

shaping health



Exchanging on social power in health

Building social power and participation in local health systems: Learning from practice

Rene Loewenson
with

Peter Bezneć, Vera Coelho,
Lucia D'Ambruso, Jo Dorras, Ruth
Dudding, Patricia Frenz, Patricia
Gerrity, Deborah Howe, Vanessa Ivie,
Don Matheson, Clara Mbwili-Muleya,
Ranjita Mohanty, David Ndeti,
Francisco Obando, Sarah Simpson,
Beth Tanzman, Bill Wagner and
Rebecca Zappelli



November 2017

Training and Research
Support Centre

With support from a grant awarded by
Charities Aid Foundation of America
from the Robert Wood Johnson
Foundation Donor-Advised Fund



Cite as: Loewenson R with Beznec P, Coelho V, D'Ambruoso L, Dorras J, Dudding R, Frenz P, Gerrity P, Howe D, Ivie V, Matheson D, Mbwili-Muleya C, Mohanty R, Ndetei D, Obando F, Simpson S, Tanzman B, Wagner B and Zappelli R (2017) Building social power and participation in local health systems: Learning from practice', November 2017, Training and Research Support Centre.

Acknowledgements:

The first draft report produced by Rene Loewenson was peer reviewed by Sarah Simpson, Patty Geritty and Susan Mende, whose comments are gratefully acknowledged. The revised draft was then presented and reviewed by delegates in the Shaping health international meeting October 2017, with thanks for their further review comments and those received from site leads. Thanks also to members of the country case study teams in all the US and case study sites.

Photographs used / adapted under creative commons license:

Cover: health literacy training, Zambia 2016 © Shana; roadmap to strengthen participation ©CESFAM MT Calcuta, Santiago, Chile 2016; MDMQ steering committee meeting, Quito LJ Lurado 2016. Other photographs used with permission and as shown under the individual photographs.

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.

shaping health



Exchanging on social power in health

Building social power and participation in local health systems: **Learning from practice**

Rene Loewenson
with

Peter Beznec, Vera Coelho,
Lucia D'Ambruoso, Jo Dorras, Ruth
Dudding, Patricia Frenz, Patricia
Gerrity, Deborah Howe, Vanessa Ivie,
Don Matheson, Clara Mbwili-Muleya,
Ranjita Mohanty, David Ndeti,
Francisco Obando, Sarah Simpson,
Beth Tanzman, Bill Wagner and
Rebecca Zappelli

November 2017

Training and Research
Support Centre

With support from a grant awarded by
Charities Aid Foundation of America
from the Robert Wood Johnson
Foundation Donor-Advised Fund



Table of Contents

Key messages	1
1. Shaping Health	4
2. Why build social participation in health?	6
3. Facilitating social power in health	8
3.1 How is social participation in health being organised?	9
3.2 What processes, tools and resources are used?	14
4. But does participation make a difference?	21
5. What shared learning and common principles?	24
5.1 Participation is intrinsic to peoples identity, a reflection of values, rights and justice and integral to health	24
5.2 Community experience and knowledge, community activism and leadership are drivers of participatory practice	25
5.3 Participatory processes in health are more likely to flourish within community settings... ..	26
5.4 supported by and eliciting more holistic models of health	26
5.5 Informal and formal spaces and processes are both key and their two way interaction enriches both	27
5.6 Information sharing and organising community evidence are necessary, but not sufficient for meaningful participation	28
5.7 Participation calls for accessible processes for co-determination linking decisions to actions and resources	28
5.8 Institutional and individual facilitators play a critical role	29
5.9 Deepening participation takes time and capacities	30
5.10 Tracking diverse forms of progress builds learning from action and demonstrates the benefit to health....	30
6. References	31

Key messages

Changing socio-economic conditions, increased education and connectedness are generating possibilities and expectations of improved health and health services. Yet socio-economic inequalities and prejudices deprive many people of these opportunities for improved health. People are affected by multiple health burdens, many arising from conditions that demand social involvement to prevent and manage them. Health systems are being challenged to develop more equitable and effective approaches to meet these challenges, to work with communities and other sectors to improve health outcomes and to reduce costs for both households and services.

Social participation in health refers to people's individual and collective power and involvement in the conditions, decisions and actions that affect their health and health services. It can take many forms and levels. It may be initiated from within the community or by outside institutions. It takes place within formal and informal, invited or claimed spaces and within different functions of health systems. It may be ad hoc and transient or sustained. In *Shaping health* we focused on those forms of participation where communities co-decide the actions and services for their health and wellbeing, through their awareness, their collective power and power to act. This paper reports our learning on how this is organised and implemented, with examples of practice from local health systems in diverse countries. As key messages, we share below principles that appear to be common to practice that builds social power and participation in health and health systems.

- 1: Participation is integral to health improvement, intrinsic to people's identity, and a reflection of values, rights, equity and social justice.** Participation is thus not only a means to improve health actions and services. It is an end in itself, integral to humanity and a democratic goal of society. The social power involved in participation is claimed rather than granted. The more embedded and claimed participation is within the community, the more it is sustained, defended and strengthened over time, supporting service personnel and yielding stronger models than when organised primarily as a functional need of the health services.
- 2: The lived experience and knowledge of communities, community activism and leadership are key triggers and drivers of participatory practice.** Participatory practice is galvanised by, starts from or, if catalysed from outside communities, engages early with community experience, culture, perceptions, and responses to injustice. Community experience and knowledge inform the evidence and analysis used in setting priorities, in joint decision making and in design of services. This implies identifying, investing in and nurturing community level activists from affected groups, and building their facilitation, communication, convening, negotiation, advocacy and leadership capacities and functional skills. Many community health activists do these roles voluntarily. However, their roles are better sustained when linked to employment or income opportunities and recognition for the changes they contribute to.



Public sensitisation activity on mental health © D Ndeti 2017

3: Participatory processes and social power in health are more likely to flourish when grounded within community settings, such as schools, markets, workplaces, sports and traditional gatherings. In these settings the interactions between communities and services are more likely to overcome power imbalances that inhibit communities in their interaction with service personnel, with processes centred on the community, rather than on the services.

4: Social participation and power are supported by and elicit more holistic models of health, in people-centred, population health and comprehensive primary health care (PHC) approaches that work with other sectors on health. Community voice in decision-making raises the focus on these approaches, calling for socio-cultural capacities and team-work in service personnel, measures for shared planning and monitoring and for resourcing population health.

