, associations supporting addicts and neighbourhood associations. At the same time, the councillors observe that these roles would be facilitated by greater involvement of facility senior management in council meetings, even though the same management sees the council as a key contributor to improved communication with the community.

Community health workers (CHWs), as non-degreed health professionals, also contribute to this interface between communities and services. CHWs are selected from those resident in the area for at least 2 years. They extend outreach services to the



Jardim Maravilha © A Calandrini 2017



Street demonstration against medicine distribution policy, São Paulo © A Calandrini 2017

community, bringing those in need of care to the UBS, mediating communication between the health system and the population. For example, in the catchment of the UBS Carlos Gentile located close to Maravilha, a big slum (shown in the photo), CHWs visit families monthly, developing a close relationship with them, collecting data on their health profile and discussing actions to improve their health. The UBS hold regular meetings building dialogue between CHWs, nurses and doctors and other health service workers. Health workers participate in ongoing education programmes to build competencies for their community work. These roles enhance the community/service interaction: *There are patients lost out there and we don't know what is happening to them! If they do not come here, we'll never know* *The community workers really help a lot --* KI health worker, 2017. From their perspective, community members see CHWs as channels through which to express their claims and have their voices heard. In parts of Cidade Tiradentes that do not have CHWs, communities rely more on councillors to broker this link with the services. While some areas have active councils and CHWs, this is not the case throughout, and key informants observed in one UBS that their communities had little interest in getting involved and did not know about the council's activities.

In addition to the LFC and local CHW work, Cidade Tiradentes has a local health council for the whole sub-municipality that meets monthly. This meeting gathers representatives – councillors, health professionals and managers – from the twelve UBS, with representatives of the municipality health secretary. Bringing together the LFCs from the

twelve UBS appeared to strengthen community confidence in making demands and common claims and to push for official responses.

Non-institutionalised forms of citizen participation in health complement institutionalised forms and take up issues that the latter failed to solve. These non-institutionalised forms may be conflictual, such as in protest, or collaborative, such as in joint work with professionals. One example of a protest occurred in response to a newly elected mayor notifying his intention to shut down the UBS internal pharmacies that provide free medicines to patients in favour of a proposed partnership with private pharmacies. This led some councilors from the community and UBS pharmacists to hold a street protest over the measures in front of the health department buildings in the city.

The interplay between institutionalised and non-institutionalised forms of citizen participation and joint professional activities helps create a zone of dialogue and mediation between two quite different

realities and experiences. At one UBS, it led to a mental referral centre being kept open after a threat of closure, due to the LFC, the local community and health professionals actively defending it. Albeit with a very small sample, the case study did not always find that UBS with active councils more effectively articulated citizen inputs.

While the UBS with active councils did have evidence of mobilisation, mediation, monitoring and conflict resolution, one UBS without an active council displayed similar achievements in relation to mobilisation, mediation and facility improvement. In general, participation appeared to be enabled by the presence of an active health council, by the processes they use and the presence of the Family Health Strategy. The evidence suggested the role played in participation by non-institutionalised forms of participation and by the experience and capability of the elected councillors and their involvement in local politics and links to social movements and local associations.

Table 1: Achievements of the participation work in the four UBS, Cidade Tiradentes, 2017

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

In contrast, the councillor role may be weakened by its voluntary nature, but also by councillors seeing themselves in this role as 'local elites'.

Outcomes from the work

There is evidence in published literature from Brazil on the impacts of these measures on health and social participation. Various studies (references in the full case study) on the performance of health councils suggest that they contributed to modest improvements in incorporating the demands of civil society in health policy-making and social control and citizen oversight over policy. Later studies, however, point to their generating favourable contexts for mobilising and, including those in more vulnerable conditions, in decision-making. Coelho and Waisbich (2016) found that health councils have facilitated civil society and health worker voice in health policies and in more inclusive decision-making.

The factors affecting this include how far social leaders and movements are accountable to their communities; whether health managers and professionals block or enable meaningful community roles; and how far collaborative links can be built between managers, service providers and users.

In the case study site, the participatory practices described have contributed a wide range of actors defending the SUS and a mental health service against closure; to improved measures to tackle violence; to changes in facilities to support service access for people with disabilities; and to actions to support pharmacists and access to medicines. There is evidence that coverage has increased between 1995 and 2010, such as for antenatal care and immunisation, local health funding has improved and infant mortality and life expectancy have both shown improvements. However, many factors may have affected this.

Areas for shared learning

The case study highlights that building institutionalised spaces helps to bring state and society actors closer. Nevertheless, it depends on a range of related processes for building capacity in those involved, dialogue forums for exchanges that facilitate mutual learning and processes that enable identification, pursuit and review of shared goals. Key findings of this study that could potentially inform practices elsewhere include:

- Promoting an alliance between civil society organisations, health professionals and managers to support a universal health system;
- Investing in local institution building (local councils and processes) to provide forums and programmes and open spaces for citizen engagement and health professional links with the community;
- Organising meetings that bring civil society, health workers and public officials together to promote and protect social rights in the public debate;
- Fostering the role of elected community health councilors in bringing citizens' demands, perceptions and suggestions to health managers and professionals;
- Fostering team work and health personnel competencies to enable their connection to communities;
- Supporting the work of community health workers in mediating the relationship between citizens and health professionals, making services more aware of and responsive to community needs, while promoting health and supporting access to and uptake of healthcare in disadvantaged groups.

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3.2: Citizen Participation and co-management for health in Chile

For the full report see: Frenz P, Alfaro T, Mazzei M, Sgombich X (2017) 'Case study: Citizen participation and co-management for health in Chile,' Shaping Health programme on Learning from international experience on approaches to community power, participation and decision-making in health, Universidad de Chile, TARSC: July 2017. <http://tinyurl.com/y78y6jvn>



Key features

Chile's health system includes citizen participation as a key axis of a rights-based health system, supported by a biopsychosocial health model applied in most primary care services. The six experiences in this case study point to the positive role of empowered, formal citizen councils and processes and community-led processes in historically mobilised neighbourhoods to support inclusion and decision-making control of vulnerable groups, including youth and immigrants. From formal spaces, participants are increasingly forming networks and organisations to drive demands for decision-making power and state support for their claims. Participation is not only a means to health goals, but an objective in its own right and, albeit a 'work in progress', raises areas for shared learning, including:

1. Defining the social roles, objectives and intended results of participatory practice, involving the community in design from the outset, backed by concrete, funded and monitored interventions;
2. Taking an area rather than centre-based approach to participatory governance, engaging people where they live, study and work, particularly for socially vulnerable groups;
3. Having a comprehensive primary healthcare model to support inclusion of marginalised groups and participatory, often visual tools, to support processes;
4. Forming citizen councils, with elected members that include users, community and health worker representatives, recognising and integrating the knowledge each provides.

The country and local context

Chile has 17.5 million inhabitants in 15 administrative regions and 346 municipalities with elected mayors. Sustained economic growth has led to improved wellbeing and a dramatic fall in poverty, although with a highly unequal income distribution. The immigrant population has doubled in the past decade. While the average life expectancy of 80.5 years is the second highest in the Americas, health is affected by an ageing population, environmental pollution, stress, social isolation, substance abuse and unhealthy behaviours, leading to high levels of non-communicable disease. The country has nearly universal health coverage through a two-tiered insurance system with mandatory contributions to

a public fund (FONASA) covering 75% of people, and private insurance (ISAPRE). FONASA funds national public health services and limited access to registered private providers. The public system includes 29 sub-regional, integrated networks of public hospitals and municipal primary healthcare (PHC) centres, the latter being the main entry point to care. An AUGE entitlement plan guarantees services for 80 prioritised health problems in public and private sectors, while intersectoral approaches integrate health and social protection.

The public health system has four integrated governance axes: citizen participation and user satisfaction, health- team strengthening, efficient

and effective healthcare and intersectoral action. A biopsychosocial family and community health model is applied in most Family Health Centres (CESFAM) throughout Chile, using a life-course preventive and promotion approach. The high demand for medical care, however, still skews resources towards the more biomedical AUGE guarantees.

Citizen participation at all levels is provided for in law, norms, guidelines and performance incentives as a social right. This is backed by mechanisms for information, public accounting, participatory public administration and non-discrimination through: social accountability through annual [public accounts processes](#) and reporting on policies, plans, programmes, budgets and spending; physical and online information and feedback in a system that is mandatory in all public services; practices supporting non-discrimination and inclusion, such as [friendly hospitals](#), intercultural programmes and approaches developed with [indigenous communities](#), immigrants and [gender](#) groups; civil society and citizen councils, as formal bodies at all levels, with advisory and deliberative roles; citizen consultation and dialogue meetings, involving communities in priority setting, service design and participatory budgeting; and community health workers and other resources for outreach to communities.

The site and its practices

The case study explores participatory practices at different levels of the public health system, ranging from local primary healthcare centres (CESFAM), subregional health services, municipal health promotion, and an autonomous community initiative. These six experiences, located in areas shown adjacent, are illustrative of practices, progress and challenges of citizen participation in health in Chile that have relevance for global learning. They involve community leaders, citizens and immigrants and their organisations, particularly from vulnerable and marginalised groups, with health and other sector professionals and workers. Each site experience is outlined below.