5: Informal and formal spaces and processes both play key roles in participation. The two-way interactions between them enrich both. Informal spaces are more flexible, inclusive, more able to use the processes, places and tools described in the report that are accessible to communities, especially to reach and involve groups often excluded from formal processes. They can build the collective power and confidence for formal interactions. Formal mechanisms, often legally constituted, provide a means for joint community and service participation in dialogue, co-determination and oversight.

This participation is more meaningful if community members are elected, inclusive of different social groups, if they co-decide or are informed on the procedural rules, and if the evidence and processes are accessible to and enable input from them. The various ways of doing this are detailed in the report. Participatory practice generally involves a two-way dynamic between a multiplicity of formal and informal mechanisms and processes, to build the dialogue, relationships and trust over time between communities and services.

6: Sharing information and participatory processes to gather, analyse, discuss and use community evidence and knowledge in planning are necessary (but not sufficient) for meaningful social participation.

Communities and services share information in a range of ways, person-to-person, collectively and online. Information exchange alone may, however, have little impact on social power. Community evidence and knowledge needs to be used in decision-making for more meaningful forms of participation. There are a range of ways communities actively gather and analyse evidence on health and its determinants, identify problems and their causes, and prioritise those to act on. Community evidence and analysis, combined with service evidence, enriches planning, particularly when communities are involved in decisions using the evidence, with the criteria for decisions - such as what will best improve health equity –agreed between service and community personnel.

7: Community involvement in accessible processes for decision-making that link and lead to shared plans, actions and resources are central to meaningful participation.

Involvement in decision-making (co-determination) takes place in formal spaces, and is influenced by informal processes and interactions. However it demands more than the presence of mechanisms. With the different interests and power involved, a range of further features facilitate social power in decision-making. These include: elected and inclusive community representatives who are involved in community processes, communicate with and draw feedback from communities; transparency on the procedures and principles that govern decision making, agreed with communities; processes that integrate socio-cultural features (language, literacy) in their methods; and shared goals and outcomes with measures, such as progress markers, to assess and review step-wise progress, with short-term ‘wins’ to build confidence. These measures are bolstered by linking decisions to resources, such as through certification, community grants, incentive funds and participatory budgeting. Community and services support is fostered when decisions are monitored, progress reported, and where there is wider social accountability, such through social audits with public hearings.

8: Institutional and individual facilitators play a critical role.

International experience suggests that one or more strategic, consistent ‘facilitators’ play a key role, as organisers, catalysts, enablers and supporters of these processes. They may come from local health or other services, local authorities, non-state institutions, social enterprises, or be key individuals. Communities and services see them as credible, competent and trustworthy. Institutions that take on this role have various features: a visionary and enabling management, adequate staff or volunteers; an experience of collaborative work; a funding base, resource strategies or wider support that enable programmes and a degree of organisational freedom to test, develop and sustain new practices. Setting achievable goals and monitoring and making visible to all involved the progress made in addressing shared concerns contribute to confidence in the processes.

9: Deepening participation takes time, consistent presence and capacities, to let models evolve, to identify how best to contribute, to embed mentoring and capacity building

and enable horizontal connections and spread across communities. While demanding of time and often facing opposing power, growing social power and trust and shared strategic review with those involved, including employees and community members, helps to build and sustain the work.

10: Strategic review and evaluation can track and show diverse forms of progress in health and social outcomes and build learning from action.

While evidence is often gathered to build policy, funder and management support, evidence gathered through participatory approaches is vital to support constructive criticism, strategic review and learning from action. From the outset this should recognise and value a mix of social, system, service and health outcomes, the time they take to emerge and the different ways they are gathered and measured, as described in the report. Such evidence can build confidence in shared progress in those involved, and shows the contribution of social power and participation in health.



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

1. Shaping Health

People are not simply passive patients or consumers in health. Individually and collectively they also actively contribute to a culture of health. They are citizens with rights to participate in the decisions and actions that affect their conditions for health and their health services.

What do we mean by ‘social participation’ in health? As discussed more fully in a [separate background paper](#) (1), it refers to people’s individual and collective involvement in conditions, decisions and actions that affect their health and health services. This can take many forms, as it is motivated by different interests amongst those involved. It assumes different levels, from manipulation and consultation through to co-determination and control. It may be initiated organically from within the community or by outside institutions. It takes place within formal and informal, invited or claimed spaces, within different functions of health systems, and may be ad hoc and transient, or sustained. Within this diversity of form, participation reflects and transforms the [power relations](#) that exist between communities and services and other personnel (1).

In 2016/17 the *Shaping health* project explored how local health systems in different countries have built social power and participation in health, and the challenges they face. As a community of people and institutions involved in this field of work, we shared experiences and insights on how communities build the power, confidence and capacities to identify their health and service needs, to set priorities and participate in decisions on the actions and services that address these priorities. We focused specifically on local-level health systems and the communities that interact with them to promote population health.

The project, led by [Training and Research Support Centre](#), was implemented with partners from five sites in the USA and twelve countries internationally, shown in *Figure 1* below. It was supported by a grant from Charities Aid Foundation of America from the [Robert Wood Johnson Foundation](#) Donor-advised Fund.

This paper synthesises the experiences and learning across the work to address four questions:

1. Why build social power and participation in health?
2. How is social participation in health organised, with what tools and resources?
3. What insights and principles can we share on enabling social participation and power?
4. Does social participation make a difference?

This paper draws on various documents produced in the project. Given the desire to provide a concise document from a significant and ongoing body of work in the project, the text has hyperlinks to original materials for deeper information on the issues and practices raised. The paper draws on a [conceptual framework](#) (1) [an annotated bibliography](#) (2) and an inception meeting report (3). It draws on briefs on their work and management of change from the five US sites (4,5,6,7,8,9,10,11,12,13,14,15). It draws on experiences reported in case studies from twelve countries internationally (16,17,18,19,20,21,22,23,24, 25,26,27), with [Volume 1](#) and [Volume 2](#) summaries of this work (28;29) as well as from exchanges between project participants in the *Shaping health* website discussion forum.

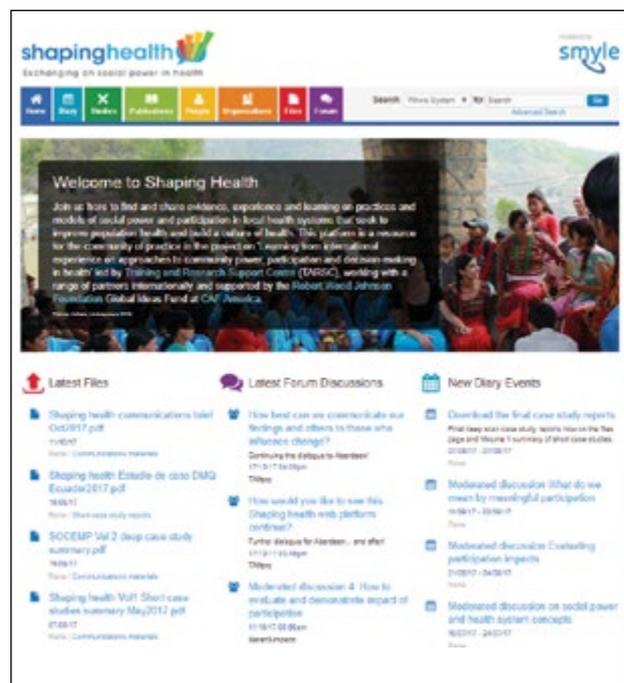
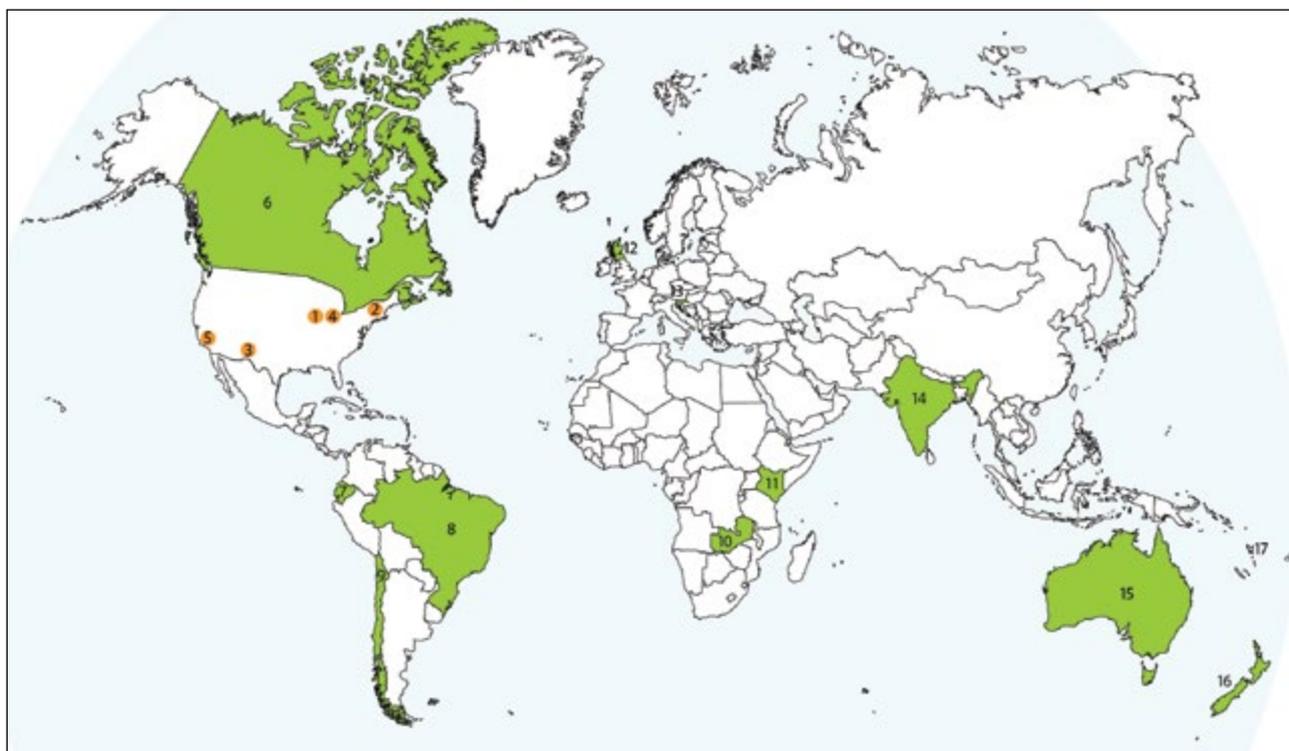


Figure 1: Map of the countries and US sites in *Shaping health*



KEY

#	Site	Country
1	Athens City-County Health Department, Ohio	USA
2	Blueprint For Health, Vermont	USA
3	Centro Sávila, New Mexico	USA
4	11th Street Family Health Services, Pennsylvania	USA
5	PIH Health, California	USA
6	Bridge for Health, Vancouver	Canada
7	Metropolitan District of Quito	Ecuador
8	Cidade Tiradentes, São Paulo	Brazil
9	Ovalle, La Reina, La Bandera, Pte Alto, Biobio	Chile
10	Lusaka district health office, Lusaka	Zambia
11	African Mental Health Foundation, Makeni County	Kenya
12	Aberdeen City, Grampian region	Scotland
13	CHD Murska Sobota, Pomurke Region	Slovenia
14	Sahbhagi Shikshan Kendra, Varanasi, Uttar Pradesh	India
15	Youth mental health service, Gosford, NSW	Australia
16	Ngāti Porou Hauora	New Zealand
17	Wan Smolbag, Port Vila	Vanuatu

2. Why build social participation in health?

There is growing recognition that people have a right to participate in decisions on their health and health services and that this has value for both communities and services (1).

In the Shaping health project we are focusing on those forms of participation where communities, as a right, have built the evidence, voice, capacity and self-determined thinking and action to participate in, influence and co-determine actions and services for their health and wellbeing.

Whether organic or externally induced, this 'meaningful' form of participation involves a 'bottom-up' growth in the social power within affected communities to transform conditions affecting their health.