Grupo Llareta has thirty years of autonomous community-led work, generating supportive networks in a historically mobilised, low-income municipality of Santiago. In the early 1980s, the group trained community health workers, *monitoras*, with EPES, a non-governmental foundation working with popular education and was active in defending human rights, health and quality of life with other social movements during the dictatorship (Grupo de Salud Llareta, 2000). After the transition to



Map of Chile and the sites in the case study, adapted from map in © [Chile travel tours 2017](#)

democracy, in the late 1990s the Grupo Llareta focused on social determinants of health (SDH). *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 --* KI Grupo de Salud Llareta, 2017.

Their approach is ideological, building empowered collective action through murals, theatre, workshops, campaigns and counselling, working from their own community space, [Casa Llareta](#), linking with a network of collaborators. They use Facebook and WhatsApp to arrange meetings, to communicate with networks, and community workshops for training, awareness and to facilitate action. Llareta critiques health system-driven spaces for participation as being too narrowly focused and underestimating community capacities.

In contrast, **Adelaida in Biobío works through formal citizen councils** at local and provincial levels of the health system, leveraging intersectoral action on SDH, particularly for people with disabilities, and co-ordinated by the [Citizen Participation](#) Unit of the Biobío Health Service. Thirty formal citizen councils involve members, largely elected from the community, civil society and health workers. They work with health service and CESFAM teams to train and involve community members and organisations in the design, implementation and evaluation of municipal health plans and programmes. The councils draw on an existing social and organisational base of people with disabilities in Municipal Community Disability Councils, co-ordinating through a Provincial Disability Network in monthly meetings.

Through the citizen councils, community members participate in healthcare management, reviewing waiting lists for medical and home visits, supporting service users, and engaging in health promotion actions and campaigns. With resources from participatory budgeting, they have trained community health monitors, generated a network of eco-orchards, using recycled organic material in health and education establishments, and enhanced community green spaces and healthy eating. These processes are supported by direct online consultation, dialogue events, social media such as [CCDMulchen](#), [Red provincial de la discapacidad](#), [participación ciudadana SSBB](#) and radio outreach to more isolated communities.

The Santiago CESFAM, Madre Teresa de Calcuta, developed a citizen participation plan with community representatives in a neighbourhood with weak social cohesion and public infrastructure and dispersed community resources. In 2016, the Ministry of Health required PHC centres to develop and implement participation plans in conjunction with their communities, following the biopsychosocial model. This CESFAM used this opportunity to build a network of service users and health teams, allocating a social worker and health worker for the process. The initiative was launched in 2016 with public, municipal and health worker presence, with a logo to identify activities posted on the CESFAM [blogspot](#).



A diagnosis of the situation, including prevailing forms of participation, was carried out through focus groups and a community survey. It highlighted low awareness and involvement in existing mechanisms for participation. In a workshop, the community prepared a *roadmap* of activities *to travel during the years 2017 and 2018 to reach the goal of a community that is more active in and aware of their health with close ties to the [CESFAM] centre* – KI interview, 2017. Using drawings and pictures, participants identified the strategies and activities for the goals and plans for the CESFAM - community partnership. This included links, information exchanges, specific initiatives, such as participatory public accounts, setting up an elected health council, and citizen dialogues.



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

The draft plan was reviewed by the community in a participatory dialogue, the strategies adopted, and community focal points (kindergartens, senior citizen clubs, schools, churches and community organisations) identified. Information dissemination through social networks, wall diaries and bulletins and quarterly and annual evaluation mechanisms were included. The plan is now being implemented, although with challenges of working people's time constraints and still varying levels of participation (CESFAM Madre Teresa de Calcuta, 2016).

Psircutopia in the northern municipality of Ovalle engaged deprived and socially vulnerable youth for prevention and treatment of drug and alcohol abuse, given their low uptake of health services, unless referred from family and criminal courts (Ilustre Mun. de Ovalle, 2017). In 2011, the health services reached out to schools through a psychosocial team to diagnose, counsel and refer adolescents for treatment, and provided individual and family group psychotherapy, mental health consultations, home visits and group psychosocial interventions. In 2012, the health department created a physical space in a marginalised neighbourhood to develop activities with the adolescents, bringing in a theatre director for workshops in theatre, circus and music and creating Psircutopia. Psircutopia is open to all adolescents, whether volunteering or referred, provided they are in school, have a family bond and moderate or less harmful drug use. About 30 adolescents enroll annually in an 18-month treatment programme, and many who have completed the course continue to participate in the workshops.

Psircutopia has now expanded to offer courses and workshops on circus, cinema production, theatre, art therapy, music and construction of musical instruments. Adolescents actively participate in and define the rules of conduct for the workshops. The Psircutopia team is also training community workers to support self-help groups with weekly sessions on issues such as prevention of drug consumption and domestic violence. When community workers graduate, they form self-help groups of 12 people as supportive, totally confidential conversation groups: *... the group is about trust... with people who share your problem, any pain they have...* -- KI Ovalle, 2017.

In [Santiago Sano](#), the community participates in the diagnosis, definition of priorities, design and content of initiatives on health, and in their budgeting, implementation and evaluation. These include: [a network of healthy food carts/kiosks](#) to increase availability of healthy products; [Healthy Spaces in Santiago](#) to remodel public spaces; a

[Let's make a deal for good treatment](#) campaign; and a communication strategy to promote child rights. In one innovative experience, adolescents from six municipal high schools co-designed and developed a sexual health manual: 'Building Healthy Environments in Santiago: 100 Questions on Adolescent Sexuality' (Mun. de Santiago, 2016).

Adolescent friendly teams from the municipality held sexual health workshops in the schools, and participants anonymously raised questions, concerns and suggestions in a suggestion box to design future activities. The questions and answers were published in a manual led and with questions chosen by an adolescent committee, working with relevant expertise on the answers: *We realised that we did not know very well what adolescents were like, how they communicated, what things were of interest... So we decided to create a committee of adolescents, letting them make those decisions; essentially all the editorial decisions of the book -- Santiago Sano Group interview 2017.* The book was launched in 2016, and while a debate on its content limited widespread distribution of printed copies, many parents, adolescents and municipalities supported it, and the [digital version](#) is available.

CESFAM Juan Pablo II, in Santiago, developed a receptive environment for immigrants' health rights in a neighbourhood with high social and economic deprivation and a growing migrant population, many undocumented and without social support networks or knowledge of how to access services. The CESFAM teams developed an intercultural project to support migrant health rights and respond to their needs. They set up a registration system to handle undocumented clients and consulted representatives of the immigrant community, civil society, PHC teams and other municipal sectors to better understand migrant needs.



Mapping family health with Haitian users © Isabel Riquelme, CESFAM JP II, 2016

Haitian migrants were prioritised as a rapidly growing group, with specific language and social needs. All health centre personnel received intercultural sensitivity training, materials on how to access services were translated into Creole and a Haitian community facilitator hired for outreach. The migrant community are now represented in the local health councils, and an annual *No Discrimination Day* was instituted (Mun. de La Reina, 2016).

Outcomes from the work

Participatory governance in Chile is still in a transition from passive, consultative approaches towards more deliberative, empowering forms, not just as a means but as a goal. While processes are still poorly documented and not evaluated, KI and other

sources reported progress in citizen participation and perceived positive social and health results.

Backed by law, policy, rights-based and comprehensive PHC approaches, various communities, including migrants are using formal spaces to claim greater autonomy, forming networks and generating demand and ideas through civil society networks. There is a greater presence of social media, greater visibility of initiatives led by communities, and report of strengthened social awareness of health and its determinants and of uptake of services, including in marginalised communities. At the same time, communities also seek to affirm their own collective identity, learning and processes, and the support for this.

Areas for shared learning

While Chile's experience is a work in progress, it raises a number of areas for shared learning, including:

- Defining the social roles, objectives and intended results of participatory practice, involving the community in design of initiatives and materials from the outset and throughout the processes, backed by funding and monitoring of change.
- Taking a territorial and not a centre-based approach to participatory governance, engaging people where they live, study and work, particularly for socially vulnerable groups who are not accessing services, with the construction of networks, capacity building of community, health and other sector personnel.
- Having a comprehensive primary healthcare model to support inclusion of marginalised groups.
- Many tools support these processes, including online guidance and participatory diagnosis with citizens and social organisations using brainstorming, sociograms, problem trees, flowcharts, and problem/solution matrices, with many visual methods.
- Citizen councils can be adapted elsewhere, with elected members that include service users, community and health worker representatives, and recognition of the knowledge each provides.

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3.3: Mental health in Makueni County, Kenya

For the full case study report see: Ndeti D, Musyimi C, Musau A, Matoke L, Mutiso V (2017) 'Case study: Mental health in Makueni County, Kenya,' AMHF, TARSC:, July 2017 <http://tinyurl.com/yaq97rxg>.