The background literature, US and case study sites point to a number of factors that motivate recognition of and action on social participation in health, both for the US sites and for those in other countries (28;29;5;7;9;11;12;13):

- 1. Socio-political norms, values and rights play a central role in improved health.** They define active citizenship and co-determination as a right in democratic systems. They arise from historical culture or as a result of social activism. While these values may be consolidated in legal frameworks, such as the [Community Empowerment Act Scotland](#) (2015)



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

(18) or the constitutions and statutes of Brazil and Ecuador (17;22), they do not depend on this. Rather, they are intrinsic to people's sense of identity, belonging, citizenship and self-determination, where people do not wait "...for the system to respond to or provide the invitation to participate, but instead mobilise a collective ground swell to make and create opportunities for participation" (B4H, 25 p8)

- 2. Social change is bringing opportunities and challenges for health.** Changing socio-economic conditions, increased education, social literacy and information connectedness are generating possibilities, expectations of and demand for improved health and health services. At the same time socio-economic inequalities and prejudices deprive many in society of these opportunities, generating distrust and frustration, but also social activism on health and its determinants.
- 3. Populations are affected by multiple health burdens that arise from preventable social conditions.** The country sites in *Shaping health* report rising health burdens from alcohol and opioid addiction, chronic disease, stress and mental disorders, and from food and income poverty, poor living environments, social exclusion and isolation of older people. Youth, poorer, marginalised and immigrant communities face barriers to service uptake. Disasters, climate change, population movements, epidemics and violence, and buried or stigmatised health issues such as mental disorders, raise health risks that, beyond service interventions, demand changes in social norms, awareness and action to prevent and manage them.
- 4. Health systems are being challenged to develop more equitable and effective approaches.** The multiple, sometimes poorly co-ordinated providers and benefit systems for different health problems generate public frustration and service inequities and inefficiencies. People are organising and building social literacy to understand, navigate and claim entitlements and to use services. However, service personnel also raise the need to better engage with community-level resources and to develop people-centred approaches to prevent

3. Facilitating social power in health

Exchanges in *Shaping health* suggest that the question for many is less one of why build social participation, but how to initiate and do it in a way that builds cycles of achievement, confidence and learning for both communities and services. This section shares our practices and insights on this question.

Social participation may be rooted in history and culture, or may derive from socio-political activism for health (28;29). Both foundations build a political culture in which people “...do not see themselves as mere recipients of state provided health services, in which they are claiming the right to participate. Rather, they see themselves as in control of their own destiny” (23 p13).

In the US sites, the absence of a rights-based, universal, single payer health system, and the current legal uncertainty were noted to set a less enabling context for their efforts to strengthen social participation. However, the rights-based and universal systems that enable co-determination in other countries were not always present and had to be fought for (17;19). The Brazil and Chile case studies describe the local struggles, including during harsh times, that contributed to these national contexts (17;19). In central Chile, the Group Llaretta community and non-state actors allied with wider social movements from the 1980s, using [Paulo Freire’s popular education](#), to organise communities and train community health workers during the dictatorship to defend and advance health rights that are now integrated within national policy (19).

The change may thus start locally, inside or outside the formal health system, and evolve organically over time (25;26).

Participatory approaches have been initiated by community and civil society networks, such as Bridge for Health (B4H) in Canada (25) and Sahbhagi Shikshan Kendra (SSK) in India (21) and by organisations and informal mechanisms that engage formal processes, as in Slovenia’s Pomurje Regional Action Group (RAG) (16). They have been instigated in training and dialogue forums, as in Makueni, Kenya (24), or by local governments organising new approaches, as in Quito, Ecuador (22), or Lusaka, Zambia (20). While communities themselves are diverse, with different levels of voice and power within them, these efforts often benefit from a strong sense of community belonging, shared identity, history and values (19;22;23). Organisations with values-driven leadership and socio-political and technical competencies have also played a role in stimulating participation. Through their work and honest relationships, these organisations have built the trust of communities and authorities (20;21;22;25).

Collectively, the US sites have a number of these levers for participation, including: a community that shares a history and identity; local citizen action groups and resident service employees who share an intent to improve their local conditions; organisational and policy mandates for participation, with support and partnership from elected officials and other sectors; trust in facilitating organisations built through information sharing; responsiveness to community concerns and investments in social roles over time; and a local organisation of stakeholders, partnerships and resources to build support for social roles (5;7;9;11;13).

The next sub-sections outline how, from these entry points, social participation has been organised and the tools and resources applied.

In Vanuatu, for example, the theatre group called itself [Wansmolbag](#), meaning ‘one small bag’ in Bislama (the language of Vanuatu), to show that it could go anywhere. It reflects Wans Smolbag’s (WSB) origins as a small theatre group of fifteen voluntary actors touring the country using drama to address social issues. [WSB has now grown over 25 years](#) into a multi-issue, multi-actor organisation with reach across many countries (26 p3).



Stamp series for WSB work over 25 years, Vanuatu

3.1 How is social participation in health being organised?

How participation is organised affects how far people are empowered. [Power is central to participation](#), and refers to the capacity to make a difference and to transform, either through individual or collective action.

We often hear of *power over*, as a form of domination and control, but there are other forms of power: The self-confidence and consciousness to support decisions and actions is a form of *power within*. The ability to act, to influence change, is referred to as the power to, while the power created through collective action is termed the *power with* (1). While they may be facilitated, these forms of power are claimed rather than granted.

The experiences in *Shaping health* provide some insight on how participation in health is organised to enable this growth of the consciousness, or *power within*, the collective power with and the power to act.

Organised within community settings: In many countries, participation is organised in spaces [owned by or familiar to the community](#) (19), including schools, workplaces and market places, with service personnel going into these familiar settings (22;25). In NPH New Zealand, where social power derives from the indigenous culture, health workers are largely recruited from and live in the community they serve and are active in community gatherings. These interactions build communication and trust between services and the community (23).

Organising and interacting with services *within their own settings* appears to be important for inclusion of different social groups and, together with other processes described in this paper, help to address the power imbalances that often exist between communities and professionals. It also offers the opportunity to *make a more direct connection with the social determinants of health and with health promoting economic opportunities*, such as in Scotland (18), India (21), or in the Slovenian experience below.

In Slovenia's Pomurje region, health was raised within a social dialogue involving community associations and various sectors as a key element of the economic and development agenda, and taken up through an informal mechanism termed the [Regional action group \(RAG\) Mura](#). The assets, capacities and interests of all involved were used to identify and prioritise actions that could improve health equity. This led to the interest of and actions by the local community, schools, kindergarten councils, city councils and municipalities. For example, the local farm community now supplies schools and kindergartens in the area with locally grown produce. This practice is incentivised by national public 'green procurement' systems that encourage healthier choices, especially in the education and health services where a healthy diet is most needed. In a **healthy tourist offer** programme, local foods are sold in tourist sites, generating jobs in food processing and restaurants. Working with civil society associations, enterprises and the municipality, this programme includes health-promoting cooking and physical activity programmes that have created local jobs and an infrastructure that benefits both tourists and local inhabitants (16).



Nordic walking, Pomurje, Slovenia. © CHD 2012

Mobilised by health activists and in informal spaces: While organisations outside the community may play a catalytic or supporting role, *community organisation and participation are largely mobilised and facilitated through the activism of community members, volunteers and citizen leaders* (19;21). They may be health literacy facilitators, local community leaders (17;20;21), community volunteers and teams

(22) or expert patients in peer-to-peer networks, such as the peer support provided to young people with mental illness in NSW, Australia (27).

Community health workers (CHWs), elected by residents and recognised by services, can also act as health activists. In addition to their role as a link between the community and services, they

create health awareness and mobilise communities on health (17;21). *Being elected by residents* is important for them to have a close and accountable relationship with the community, so that community members see them as channels to express their needs, claims and ideas (21). Having a role in family care and community health and recognition by health services helps to strengthen their local credibility,

provided that they receive adequate support from the services, and that procedures do not make them more accountable to the services than to the communities they come from (1;2).

CHWs thus need to link with, complement and not displace other forms of citizen leadership and organisation, such as that in Varanasi, India, below.

In Varanasi, India, excluded communities collectively organise in community-based organisations (CBOs) with support from [Sahbhagi Shikshan Kendra](#), a non-government organisation. The CBOs provide a critical space to facilitate diverse activities, shown in a [video](#), including sharing information on entitlements to state benefits, strengthening market skills in weaver groups, and building literacy, music, sport, education and vocational skills for adolescent girls to tackle early marriage, reproductive health and access to health services. A *Citizen Leadership Programme* builds citizen leaders in villages and CBOs to facilitate these actions and to engage with *panchayats*, state departments and health services, while meeting in their own forums to network and share ideas (21).



Discussion with women and health services in a SC hamlet, Munari-Burkaini, India, © SSK 2017

Social enterprises and co-operative models, while often catalysed by organisations outside the community, have also facilitated collective leadership and shared ownership. [Bridge for Health](#) Canada, for example, started as a network and evolved into a co-operative association, to enable diverse members from different backgrounds to engage in decision-making on health, and to generate solutions for their health concerns (25). In Scotland, social enterprises generate resources that have supported community level economic and networking activities for homeless people and for those living in food poverty (18 and see example overleaf).

Many of these community-based organisations (CBOs), enterprises, associations and networks provide a vehicle for sustained forms of participation over time. They provide social support, counselling or assist people to claim benefits. They may also organise more transient, *ad hoc approaches* (18;19;21), including creative activities and events (murals, theatre, music, sport), meetings, skills-building workshops, issue-specific health advocacy campaigns, forums (19;21; 24; 25), social audits and public hearings (21).

Social media provides useful means to share information beyond the common 'person-to person', approaches. It extends the reach of information, including through blogs, websites, Whatsapp, community newsletters and radio (28;29).

In New Zealand, for example, patients started a [Huringa Pai facebook page to support health promoting activities in those with diabetes and heart disease](#), supported by NPH. Community members integrated information from NPH with their own ideas to compose communication messages and used a Facebook page to reach people, for them to record the actions they had taken to inspire others (23). Social Bite has also shared homeless people's stories in social media to challenge negative stereotypes that affect decisions (18).

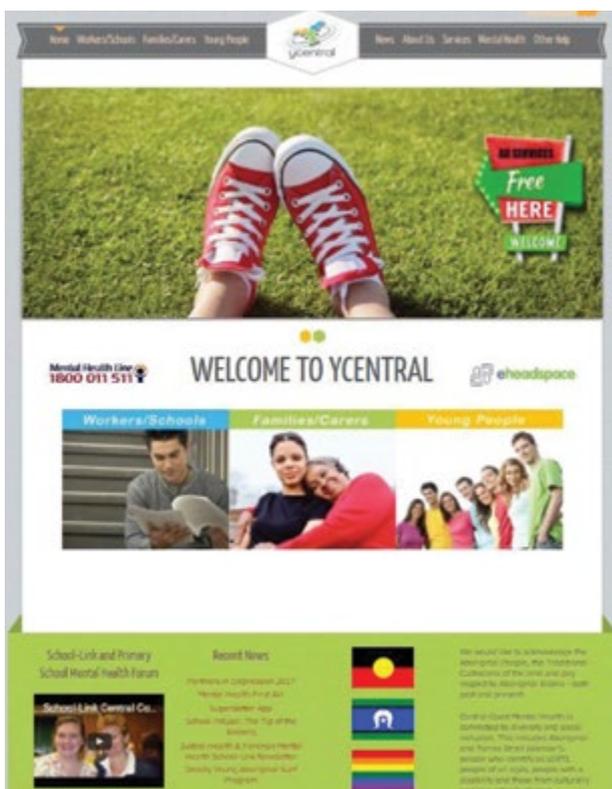
Online methods can provide spaces that enable participation in circumstances where stigma and physical factors discourage people from meeting, or for groups who find social media accessible. For example, this was applied in youth networks and to support peer-to-peer links on youth mental health (YMH) in Gosford Australia (27).