Key features

Makueni County is one of the poorest counties in Kenya, with high levels of poverty. Mental illness is poorly documented and managed. There is a relatively well-developed mechanism for involving community members in development plans and budgets from village to county level, but focused more on visible areas of infrastructure. The case study indicates that bringing attention in these formal committees to less visible areas like mental health calls for increased community awareness and collaborative community systems to raise and respond to the needs of people with mental disorders. The processes applied to this included:

1. Building common language, using local terms, to avoid groups being alienated;
2. Facilitating information sharing, dialogue and respect for the knowledge of personnel in the community - traditional health practitioners, community health workers – and in local health services;
3. Agreeing on roles in an integrated system with capacity building and mentoring of community and service personnel within a shared framework to achieve shared goals;
4. Building community awareness and support through local media, sensitisation meetings and information outreach in community settings, such as churches and market places.

While changing social attitudes, practices and relationships takes time, such features could be adapted in other settings to address 'buried' and stigmatised health issues.

The country and local context

Kenya is a low income East African country with a steadily rising population. It has experienced improvements in life expectancy in the most recent decade, as AIDS and infant mortality rates have fallen. Kenya's economic growth has been associated with a decline in poverty from 56% in 1997 to 46% in 2006. Makueni County is one of 47 counties in the country, and among the poorest, with over 60% of the population living in poverty. Its one million people are mainly Kamba ethnic, with 44% under the age of 15 years. Despite being drought prone, the residents mostly depend on agriculture. There are various community networks for social support, including informal co-operative societies

or micro-savings groups locally known as *chamas*. The county experiences a mix of communicable diseases and reproductive health problems. Chronic conditions are rising in the country, but mental disorders are poorly documented both nationally and in the county. Studies have estimated that up to 25% of outpatients and 40% of inpatients in health facilities suffer from mental health problems, particularly depression, substance abuse, stress and anxiety disorders and psychosis were the most commonly reported mental disorders in the county (County Gvt Makueni, 2015).

Health service delivery is organised in four levels: community, primary care, county referral and national referral levels. Community services include

community health workers (CHWs) appointed by the primary healthcare management team and endorsed by a village health committee. The village health committee articulates community interests and decisions and oversees local health services. A community health extension worker (CHEW) - nursing or public health trained - provides technical support to this level and links it to health cadres at primary care level. Primary care services offer basic outpatient care, minor surgical and laboratory services, maternity care and limited inpatient care, and refer cases to county referral hospitals and from there to national referral hospitals. Community and primary care services provide little or no diagnosis and treatment of people with mental disorders, so people visit referral hospitals for this care. Psychiatric nurses from county hospitals also visit primary care and community levels, including schools, to offer individual counseling and health education. Many with these problems in the community prefer to visit traditional health practitioners (THPs) - that include traditional healers, herbalists, diviners and faith healers - and community health workers for being more accessible and more affordable. Many people in Kenya thus seek treatment for mental health

conditions from THPs. They use different methods: diviners use ancestral spirits to identify the cause of illness and misfortune, while herbalists/traditional healers use herbs, massage and dietary advice to treat disorders. Faith healers use prayers and other religious rituals.

The site and its practices

The Kenya case study reported on how community actors have been involved in improving health system responses to mental health in Makueni County. It describes how the local community was involved in identifying and adopting local names for common mental health problems, the approaches used to promote dialogue between health workers, THPs, community health workers (CHWs) and the community to improve mental health services and provide follow-up of clients.

In Makueni County, people generally believe that mental disorders are a result of witchcraft or a curse that can be passed down generations. Mental health problems are thus seen as personal issues that should be dealt with privately by the family.



Training of THPs to detect mental illness Makueni, © D Ndeti 2017

THPs are preferred over healthcare workers for these conditions, as local beliefs on their ‘spiritual’ or ‘cultural’ aspect are not seen to be resolved by western medical services. Those who go to healers prefer to visit those outside their communities, in part due to the stigma associated with mental illness and that people only visit health facilities if the other options have failed: *...mental illness doesn’t have a direct treatment since it’s both cultural and spiritual* – KI faith healer 2017.

THPs as a form of health workers embedded in the community were thus a key focus for this work. A dialogue with the community and THPs was held to identify the problems and terms used for common mental health problems in the community. Communities referred to psychosis as *mundu wa nduuka* (a mad person) or *mbusu* (a person in a confused state), depression as *theva* (sadness or mourning) and epilepsy as *mung’athuko* (unnecessary falls). Conditions are named locally according to their symptom manifestation, while different social groups have different names for the same condition. For example, a traditional healer used the term *mbusu* to refer to psychosis, while a CHW referred to it as *mundu wa nduuka*. These terms were integrated and discussed in the follow-up training and dialogues.

Collaboration between healthcare workers and THPs is one of the priorities in the 2015-2030 Kenya mental health policy. As a first step towards this in Makueni County, African Mental Health Foundation (AMHF), the Makueni county government and National Traditional Health Practitioners’ Association initiated a dialogue between THPs and primary care healthcare workers (nurses and clinical officers) to identify and address barriers to their collaboration and to discuss how to enhance respect between these different practitioners. THPs said that they refer to health facilities but that their referrals are not well received and that clinical personnel rarely refer people back to them, despite their contribution to care. Both groups recognised their shared goal of improved patient wellbeing and the need to show mutual respect and work together. Recognising that differences between them call for a more sustained process, they proposed joint training for THPs on how to identify and manage priority mental health problems.

Following its testing for cultural relevance, the [WHO mhGAP-IG](#) approach was used in a two day workshop to train THPs on the causes of mental illness and on measures to identify and provide psychosocial interventions to patients with depression. It involved a highly interactive experiential learning using small

group work and role-plays. An evaluation three months after the training found improved confidence, knowledge and skills in THPs to manage mental health problems and a reduction in symptoms of depression in THP clients (Musyimi et al., 2017a).

Beyond the THPs as community-level providers, communities were also involved in these processes through their CHWs. In Makueni, CHWs are selected by the community through a *baraza* (a meeting with community elders) with input from community members. They are linked to primary care facilities and visit homes in the community. CHWs received two days of training on their role in support of people with mental disorders, including keeping a record of such people to support service uptake and community-level follow-up of clients.

Various avenues are used to increase public awareness, challenge stigma and encourage participation in care and support for people with mental disorders and their families in the county. They include local mass media/radio, print media, and posters, sensitisation meetings and information outreach in community settings such as churches, market places and county structures for public participation - Village, Ward, sub-county and county administrators’ meetings – described below.

An annual [state of the county address and forum](#) was used to inform on the mental health activities in the county. Low internet access means that internet-based strategies have had more limited use in relaying information to the community. More intense person-to-person approaches have been used to change perceptions around the stigma associated with mental illness and to build social awareness on the actions taken in the community by CHWs, THPs and services, including road shows, public meetings and direct information sharing by local community leaders with those affected and their families.

These actions on mental health intend to create a synergy between public awareness and reduction of stigma and community, traditional and primary care service to support dialogue and bring the issue more constructively into the formal county mechanisms for public participation. They represent investments in informal processes to better engage with formal processes that have not yet adequately addressed the issue of mental health in this setting. They respond to the call expressed locally for dialogue between the THPs, healthcare providers and others involved to establish trust and collaboration for a more constructive system for those with mental health issues and their community to engage with.

The Kenya Constitution and laws support direct public participation through elected representatives and, in devolved governance, for citizens to ensure their rights, to make choices and set priorities for how resources are used for development activities. Elected community representatives in development committees and forums from local to county levels hear and review community concerns, proposals and priorities in formal engagement with the state and include agreed areas in the county budget.

Within the health services specifically, village health committees include members from groups involving women, youth, faith-based organisations, and people living with disabilities with the chairpersons elected by the community and with the technical support of the CHEW. These committees discuss health issues, address those that can be addressed locally and take others up through wider formal participation mechanisms.

The formal committees exist from village to county level in: village development committees; village cluster development committees; a sub-ward forum, involving members of three to five village cluster development committees and representatives from national and county government; biannual meetings of a ward people's forum that gathers members of

two sub-wards, elected leaders, administrators, organised groups and government representatives; and a county people's forum that brings together members from each of the sub-ward development committees, county government officers and organised groups. The county forum is co-chaired by the County Budget and Economic Forum, the Governor and his deputy and a representative of the community. They discuss county plans, fiscal strategy, budget and future outlook. [A media story of the forums describes the debates on how they have worked in Makeni](#), also presented [in a video on the work](#).

These mechanisms provide the formal means to consolidate resources, spread and review practices initiated in the county, and to build community ownership of these wider plans (County Govt of Makeni, 2017). To date these processes for public participation in the county have led to water, sanitation and infrastructure developments and decisions to remove charges at point of care for medical care. The investments described earlier in the informal processes mean that mental health issues can now be brought into these more formal mechanisms in a way that has stronger, shared and local ownership.



Public sensitisation activity on mental health © D Ndeti 2017

Making this link is important not only to institutionalise local processes, but because community involvement in the discussion and decisions on the proposed actions on mental health puts people in a stronger position to oversee and ensure social accountability on their implementation.

This was, for example, raised by one community member: *We are pleased because we get to know how much our dam will cost, and that way we know there is no stealing of money and we will finally assess if the dam is worth that amount of money. If there is any problem then we can discuss it --* KI community, Makueni sub-county 2017.

Outcomes

The formal data to assess uptake of services were not yet available, but one study found a reduction of symptoms in people affected by common mental illnesses (Musyimi et al., 2017b). Key informants reported improved care of people with mental illnesses and more positive conditions for them and their families: *like one who never used to work because they were sick can now do something for their lives. ...even the families came together* – KI health worker, 2017. They also reported increased knowledge about mental health in the THPs and health workers and improved dialogue and teamwork between formal and informal providers and community on how people with mental health disorders are responded to and treated.

Areas for shared learning

There are relatively well-developed mechanisms for public participation in Kenya, but their focus appears to be biased towards more visible areas of infrastructure development than toward less visible areas like mental health, unless there are processes to support both community awareness and more collaborative community systems to raise and respond to the needs of people with mental disorders. This work describes processes that build collaboration, dialogue and mutual respect between local health service workers and various traditional providers in the community as a means to overcome the significant deficits in mental health services by engaging existing community resources.

The processes applied are important for this, building common language and using local terms to avoid groups being alienated, facilitating information sharing and respect for the different knowledge and experiences of different actors across those involved, identifying roles in integrated systems and facilitating a sustained dialogue, capacity building and mentoring needed to achieve shared goals. Bringing improved evidence would further support these processes. The investment in these processes, while informal and perhaps needing review and guidelines to support wider practice, is argued to be necessary for communities and local providers to raise and propose actions on mental health in the formal mechanisms for co-determination.

While changing social attitudes, practices and relationships take time, specific features of the work could be adapted in other settings; they include: the (informal) processes used for building common terms, the structured dialogue on barriers, roles and actions and evidence-based training and wider community awareness to support collaboration between community-level and system actors. These may have relevance to other 'buried' and stigmatised health issues, to facilitate the interactions and awareness needed for them to be applied within more formal mechanisms for social participation.

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3.4: Ngāti Porou Hauora, New Zealand

For the full report see: Matheson D, Matheson K (2017) 'Ngāti Porou Hauora, New Zealand, case study' in the Shaping Health programme on Learning from international experience on approaches to community power, participation and decision-making in health, in association with NPH. TARSC: July 2017. <http://tinyurl.com/ydbkwzsl>



Key features

This case study reports on the experience of community participation in Ngāti Porou Hauora (NPH), an indigenous health service provider in New Zealand serving a rural population of indigenous descent. Māori culture is alive and highly visible in the area. The isolated and remote nature of the communities forges close links and solidarity between people. The case study highlights various features:

1. It indicates that participation is more likely to be sustained when designed and embedded within the cultural practices and belief systems held by the community, than when it arises primarily as a functional need of the health service.
2. It points to two-way participatory process: communities participate in NPH staff recruitment, in planning, policy and research processes and lead health initiatives. Health personnel, in turn, are largely recruited from the community served, have a broad concept of 'health work', and engage community members in community discussions and events on their own ground, and not only when they visit the health service.
3. The health service is a major employer in the area and thus a positive influence on the local economy and the wider determinants of health.
4. While national policies may articulate commitments to participation, the national and meso-level incentives for this need to be aligned and sustained for participatory approaches to fully develop.
5. Beyond improvements in areas of service coverage, social participation has often changed service priorities from being largely (or completely) clinically focused towards social and cultural components.

The country and local context

This case study reports on the experience of community participation in Ngāti Porou Hauora (NPH), an indigenous health service provider on the East Coast of the North Island of New Zealand. It serves an area that stretches across 200km of coastline, one of the first places in the world to see the sun each day. The 10,000 people served are rural and urban, most Maori, with Ngāti Porou tribal affiliation. Almost all live in deprived socioeconomic conditions with average incomes a third of the

national average and poorer health status than other areas of the country (NPH, 2016). People mainly work in the health, education, farming and forestry sectors, with a third of young people unemployed, raising the risk of poorer health, depression and early, unplanned parenthood (NPH, 2016). While New Zealand's population has high health status overall, Māori people, along with those of Pacific Islands descent and low-income people of all ethnicities, have poorer health. People in the region covered by NPH have the highest mortality rate in New Zealand (NPH, 2016).

New Zealand has a predominantly tax-funded health system. Access to public hospitals is free, but charges apply for primary care services, except for people 13 years and under. Patients enrol with their chosen service provider and a state capitation lump sum is paid for each person enrolled. Service providers thus 'know' their enrolled population, potentially facilitating a population health approach. District health boards (DHBs) plan and fund health services in their areas and provide hospital services. Primary health organisations (PHOs) work with general practices and other providers to deliver comprehensive primary healthcare. Local boards run the DHBs with the intent to foster community participation. Participation was, however, a reality for only a small proportion of providers prior to 2000 (with NPH as an exception).

Community participation became an explicit part of government policy in 2002: *PHOs must demonstrate that their communities, iwi [tribal authorities], and consumers are involved in their governing processes and that the PHO is responsive to its community...The DHB must be satisfied that community participation in PHO governance is genuine and gives the communities a meaningful voice* (King, 2001, p.4). Community participation in New Zealand's health sector has waxed and waned over the last sixteen years, and has had less policy attention in recent years.

The site and its practices

Ngāti Porou Hauora (NPH) is a community healthcare provider within the Tairāwhiti District Health Board (Hauora Tairāwhiti). Tairāwhiti has one of the smallest DHB populations in the country, and NPH is the smallest primary health organisation in New Zealand. NPH has enrolled 98% of the people in the East Coast rural areas, but still seeks to increase its urban enrolment. It has the highest proportion of Māori enrolled in a primary health organisation, with 88% of its enrolled population Māori (NPH, 2016).

NPH differs from most primary healthcare providers in New Zealand in a number of respects. It is both a primary health organisation and a provider of services; it serves a smaller population than other primary health organisations; it is owned and managed by the local tribe and serves one of the most remote parts of the country. It has six rural primary healthcare centres, one urban health centre and the Te Puia rural hospital, situated 110km north of Gisborne city. It provides free access in all its rural services and has a modest charge (US\$3.5-\$8.3) for

standard consultations for registered patients over 14 years of age in its urban health centre.

NPH contributes significantly to the local economy directly by providing employment, which in turn supports economic activity in an area with low employment and few economic opportunities.

Māori culture is alive and highly visible in the area where NPH operates. People speak both Māori and English, including in formal gatherings, churches and community occasions. The isolated and remote nature of the communities forges close links and solidarity between people, with NPH seen as an extension of this already existing community culture. Elder members of the communities are knowledge storehouses and guardians, providing leadership in relation to tribal knowledge, genealogy, traditions and culture.

NPH's concept of participation is shaped by the history and cultural beliefs. From the time of first settlement, independence and unity have been strongly held values. The 1840 Treaty of Waitangi reinforced this deeply held sense of independence and defines how Māori people currently view their relationship with the state, including for health services. The Māori Health Strategy, known as [He Korowai Oranga](#), is built on concepts that had their origin in the Treaty, with *Rangatiratanga* capturing people's right to both control and participate in making decisions about their health and to have meaningful ways to decide how health services are provided for their benefit.

Participation is thus not primarily seen from a utilitarian lens, motivated by its role in improving programme effectiveness. Rather, it is seen as a fundamental right and entitlement. Ngāti Porou do not see themselves as mere recipients of state-provided health services, in which they are claiming the right to participate. They see themselves as in control of their own destiny, where the onus is on the external party, such as the state, to participate as an equal partner in their processes or journeys.

NPH thus sees participation as a two-way process. The health service actively participates in the life of the local community and is inseparable from the communities participating in the health services. Health workers are largely recruited from and live within the community they serve, including *kaiawhina* (community health workers). They are active in community events, including some that would not usually come under a health mandate.

Health workers take a proactive role in maintaining a connection with community members and patients, facilitate a wide range of community-based programmes in areas where the community has identified a need and connect people with health and other services. Health workers make regular home visits and participate in events that are of significance to the community and community gatherings, raising health issues within these forums. They also participate in funerals, termed *tangi*. These are major community events that last about three days with extended family members attending from all over the country. NPH staff establish temporary clinics in larger funerals and may be involved in food preparation, in direct support to the bereaved family, through to formal roles greeting arriving mourners.

As a further example, in response to high rates of sudden unexpected infant deaths in Māori babies, community health workers have taught expecting mothers about a Māori safe-sleeping device, the *wahakura*, while also sharing information on safe sleeping, breast feeding and health plans with each mother. These interactions are a crucial component in building direct communication channels and trust between the health service and the community.

The culture of participation within NPH has varied over time. In the past, the NPH Incorporated Society Board had a representative from each sub-tribe who would liaise monthly between the board and their community, perceived to give every community a voice: *If you maintain Te Tiriti (The Treaty of Waitangi*



Ruatoria Health Centre © K Matheson 2017

Te Reo Māori version) – that means we must protect the rights of the tangata whenua (indigenous people, people of the land) to make decisions, and let them be at the level of decision making. – NPH community member and employee, 2017. This mechanism has since been replaced by board appointed by the tribal authority, TRONPnui, to assist the organisation manage financial difficulties. Appointments of community members to the NPH Board through the TRONPnui is seen by some to be less representative. NPH board members and senior management still directly engage communities, however. These engagements cover decisions on strategies and resource allocation.

NPH aims to have a meeting with each community once a year, with smaller engagements if needed. The meetings use a traditional format. The *Pakeke* (elder) from the community begins with a *karakia* (prayer), acknowledgement of history and connection to land and ancestors and song. The forum is opened to facilitate debate, and people talk until a consensus is reached: This can take time and may occur multiple times as the meeting is taken to each of the coastal communities.