[Social Bite](#) is a social enterprise supporting people to move out of hunger and homelessness. Social Bite sandwich shops and cafés serve the public and use the profits and donated meals (in a *paying forward* scheme) to provide a social space for homeless people to have a sit-down meal. These *social suppers* also provide a vehicle for counselling, skills building and one-to-one support for housing and health care. They are volunteer and peer-led, including by homeless people, and attendees are encouraged to volunteer. They are seen by homeless people as less segregated and stigmatising spaces to meet. With [stories of homelessness](#) and a [social media](#) presence, they have provided a 'voice' for the homeless community and have challenged stereotypes, as shown in a [video](#) of the work. Social Bite has an academy that takes homeless people through a process of supported employment, helping with accommodation, training, qualifications, work experience and ultimately a full-time paying job. It builds skills in CV writing, job-searching and referrals and provides employment in the Social Bite cafés and kitchens and job placements in cafés, hospitality groups and retail outlets. It thus provides a 'pipeline of support' to overcome disadvantage, summarised below:



Source: Social Bite, 2017 in (18)

In Gosford, Australia a ycentral physical site, a [YMH specific website](#), and a mobile YMH team provide support from health workers and other youth to young people at locations in the community that suit them, including schools, emergency departments, community health centres and in their homes (27).



ycentral website screenshot, Australia © D Howe 2017

Engaging with services in formal mechanisms:

Interactions between communities and services also take place in *formal mechanisms*. These are usually set up within local government or health systems. They are generally backed by national policy and law as sustained institutionalised spaces to facilitate public input to services, such as Ecuador's [Comités Locales de Salud](#) (CLS) (22), Zambia's neighbourhood health committees (20), Chile's citizen councils (19) or Brazil's local facility councils (17). They involve multiple stakeholders, including health workers and community representatives, and are organised from community/ primary care level upwards (17;19;20;22;24). Generally, local residents elect their community representatives.

These mechanisms are not always a health sector structure. They may have wider development roles, such as the Panchayati Raj institutions in India (21) or the development committees in Kenya (24), bringing health issues under wider local government co-ordination (22;24).

As formal spaces, they offer many opportunities for co-determination. However, their processes are not necessarily on the 'community's terms', unless procedures for this and different forms of evidence and voice are specifically negotiated, and unless representatives have strong links back into their communities.

As formal institutionalised participation mechanisms, the local facility councils (LFCs) in Cidade Tiradentes, Brazil represent citizens, health workers and health managers. They hold regular meetings, with a collectively agreed agenda. Although anyone can attend these meetings, only council members can vote, and decisions are usually made by consensus. While councillor elections and their results are always publicized, the turnout is often low thus undermining their representativeness, especially of more marginalised groups. Council members may be included in short capacity building courses on citizens' rights and on the structure, policies, financing and processes in the health system. Councillors interact directly with community members for input. Communities can also make input to the LFCs through: suggestion boxes, by invitation for input on specific agenda items, or by petition. The role of the councillor appears to be critical for how far the community is mobilised and how effective the community voice is in the LFCs. Councillors that participate outside the LFC in community associations and social movements appear to build a stronger social voice and agency for health both inside and outside these formal mechanisms (17)



Local health council meeting in Cidade Tiradentes, Brazil © A Calandrini

The presence of such formal spaces may enable, but cannot be assumed on their own, to provide meaningful participation. 'Consensus' decision-making can disguise power imbalances. The community members involved may not represent the spectrum of needs and interests in the community, they may not be elected and the committees may have limited real authority. Even where communities have claimed their inclusion in these mechanisms and elect their representatives (20;21;22), the procedures and tools used in the meetings need to be organised in a way that genuinely enables voice, recognises and respects different experiences, knowledge and roles and facilitates co-determination (25). This is further discussed in the next subsection.

These challenges are often greater for people that are stigmatised or discriminated against, such as people with mental health problems (24;27), women from specific social groups (21) and undocumented or new migrants (12;19). Further measures may be needed to reach into these communities through trusted people in places that are seen to be safe, to work within their own language and cultures and to build service support for these interactions, and for the networking and growth in leadership in these groups (19;21;24; 27). The CESFAM Juan Pablo II experience in Santiago, below, reflects features of such approaches with new immigrants from Haiti (19).

Generating synergies between formal and informal mechanisms:

Formal mechanisms provide a key platform for co-determination. However their limitations, described above, mean that participating in them does not preclude community members taking other forms of action outside them. These actions may include building collective power and knowledge for these formal engagements, or they may be triggered by dissatisfaction with how issues have been resolved. In São Paulo, for example, when a newly elected mayor notified of his intention to shut down the primary care pharmacies that provide free medicines in favour of private pharmacies, some community-level councillors, community members and pharmacists took their protest over the measures to the streets (17).

Indeed, as highlighted in a [CEBRAP video of the experience in Brazil](#), there is an important two-way dynamic between formal and informal spaces and levers in social participation (17). Institutional formal mechanisms interact with the informal, bottom-up processes described earlier (16;17;18;19;21;24;25;26).

In Chile, for example, formal citizen councils, CHWs, [public accounts processes](#), participatory budgeting pilot activities in eight health services and formal information systems interact with more informal spaces and measures.

CESFAM Juan Pablo II in Santiago, Chile, is in an area of high social and economic deprivation, with a growing migrant population. Many migrants are undocumented, without social support networks or knowledge on how to access services. The CESFAM teams sought to engage this community, to support their health rights and respond to their needs. They registered undocumented clients and consulted representatives of the immigrant community, civil society, PHC teams and other municipal sectors to better understand migrant needs. Haitian migrants were prioritised as a rapidly growing group with specific language and social needs. Health workers received intercultural sensitivity training. Materials on how to access services were translated into Creole and a Haitian community facilitator hired for outreach. After these steps and outreach work with the community, the migrant community now send representatives to the local health councils. An annual *No Discrimination Day* has also been instituted, building wider solidarity with the migrants (19).



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

In Chile, intercultural programmes, such as shown in the box above, have been developed with [indigenous communities](#), immigrants and [gender](#) groups applying a range of consultation and dialogue meetings (19).

Informal spaces provide the room to innovate and build new relationships and approaches for social participation. In Slovenia, a locally constituted informal mechanism, described below, provided space for new interactions and shared proposals that could be taken to the formal regional development council (RDC) (16).

In 2001, [Programme Mura](#) initiated an investment in health approach to support the region's economy and reduce health inequalities. While the institutions to deliver the programme interventions were in place, the co-ordination mechanisms to make them happen were not. With health a regional priority, and backed by national support, the Centre for Health and Development (CHD) was founded and a [Regional action group \(RAG\) Mura](#) set up for participation of all local groups and state sectors. Participants are delegated by their institutions through a letter of intent and all participate as full members. The structure is kept informal to avoid legal and other barriers to co-operation. The RAG decision-making body is the assembly, where each member has a vote. Working groups on specific issues decide their own procedural rules and the CHD provides secretariat support. Decisions of the informal RAG body are developed into formal proposals and presented to the formal Regional Development Agency and (RDC) to integrate them into the regional development plan and public funding (16)



Inaugural RAG meeting, Slovenia © CHD

The US sites have a range of existing assets to apply to such approaches for organising participation, such as information exchange with community networks and associations (5;6;9; 13); community-led citizen action groups, coalitions, networks and community health workers (5;8;12); interest and leadership from

councillors and elected leaders (5;11); community spaces such as schools, workplaces, libraries, faith centres, public forums and creative gatherings (5;6;12;13); and governing or advisory bodies that include community members (6;12).