As community time is precious, board members coordinate with other ongoing consultations to avoid exhausting the community, although its importance in linking participation to health was well understood: *When people are assertive around their own care – my care isn't sitting there in a file on the doctor's computer, it's me and my actions --* community member and NPH employee, 2017.

[Websites](#), [social media](#), community newsletters and [radio](#) are also used as communication channels to give the community more options for where and how to engage, although community members do not see it as a substitute for face-to-face meetings. The [Huringa Pai facebook page](#), for example was started by patients to respond to diabetes and associated heart disease, supported by NPH. Community members held an open development meeting that heard information from NPH on diabetes and brainstormed what the programme should include, and what communication channels to use. The ideas that came out of this meeting were used to develop the content of the programme, including activities such as walking groups, climbing, *Zumba*, information sessions on nutrition and reading food labels and cooking classes. A public Facebook page is used to manage communications, share ideas and record the journeys of the members and inspire others.



Community Member Maaka Rewiri
© K Matheson 2017

In the [Huringa Pai audio interview](#) a community member Maaka Rewiri shares his experience.

Beyond this, every Monday morning the NPH executive team attends a meeting on the ward at Te Puia Hospital, where staff and patients gather. This meeting begins with a prayer, and then all present have an opportunity to raise current issues or provide updates on events of the coming week. The executive team, nursing staff, cleaners or patients may raise issues related to the health service and issues of concern to the community.

NPH does not have a manual or toolkit specifically for community participation. Where examples of community participation are articulated in operational documents, it is often for compliance rather than to inform or enforce practice. NPH personnel said that practices or systems for participation should be flexible and that what is more important are the overarching values and associated principles.

Commonly articulated values are honesty and transparency. The community expects that NPH will take the time to explain in an accessible way the situation under focus, including the finances, political and external processes, before asking for feedback.

This includes giving space to staff and others to criticise the organisation, provided it is done constructively: *You have to tell the community everything, warts and all. Sometimes you will get a pat on the back, other times you will get your butt kicked. At the end of the day people appreciate transparency, and we end up on the same page when all the information is there, because we have the same long-term kaupapa (principle) -- Community member and NPH employee, 2017.*

The organisation has faced challenges, particularly as the resources available are insufficient to meet the level of health need in a geographically isolated community. (The district health board has reduced its support for NPH in response to its own budget deficit.) The funds NPH receives are also tied to particular activities, limiting its ability to tailor services to meet specific local needs. This also weakens the confidence the local communities have in NPH and its ability to attract and retain skilled health workers, putting further strain on community participation practices.

Outcomes

Despite these challenges, NPH has been able to provide a level of service coverage for its population above that of many other primary health organisations in New Zealand, with higher rates of consultation compared with the national average (NPH, 2016). In 2015, NPH outperformed most other PHOs in breast cancer screening, childhood immunisations for 2-year olds, and cardiovascular disease risk assessment (NPH, 2016). In the Tokomaru Bay area, all new mothers on the Wahakura Programme are breastfeeding, and have complete health plans they are following. NPH has developed innovative practices and protocols accepted by the community, with those related to genomic research and bio-banking having informed national guidelines. NPH has employed the majority of its 150 staff from the local Maori population, with positive economic impact. Social participation has often changed the hierarchy of priorities from being largely (or completely) clinically focused, towards social and cultural components.

Areas for shared learning

The case study highlights that participation can be sustained when it is embedded in the existing cultural practices and belief systems already held by the community. Exploring and understanding the specific cultural and historical context and designing participation on that basis are likely to build stronger models than when participation arises primarily as a functional need of the health service.

The two-way nature of the participatory process is important. Communities participate in NPH staff recruitment, in planning and policy processes and in research. Health personnel are largely recruited from the community served and have a broad concept of what 'health work' involves. They engage community members in community discussions and events on their own ground, not only when they visit the health service, and community members lead initiatives to design health programmes with health worker support. The service adds value to the community, not only directly in health service provision, but also by providing local employment, with the positive impact this has on the determinants of health.

The case study also found that national policies and structures may articulate commitments to participation, but these do not always translate into lower levels of the system. National and meso-level incentives need to be aligned to the extended period of time needed for participatory approaches to develop.

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4. Te Runanganui o Ngāti Porou (2017) *Rangatira / Leadership*. Te Runanganui o Ngāti Porou: Gisborne.

3.5: Empowerment approaches to food poverty in NE Scotland

For the full case study report see: D'Ambruoso L, Abbott P, Douglas F, McPherson E, Okpo E (2017) 'Case study: Empowerment approaches to food poverty in NE Scotland,' in the Shaping Health programme on Learning from international experience on approaches to community power, participation and decision-making in health, University of Aberdeen, TARSC: July 2017. <http://tinyurl.com/y7s55jeh>



Key features

In Aberdeen City, Scotland, people who are 'working poor', unemployed, dependent on state welfare or homeless are at greater risk of food poverty than others in the community. A 2015 Community Empowerment Act (Scotland) mandates co-determination involving communities in all sectors. In Aberdeen, two social enterprises involve those affected by food poverty as peers and volunteers: in pathways to employment in a café and community food outlets; in training activities to support employment; and in providing 'social suppers' to eat, meet and obtain skills and support for benefit claims, housing and healthcare. Two rounds of participatory budgeting by the local council provide community grants for such initiatives and participatory decision-making on public resources.

The work raises the value of:

1. Statutory law and rights-based approaches to empower people to claim rights and benefits that start in familiar community spaces, involve community workers and expand after feedback and review;
2. The freedom to innovate, test and develop practices through social enterprise models and non-state actors that can address outcomes and determinants, providing safe spaces, training and supporting people to move out of vulnerable situations and claim services;
3. Defining expected outcomes and gathering evidence to report publicly on changes achieved and to support internal participatory and strategic review.

The country and local context

Grampian, one of eight regions in Scotland, is made up of three local areas -- Aberdeen City, Aberdeenshire and Moray -- with a population of about 500 000, half of whom live in Aberdeen City. The region is relatively affluent, but has areas of deprivation, including 8% of Aberdeen's population. Falling oil prices slowed growth after 2014, and unemployment has risen in the city and surrounding areas. The extent of food poverty is not well measured, but people who are working poor, unemployed, dependent on state welfare or homeless are at greater risk than others

in the population. These groups overlap and people move between them. Use of food banks is increasing in the UK and in Scotland, with changes in benefit entitlements and processes, increased living costs and increased precarious employment. At least half of all food bank use is due to people facing barriers in [claiming state benefits](#) to which they are generally entitled (SFC, 2015). The Scottish Government is committed to eliminating food poverty beyond the welfare, health and local authority systems, with some reliance on social enterprises rather than state services. Scotland is committed to the [Sustainable Food Cities](#) approach of intersectoral partnership for

transformation of food systems; [Social Investment Scotland](#), established in 2001, is a not-for-profit finance agency with private-sector funding that provides loans to social enterprises.

Health indicators in the region are around the Scottish average or better, but with more deprived areas having poorer health outcomes. Since 2015, local and health authorities in Scotland have been required by law to provide [integrated health and social care](#), although the voluntary sector has become increasingly responsible for filling gaps in service delivery. Health authorities play an [investigative and advisory role](#) and work with providers and communities in a [Community Learning and Development CLD](#) to tackle hunger and homelessness, supporting and collaborating with the voluntary sector. The government is also committed to community planning, passing in 2015 the [Community Empowerment \(Scotland\) Act](#), which aims to improve the process of community planning across all sectors and to ensure that service providers work closely with communities (Scottish Govt, 2015).

The site and its practices

The case study examines empowerment approaches for people living in food poverty in Aberdeen city. It involves four agencies: Aberdeen City Council (ACC) and National Health Service (NHS) Grampian; and two non-government enterprises, Social Bite and Community Food Initiatives North East (CFINE). Three practices in the city engage communities in addressing food poverty: i. enabling pathways to employment, financial capability and housing (by Social Bite); ii. supporting poor households to move sustainably out of food poverty (by CFINE); and iii. community grant-making in low-income urban areas through participatory budgeting (ACC).

Those involved or covered include: the wider community, and vulnerable communities experiencing food poverty, unemployment, working poor people living in Seaton and Tillydrone, two

neighbourhoods that are among the most deprived in Scotland. Adult residents of these areas are more likely to be born outside the UK, unemployed or in low-paid unskilled or low-skilled work, in rented housing and with more limited digital use. Homeless people at risk of food poverty include rough sleepers, those living in hostels, shelters and temporary support or 'sofa-surfers', dependent on staying with other people. The initiatives involve professionals working in public institutions and social enterprises and community members in supported employment or volunteering in social enterprises.

[Social Bite](#) is a social enterprise supporting people to move sustainably out of hunger and homelessness. It provides food to homeless people and, through this process, enables pathways to supported employment, financial capability and housing. Sandwich shops and cafés serve the public, and use the profits from this to provide these services for homeless people. Customers are also able to buy donated meals for homeless people when they buy their own in a 'paying forward' scheme. The café is used as a social space where people in various stages of homelessness can come in for a sit-down meal using donated food and food not sold after the shop has closed for the day. Termed 'social suppers', in addition to food, people obtain counselling, skills building and one-to-one support for housing and healthcare. The social suppers are volunteer and peer-led and attendees are encouraged to volunteer. For homeless people, receiving food at locations other than emergency food outlets is less stigmatising, and the social enterprise model provides flexibility to address *...those things that everyone thinks should happen but no-one has the time or money to do...* -- KI community, 2017.