For example, [Centro Sávila](#) has come together with a local [community supported agricultural programme](#), a [community organising programme](#), an [artists' collaborative](#) and community members to participate in design workshops and to build a community table, where meals and stories can be shared. The community table is located next to a therapeutic garden. Community members and their healthcare providers interact in activities for the garden, and use this space to discuss and address the challenges they are facing in their lives and issues related to food insecurity, nutrition and healthy living. This approach brings land, food and community together in one setting. Such approaches not only address health needs. They build and nurture spaces where community actors participate in the collection, analysis and interpretation of evidence that can be used to inform public health policy, while simultaneously becoming involved in the political processes that shape health interventions (12 p9).



Centro Savila website screenshot, 2017

As noted earlier, even where there are inclusive spaces and mechanisms, the processes and tools used affect how meaningful this is for communities. This is discussed further in the next subsection.

3.2 What processes, tools and resources are used?

The US sites already apply a range of processes and tools to support participation, including various forms of information exchange in person or online (5;6;9;13), or in local languages (12). They implement mapping and surveys of stakeholders and of community needs, assets and barriers to service uptake (5;8;12); hold social dialogue to identify priorities for action using diverse sources of evidence, including evidence from communities, and support transparent decision-making on actions (4,5).

One of the tools used for this is the [Creating Health Assessment and Group Evaluation \(CHANGE\) Tool](#) in Athens County, Ohio (5) (used also in Ecuador). In some US sites, priorities identified in social dialogue with communities are implemented with support from grant funds, or are incentivised by certifications or awards for community-led health improvements. For example, Athens County Health Department provides a *Creating Healthy Community Award* (5), implemented across [Ohio](#) with other statewide policies, such as a 2018 requirement to demonstrate community engagement for public

health accreditation (5). The experiences in other countries may enrich and add to these existing initiatives in US sites.

Informing and consulting communities are generally regarded as the most basic processes in participation. They are necessary contributors, but are not sufficient, to give the community a greater say in decisions or greater control over processes (16). They may increase the power within but do not necessarily build the collective power to act. Information sharing takes place in a range of ways: in face to face through meetings, community forums and workshops, indirectly through various forms of media, or electronically through Facebook, WhatsApp and other social media (28;29). The processes may be ad hoc, or they may be regular, as for example in the annual [state of the county address and forum](#) in Makueni county, Kenya, to inform on local mental health activities (18). In Biobio, Chile, online consultation and social media such as [CCDMulchen](#), [Red provincial de la discapacidad](#), [participación ciudadana SSBB](#) and radio connect even isolated communities with information exchanges that support participation (19).

The way information is shared may empower or disempower. Beyond engaging in community settings, the process itself should facilitate social input. NPH interactions in New Zealand take a traditional format. Led by the Pakeke (elder), with processes that acknowledge local history and

culture before discussions are opened, they are co-ordinated with other ongoing consultations to avoid exhausting the community (23). *Using local languages and terms helps to build a common language* for information exchange, as was applied with rural community practitioners in Kenya and in

work with migrants in Chile (19;24). Visual forms of information sharing may overcome literacy barriers (20), and art, drama and other creative activities can be a powerful means of communication from and with communities, including on sensitive issues (19;26).

[Wan SmolBag \(WSB\)](#) uses drama, theatre, radio, TV and film, participatory workshops and peer education to communicate information and build awareness and capacities for action. [Local plays are usually followed by discussion of the issues raised](#) and publications are distributed to communities after a performance. The actors interview people on their issues and experiences to inform the scripts and are briefed by experts so that they can lead post-play workshops. In the youth drama, out-of-school youth gather for a fortnight of drama, improvising on issues and experiences they face and interacting with health workers. Material from this is used in the script (26).



The main theatre: a day school audience, Vanuatu © D Ragonmal 2017

What and whose evidence and knowledge is used in setting priorities and making decisions is a key reflection of the power of different actors. Many sites thus organise specific ways of acknowledging and organising community experience as a key source of evidence. In Quito, Ecuador (22), and Pomurje, Slovenia (16), data from the health and other information systems are presented in accessible forms.

The data are discussed in a joint dialogue involving communities and health workers, to integrate community views and inputs on the evidence and what the priorities are. Various tools are used: in Quito, the WHO Urban Health Equity Assessment and Response Tool (Urban HEART) guided the process, described below (22), while the RAG in Pomurje used a [Health Equity 2020 toolkit](#) (16).

The Quito Municipality health department (DMQ) [Barrio Saludable](#) programme gathers and analyses information on health and its social determinants to engage with residents. Evidence from various departments and surveys are analysed by DMQ using the [Urban HEART](#) tool, the US Healthy Communities program and the Ecuador Ministry of Public Health National Program for Healthy Municipalities. This evidence and issues identified by communities are discussed in neighbourhood workshops. A road map of actions is developed to address prioritised issues, with a focus on those with higher health need. DMQ is piloting competitive US\$2 000-\$5 000 incentive funds to support implementation of these community health plans (22).



Community identifies the main health and determinants of health issues, Quito © LJ Cárdenas 2016

In Pomurje, Slovenia, evidence on health trends is linked to evidence on economic, social and development resources in the region. This frames health less as a burden, and more as an entry point for shared health, economic and social improvement. In this appreciative form of inquiry the ideas, assets and resources in the community are used to decide on strategic actions (16).

Starting with evidence from the system roots discussions and plans in formal evidence. It may, however, disengage communities less familiar with, or trustful of, these forms of evidence. In some sites, therefore, the processes are first centred on evidence from the community. In the sites in Canada, Vanuatu and Zambia, the communities carry out their own research and surveys to gather evidence, with support from local state or non-state agencies (20;25;26). B4H in Canada brings community evidence on causes of ill health at work to dialogue with local businesses to co-design healthy environments, designing and testing 'Wellbeing @ Work innovation labs' (25). In Aberdeen, CFINE has collated evidence on local experiences of food poverty to engage elected officials on solutions to these determinants (18).