The Social Bite Academy aims to take ten homeless people annually through a process of supported employment, helping with accommodation, training, qualifications, work experience and ultimately a full-time paying job. The activities help with things that people with vulnerable or difficult backgrounds may struggle with in the workplace, such as eye contact

Figure 1: The Social Bite pipeline of support



and confident speaking, CV writing, job searching and referrals. Employment is also facilitated via placements in cafés, hospitality groups and retail outlets, working also with a local organisation, [Business in the Community](#). The activities involve peer and volunteer support to act on social determinants of health for homeless people and facilitate benefit claims and uptake of health and other services. This 'pipeline of support' to overcome disadvantage is summarised in *Figure 1* on the previous page. While the activities face challenges in dealing with sensitive issues, telling people's [stories of homelessness](#) and [social media](#) presence have provided a voice for the homeless community and challenged stereotypes, shown in a [video](#) of the work.

[CFINE](#) was established in 1997 to improve health and wellbeing and contribute to regeneration in disadvantaged communities by promoting consumption of healthy food. The organisation co-ordinates the [Food Poverty Action Aberdeen Partnership \(FPAA\)](#), bringing together 61 agencies responding to food poverty. It involves and employs people with varying forms of poverty and disadvantages, including homelessness, low incomes, unemployment, mental health issues, learning difficulties and offending backgrounds. Eighty percent of its employees come from these communities. CFINE provides over 250 people annually with volunteering and supported employment. It provides food for food banks, but also addresses determinants of food poverty in a range of ways: CFINE is collating evidence on local experiences of food poverty to present to elected officials, to raise awareness on the need for political solutions to these determinants. It runs sixty community food outlets selling affordable fruit and vegetables in deprived communities; distributes fresh, quality and in-date surplus to charities and community organisations and provides a training site and course on cooking skills and healthy eating in a programme supported by NHS Grampian.

CFINE is building financial capabilities for people to claim services and benefits and obtain employment; 'walking beside people who struggle' to navigate systems seen to be hostile to them; and enabling confidence and healthier lives through training, skills development and support for volunteering and for employment in CFINE and other job placements. Initially CFINE included members from the involved community on the board, but the numbers have declined due to time and other constraints these groups face. They are exploring alternatives to avoid tokenistic representation and provide more



Food collection for distribution, Aberdeen
(c) CFINE 2017

accessible mechanisms for power and decision-making to be devolved. Monthly lunches/suppers are being piloted, where people have a meal, socialise, and discuss what CFINE could do to improve, and how. One of the major constraints CFINE faces is adequate resources for these processes.

Participatory budgeting (PB) is a new process initiated by ACC as a means for inclusive decision-making over the allocation of public funds, including issues relating to food poverty, in line with the 2015 Community Empowerment Act (Scotland). PB was introduced in 2015 as an extension of existing [community planning](#) to enhance participation in local service planning. Two rounds of PB have been held in deprived areas in Aberdeen City to date. The first round in 2015 was driven by local champions to allocate £100,000 on activities for under 12-year olds in five deprived areas of Aberdeen. It was introduced in schools as familiar community spaces, and primary and secondary school pupils voted on the bids produced by community groups, as shown in a [video](#). The bids focused on fitness and health, digital media and technology, citizenship, the environment and the arts, and 28 were funded, a fifth on fitness and health. The second round in three urban localities expanded outreach using a web platform [UDECODE](#), administered by a participatory democracy platform, [Participare](#), with online publicity and an online [application form](#). Bids focused on digital skills, health, sports and exercise, food suppliers, cooking skills, hygiene and sanitation and community gardens and green spaces. The process concluded with a deliberative forum where voters could interact with bidders. The process was welcomed for engaging communities in decisions on budgets, and for its capacity building. However, concerns were raised of a bias against less organised groups without access to online resources and on the consequences of rejection for unsuccessful vulnerable groups.

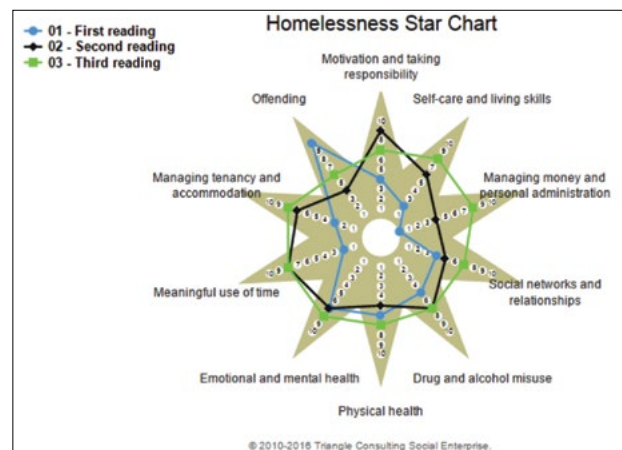
There are plans to further review and improve the process, and for government to allocate 1% of national budgets to PB processes (Scottish Govt, 2015). All three processes have benefited from an enabling legal, policy and institutional environment, but also face challenges in cuts in welfare and social funding, lack of disaggregated evidence and weakness in co-ordination across different services.

Outcomes

None of the agencies have as yet conducted outcome evaluations to assess the impact or effectiveness of their activities. CFINE reports client financial benefit through support for their claims of social security entitlements of £125,000 since April 2016, employment of 250 volunteers; increased knowledge and skills amongst client groups in cooking, food and nutrition, and increased confidence with financial management and budgeting.

Social Bite is piloting the ‘[outcome star](#)’ as an approach to mapping needs and progress for service users towards self-reliance or other goals, according to ten dimensions, shown in the figure adjacent. The star can be used for external reporting and internally for discussion of progress, and

personal action plans. Media reports tell people’s accounts of how Social Bite activities and support services have been humanising and building trust and dignity for them in transforming their situations. The first PB exercise has been process evaluated, but there are no evaluations of outcomes, or bids, funded to date. A UK-wide review of PB found that they yielded a range of social benefits for those involved (confidence, aspiration, empowerment, and increased sense of control, knowledge and awareness), but were yet to demonstrate impact on inequalities (Röcke, 2014).



Outcomes Star © Triangle Consulting 2010-2016

Areas for shared learning

In a context of economic austerity the work points to the value of:

- Statutory rights-based approaches to empower people to claim rights to overcome food poverty, backed by a Community Empowerment Act (Scotland) 2015, providing for open PB processes that start in familiar community spaces, involve community workers and expand after feedback and review. The National Standards for Community Engagement provide good-practice principles that were adopted in Scotland (see *Appendix A1*). *Appendix A2* lists online resources that support PB in Scotland and globally.
- The freedom to innovate, test and develop practices in the social enterprise model and non-state actors and the strength of food as an entry point. The innovations include paying forward, social suppers, social media activities, job placement, supported volunteering and selling affordable fruit and vegetables in deprived communities, co-ordinating action across groups and training and supporting people to move out of vulnerable situations and claim services.
- Defining expected outcomes and gathering evidence, including through visual means, like the outcome star to report publicly on changes achieved and to support internal strategic review.

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- Röcke A (2014). 'Framing citizen participation: Participatory budgeting in France, Germany and the United Kingdom. Palgrave Macmillan: London.
- Sustainable Food Cities (SFC) (2015) [30 UK cities call for government action on food poverty and warn that food banks are not the solution](#). SFC: Aberdeen

3.6: Pomurje region, Slovenia

For the full report see: Beznec P, Maučec G, Nemeš S, Nemeš D (2017) 'Case study: Pomurje Region, Slovenia' in the Shaping Health programme on Learning from international experience on approaches to community power, participation and decision-making in health, Centre for Health and Development: Murska Sobota, TARSC: July 2017. <http://tinyurl.com/y9q74yc4>



CENTER ZA ZDRAVJE IN RAZVOJ
CENTRE FOR HEALTH AND DEVELOPMENT
MURSKA SOBOTA

Key features

Since 2001 Pomurje region, Slovenia, has implemented participatory, intersectoral co-operation of stakeholders for investment in health and development, with a focus on agriculture, tourism, health and environment. An intersectoral regional action group (RAG) involves community associations, health and other sectors and promotes health as a contributor to development and development processes. Actions such as green procurement, healthy tourism, and promotion of active mobility link participation in decision-making to participation in health and economic activities, with improved outcomes in both areas. Various features of the work may be usefully applied in other settings:

1. An informal, cross-sectoral, multi-stakeholder body that provides a flexible means to build capacities, ideas, awareness, trust and approaches linking participation in health to participation in local economic activities;
2. Linking informal mechanisms to formal decision-making structures for support of plans;
3. Clear and measurable goals, with evidence and clear criteria to support priority setting and collaboration;
4. Capacity building of all stakeholders in social determinants of health, backed by evidence from assessments;
5. Sustained commitment of a technical health institution (CHD) to provide secretariat support, co-ordinate members and links between local and higher levels of the systems.

The country and local context

Slovenia had a growing economy between 1995 and 2008. By 2015, three-quarters of the population were in work, but with an unemployment rate of 7% and 14% of people living below the poverty line. Pomurje is one of the regions of Slovenia and the site of this case study. Its 2012 population of 118,573 includes a Hungarian minority and Roma ethnic community. While the region's economy has traditionally been based on agriculture, the tourism sector has grown. Since independence in 1991, Slovenia's economic development strategy has been based on sustainable management of resources and social cohesion. The

global financial crisis has, however, hit the region harder than the average in Slovenia, with higher levels of unemployment and lower levels of education and entrepreneurship and an exodus of younger workers and older, experienced, skilled workers, for improved incomes and work. A low birth rate, outmigration of young people, low rate of population growth and an ageing population have led to an increasingly elderly population at risk of poverty, social exclusion and reduced mobility, especially in rural areas and smaller towns. Retirement may begin in bad health due to poor working or social conditions. Much of the housing stock is old and energy inefficient. The Roma community is disadvantaged, with the highest

levels of unemployment, mortality and morbidity in the region. Inequalities in these health determinants and conditions across different groups result in high levels of inequality in health, despite widely health social support for equity (Beznec et al., 2015).

Slovenia has a long tradition of self-government in its twelve regions through regional development agencies that co-ordinate stakeholders. Municipalities manage assets, plan spatial development and manage local public services, including for healthcare. The country has a well-developed healthcare system at national and municipal levels, governed and financed by central government and the Health Insurance Institute of Slovenia. Based on a policy of universal healthcare, health services are delivered by public institutions owned either by the municipalities or by the state, by private providers working under a concession contract and, less frequently, private providers without a concession. The municipalities own a network of primary healthcare centres (PHCCs). While health promotion is practised, intersectoral co-operation is weak, in part due to organisational and legal barriers.

There are no formal mechanisms for direct public participation in decision-making on health policies. The public can express their demands or views on health policies through public debates, parliamentary discussions, media, social protests, people's initiatives and referendums. At local level, the public express their views mainly through elected municipal representatives, patient agents, website platforms and the media. Local and regional healthcare centres have councils with representatives from the public and non-governmental organisations that have direct influence on some decision-making processes, set by law. A government portal [I suggest to the government](#), for example, provides a space for

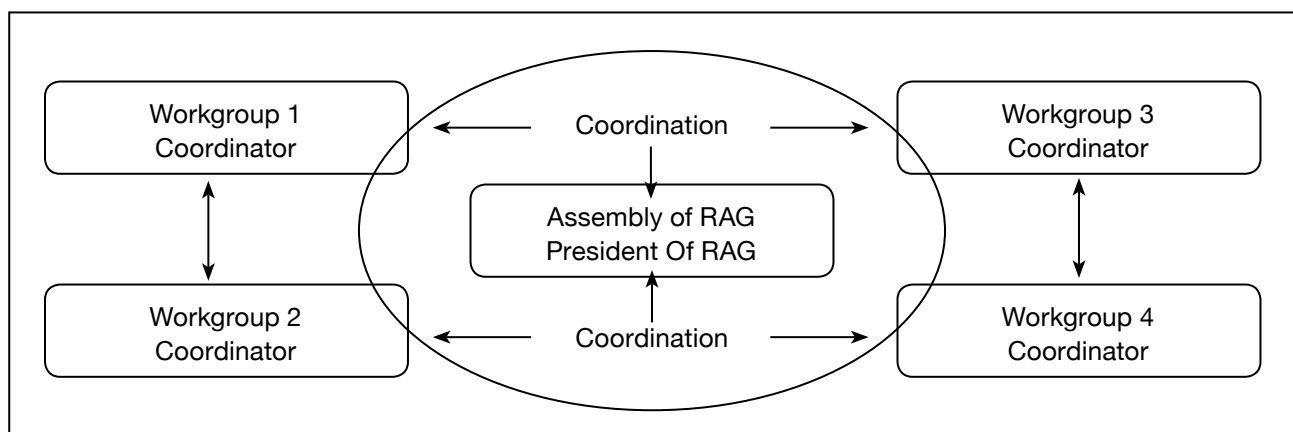
public submission and debate, such as on reducing waiting periods for specialist care. Community health literacy is implemented through issue-based non-state organisations, such as the [Alliance of disabled societies Murska Sobota](#).

The site and its practices

Pomurje region is the site for the case study on participatory intersectoral co-operation of stakeholders for investment in health and development. While not directly located within the governance of the health service itself, the health system is part of the intersectoral regional stakeholders' group implementing the work. The group initiates practices, is a knowledge provider and an implementer of programmes within it, including primary healthcare centres, the regional hospital and regional unit of National Institute of Public Health. The case study presents how active citizenship has promoted health as a potential contributor to development and vice versa, how to use development processes to promote health.

In 2001, [Programme Mura](#) initiated an investment in health approach to support the region's economy and reduce health inequalities. While the institutional resources to deliver the interventions were already in place, the co-ordination mechanisms to make them happen were not. Dedicated co-ordination mechanisms and functions needed to be set up at national and regional levels. At national level, an inter-ministerial working group was set up to co-ordinate and give strategic direction and support to the work. Backed by legal reforms for balanced regional development, political and WHO support and the inclusion of health as one of the three regional priorities, Programme Council Mura and the Centre for Health and Development (CHD) were founded. A Regional Action Group (RAG) provided

Figure 1: RAG structure



for wide participation of all groups. The assets, resources, capacities, interests in the region were used to identify and prioritise actions that had an impact on health equity and, as a result, agriculture, tourism, health and environment were prioritised.

RAG [Mura](#) was established to co-ordinate cross-sectoral and stakeholder collaboration in the actions, described later. Based on a mapping of stakeholders, the RAG involved state sectors, social organisations, associations of pensioners, people with disabilities, Roma community, civil society associations, long-term care organisations, local universities and media (The list of stakeholders is shown in the full case study report). Participants are delegated by their institutions and all stakeholders participate as full members in each of the four working groups of the RAG they seek to join, within the structure shown in *Figure 1*. Each RAG member signs a letter of intent to work within the RAG, and the structure is kept as informal as possible to avoid legal and other barriers to co-operation, noted earlier. The RAG has only one decision-making body, the assembly,

where each member has one vote. Working groups decide their procedural rules themselves. The CHD is the co-ordinator. Experienced CHD staff provides secretariat support to co-ordinate members and support co-ordination between local and higher levels of the systems.

A [Health Equity 2020 toolkit](#) assists in the phases of work to identify priorities for this, described further in *Appendix A3*. The decisions and outputs from the working groups and the RAG assembly are developed into formal proposals by CHD with the relevant stakeholders, and presented to the Regional Development Agency and Regional Development Council (RDC), where decisions are made. The Regional development plan and other directly funded projects. The proposals presented by the RAG have been integrated into the adopted programmes. Through CHD the RAG has been officially designated as the expert body for priorities in regional development for improvement of health and social inclusion.

Four key action areas identified by RAG for health and development:

<p>1: HEALTH, HEALTHY LIFESTYLE, involving: Physical activity programmes, infrastructure, accessibility for vulnerable groups; Healthy diet in kindergartens, schools; Healthy ageing; Mental health; Social inclusion, social management</p>	<p>2: AGRICULTURE, involving: Healthy food; fruit and vegetables production, diverse quality food; Local food supply, short food supply chains; Social enterprises in quality food production and processing</p>
<p>3: HEALTHY TOURISM, involving: Hiking, biking, Nordic walking, active tourism (programmes, infrastructure) Local healthy food and sustainable tourism in a 'healthy tourist offer'.</p>	<p>ENVIRONMENT, involving: Active mobility; Water resources; Renewable energy sources; Efficient energy use</p>

Implementation intends to be universal in coverage, with additional focus on marginalised groups. Some are pilot projects or innovations, and others draw from documented evidence in other settings. The work on palliative care, mental health and quality of life for vulnerable population groups gives specific focus, for example, to Roma and disabled people, long-term unemployed and elderly people in remote rural areas having higher levels of disadvantage and risk. The actions link participation in decision-making to participation in health and in economic activities. Various examples of the work are described below.

The risk factors for non-communicable diseases and other illnesses in the region made food production and supply a strategic issue. The local farm

community now supplies schools and kindergartens in the area with locally grown produce, incentivised by public procurement systems that are oriented towards preferring healthier choice, set in Slovenia at national level. This has led to great interest in and support of the development from the local community, schools, kindergarten councils, city councils and municipalities, with an example of school involvement in the adjacent photo. 'Green procurement' in education (schools, kindergartens) and the health sector (hospitals, primary healthcare centres, rehabilitation centres) is thus practised in settings where a healthy diet is most needed. In connection with the *healthy tourist offer* programme, described below, local foods are sold in tourist sites, generating jobs in food processing and gastronomic sectors.



Producing food in a sustainable way. © CHD 2014

A healthy tourist offer connects different local actors with the tourism industry, in partnership with the municipality, creating further jobs in local construction and maintenance industry. The infrastructure developed is used not only by tourists, but also by local inhabitants, improving opportunities for healthier lifestyles for all. The healthy tourist offer includes locally produced (healthy) foods that demonstrate culinary diversity, prepared and served as local specialties; cooking courses for tourist providers in hotels, tourists farms, restaurants, using healthy local seasonal produce, working with civil society associations.

Various measures have also been implemented on healthy environments, ranging from building long-distance heating systems based on biomass, to efficient energy use (insulation of buildings to reduce energy consumption), use of renewable sources of energy (biomass, sun, water, wind and geothermal energy) and social measures such as promotion of active mobility to reduce commuter traffic to work or delivering children to schools and kindergartens and promote peoples' physical activity. ([See examples of how to promote active mobility in local communities](#) on the CHD website.)

These processes have benefited from national incentives, such as green procurement and voluntary, community-led RAG capacity-building processes, meetings and dialogue. Consistent interactions have built awareness, trust and confidence. They [draw](#)

[attention to good practice](#), changing participants' way of thinking, including about their own role in health co-production, and sustaining the work and partnership over time. To avoid wish lists and dispersed projects that may not have impact or be feasible, evidence on the conditions and health equity impacts is explained in an accessible way through [The Health in the Municipality programme](#), contributing to decision-making, justifying the choices when presented to the RDC, and supporting the setting of shared goals. While funding is a key factor, the informal, flexible nature and methods of the RAG have enabled and sustained it.

Outcomes from the work

Formal evaluations identify significant improvements in population health outcomes, wellbeing and in areas such as job creation, recreational and healthcare infrastructure, and access to rehabilitation for elderly people. Results of National Health Monitoring Surveys carried out from 2001 to 2008 indicate positive changes in lifestyle in the region in terms of increased consumption of fresh fruits and vegetables, reduced use of animal fats in cooking, and reduced smoking and consumption of unhealthy foods such as fried foods, sweets, beverages, and salt, and an increase in recreation activities and exercise. KIs also noted improvements in awareness and practices in local people and policy-makers. They also saw institutional changes as positive outcomes, in terms of intersectoral co-ordination and participatory RAG processes.



Inaugural meeting of the RAG © CHD 2012

Areas for shared learning

Various features of the work may be usefully applied in other settings.

- a. An informal cross-sectoral and multi-stakeholder body flexibly implemented processes to build capacities, ideas, awareness, trust and approaches that link social participation in health to social participation in local economic activities. This informal mechanism was linked to formal decision-making structures to support plans.
- b. Clear and measurable goals and evidence and a criteria of impact on health equity are used to support priority setting and collaboration. A [toolkit](#) for gathering and using evidence (further explained in [Appendix A3](#)), and [learning from its use in various processes](#) at local and [regional level](#) are available.
- c. The RAG Mura approach was facilitated by community support for social cohesion and capacity building of all stakeholders in social determinants of health backed by evidence from assessments. It was supported by institutions and policy actors at local, regional and national levels and by WHO, by the sustained commitment of CHD for its processes and by the recognition of RAG proposals in the regional development plan in the regional development council.

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3. HE2020 (no date) [Health Equity 2020 toolkit](#). HE2020, Netherlands.

Appendices

A1 National Standards for Community Engagement in Scotland

The National Standards for Community Engagement are good-practice principles designed to support and inform the process of community engagement and improve what happens as a result.

They were originally launched in 2005, and since then they have supported community engagement, and user involvement, in Scotland in areas such as community planning and health and social care. A wide range of practitioners has accepted them as key principles for effective practice.

During 2015/2016, the National Standards for Community Engagement were reviewed and updated. The aim of this review was to reflect the developing policy and legislation relating to community empowerment in Scotland and to build on the growing range of practices.

The seven standards are shown in the figure below:



The review process was inclusive and drew on contributions from community organisations, third sector (voluntary) organisations and public sector bodies ([Scottish Community Development Centre, 2017](#)).

A2 Digital resources for Scotland and for participatory budgeting

The first part of the table shows various resources available online on community involvement and support in Scotland and the UK, with hyperlinks. The second part shows international [resources](#) on participatory budgeting, also with hyperlinks.

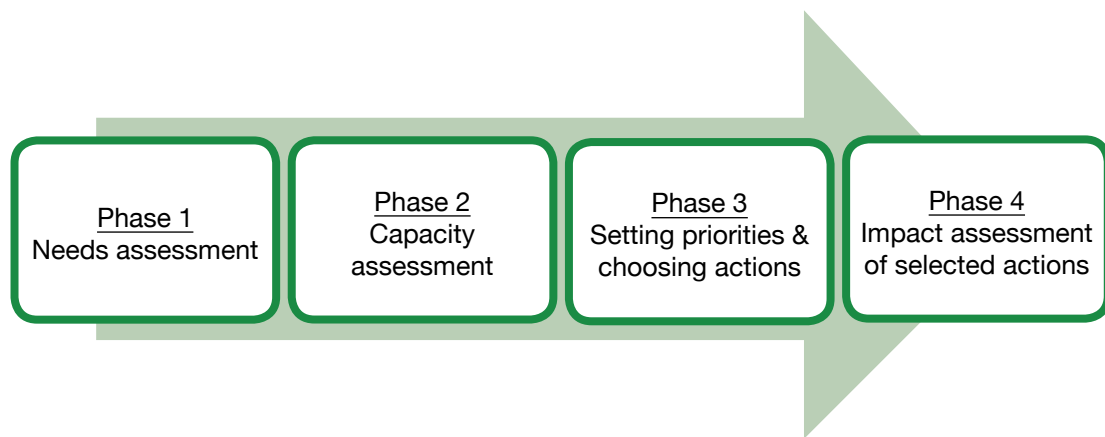
Digital resources for community involvement in Scotland	
Scottish Community Development Centre	supports community development and is recognised by the Scottish Government as the national lead body for community development
Communities Matter	is a new suite of training and development support to community organisations and people working with communities across Scotland
Visioning Outcomes in Community Enjoyment (VOICE)	is involved in setting National Standards for Community Engagement as principles to support and inform the process of community engagement and improve what happens as a result
Learning, Evaluation and Planning (LEAP)	is a framework based on the principles and values that underpin community development
Scottish Co-production Network	provides a locus for the sharing of learning and the exchange of co-production practice
Communities Channel Scotland	aims to provide support to local groups and organisations to contribute to social and economic policies
Community Health Exchange (CHEX)	promotes and supports community-led health for local communities to identify and take collective action on their health priorities
PB Scotland	acts as a hub for sharing and learning about the work done and promising initiatives on participatory budgeting in Scotland
Digital resources on participatory budgeting	
UDECIDÉ	is a new development linked to Locality Planning, to generate ideas and allocate funding in Aberdeen
Change Tomorrow	provides easy-to-use information to support participatory budgeting in a participatory democracy platform
Participare	provides easy-to-use, 'how- to' information to support participatory budgeting in a participatory budgeting platform
PB Partners	makes links to expert support for participatory budgeting initiatives
PB Network	is an independent body advocating for learning and innovation in stimulating debate and sharing information on participatory budgeting
Participedia	supports collaboration globally on new forms of participatory politics and governance
Shared Future A Community Interest Company	provides expertise, builds connections and support projects concerned with community empowerment and social enterprise in the not-for-profit sector, public sector and in 'ethical' private companies

A3 The HE2020 Toolkit (Slovenia case study)

The HE2020 toolkit provides a structured approach to decide the most promising approach in a region to address socioeconomic health inequalities, where priorities need to be set. Within the Health Equity 2020 (HE2020) project, the aim is to assist regions in drawing up evidence-based action plans to address socioeconomic health inequalities.

An important element is the development and introduction of the HE2020 toolkit. This toolkit follows a structured approach in which four main phases can be identified: 1. needs assessment, 2. capacity assessment, 3. entry points (setting priorities and choosing actions), and 4. impact assessment (see *Figure A3.1*).

Figure A3.1 HE2020 stages



Source: HE2020 (no date) [Health Equity 2020 Toolkit](#)

The process of drawing up evidence-based action plans to address socioeconomic health inequalities follows a structured approach in four phases.

Phase 1 focuses on a needs assessment: what is the current situation in the region with respect to socioeconomic health inequalities (health outcomes and determinants) and what are the desired outcomes? The gap between these two is considered to be the needs with respect to socioeconomic health inequalities. These needs form the entry points for action to address socioeconomic health inequalities.

Phase 2 focuses on the capacity audit and addresses capacities needed to address health inequalities, such as organisational development, workforce development, resource allocation, partnerships and leadership.

Phase 3 focuses on selecting entry points for action. With the information obtained in the needs assessment and the capacity audit, entry points for

action can be identified. Actions can be selected that address these entry points or priority areas.

Phase 4 focuses on impact assessment. An impact assessment of the selected actions can provide more information on the potential impact of each action and can therefore help in the process of deciding which action to take to address health inequalities. The final goal of these phases is to draw up evidence-based action plans that address socioeconomic health inequalities in the region.

For learning from the process various sites have useful information, including:

- <http://www.euregio3.eu/>
- <http://czt.si/files/investment-for-health-and-development-in-slovenia-programme-mura.pdf>
- <http://czt.si/files/positioning-health-equity-and-the-social-determinants-of-health-on-the-regional-development-agenda.pdf>

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.



Exchanging on social power in health

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