A number of the sites use [participatory reflection and action \(PRA\)](#) methods to map, identify and prioritise the areas for action on health (20;25;26). In PRA processes those most directly affected by conditions are the main source of information and the lead actors in producing and using knowledge for action and change. PRA does this through a spiral of repeated cycles, that:

1. Systematise shared information on people's lived experience and situation.
2. Collectively analyse this experience and identify problems and their causes.
3. Reflect on the findings to choose actions to address the problems.
4. Take action and review the changes as a basis for learning from action (32).

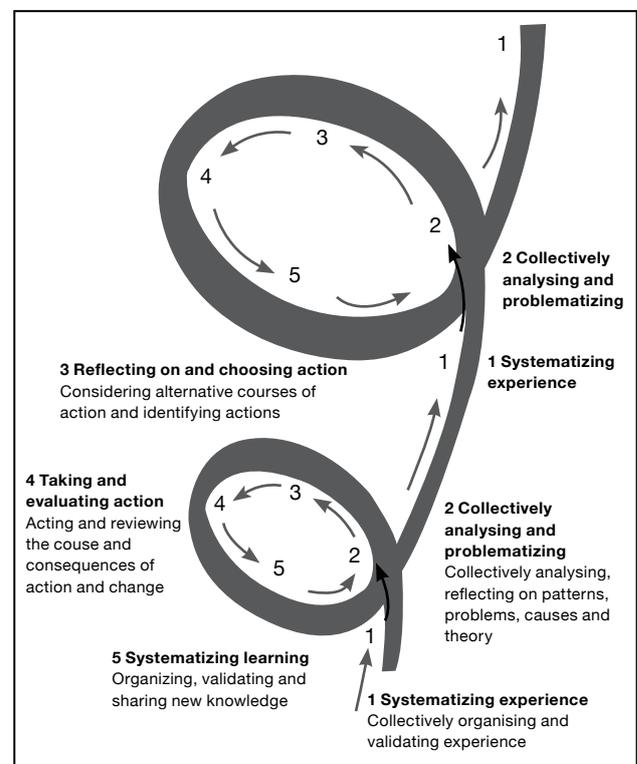
By explicitly starting with the community's lived experience and analysis and adding evidence from other sources, the process shifts power to communities and stimulates critical thinking and dialogue (20;25). It uses a range of tools and [resources](#) to support facilitators and organise evidence, many of which are visual. In Zambia (LDHO) and Canada (B4H), PRA processes were complemented by PhotoVoice, where communities are trained to take

and use photographs for digital storytelling as a form of evidence for their engagement with authorities (20;25).

Health systems differ across contexts on the type and forms of evidence being used in decision-making and the range of actors involved in interpreting that evidence. *Whatever the approach, the experiences in Shaping health indicate that for meaningful participation, communities need to play a role in producing evidence and in interpreting evidence for decision-making.*

Co-determination is central to meaningful participation: These processes and tools for sharing information, for organising and analysing evidence of health needs, are important and necessary, but also insufficient for meaningful participation if they end there. *For participation and social empowerment in health to be meaningful, they need to be used in ways that involve communities in prioritising, planning and co-deciding interventions and in co-producing change.*

The cyclical and spiral process of participatory action research (32).



Source: Loewenson et al., 2014

A simple description of process understates the complexity of what happens in these decision-making spaces. They are influenced by interests, strategic thinking, processes and practice.

In Lusaka community members, health workers and the Lusaka district health office (LDHO) used [participatory tools](#) in PRA approaches to identify and address health needs and barriers to use of health services, described in a [video](#). Health workers and communities met, initially separately and then together, to share their experience, analysis and priorities for change and to identify shared priorities. The agreed actions were implemented and regular review meetings held to reflect on progress. The process generated a wide lens on health. The actions involved health and many other sectors and actors, with support from local resources and public funds. They included clean-up campaigns, with local government support; improved sanitation, housing and maize milling; and solid waste management. Some actions more directly focused on service performance and uptake, such as use of mobile phone appointments and follow up of HIV positive mothers, or distribution and monitoring use of mosquito nets. A fall in disease levels, particularly cholera cases and deaths, and improved local community environments generated confidence in the approach (20)



HCC chairpersons planning at district level, Zambia © M Daka 2013

In many of the sites service personnel and communities have unequal status and power, notwithstanding exchanges of information and evidence. Even *within* health systems, local level service and local government personnel seeking to innovate may themselves lack power over resources to give effect to decisions, and other influential actors may block decisions that they do not see as 'rational' in their own terms (1). Communities are generally represented indirectly on decision-making bodies, through elected representatives. They can become isolated on these bodies unless they interact in wider consultative forums and actively

communicate with the constituencies that elected them. Indirect and representative decision-making, while more feasible, makes the procedures and rules applied important for participatory practice.

The rules and procedures for decisions, and the principles or criteria governing choices, need to be transparent and credible to those involved, and to communities. In many formal spaces these rules are set 'top-down' within the system. They may be discussed with communities for their 'buy-in'. The rules can, however, be developed with the community, as exemplified below.

The Youth Mental Health (YMH) services in Gosford Australia developed in dialogue with youth a set of principles that would apply in developing youth mental health services and programmes. A draft was produced from a literature review and feedback given by diverse young people, including Aboriginal, homeless, and lesbian, gay, bisexual transgender, intersex and queer (LGBTIQ) young people and relevant stakeholders involved in mental health. The principles were discussed at a NSW YMH Forum in 2007. A common set of principles was adopted, shown adjacent. The principles were endorsed by the NSW Mental Health Program Council and used for reporting on service performance (27).

Principles for YMH services

1. Commitment to a promotion and prevention framework for mental health
2. Improving early access
3. Sustainable clinical governance of youth mental health and quality control
4. Promoting 'best practice' youth mental health clinical services
5. Developing effective strategic partnerships
6. Focusing on recovery and hope
7. Establishing youth participation in governance, planning and implementation
8. Improving participation of families and carers in mental health services
9. Developing a youth mental health workforce

The Scottish [National Standards for Community Engagement](#) are good-practice principles used to inform and improve the process of community engagement in health planning. They are widely accepted by practitioners.

A 2015/2016 review of the standards drew contributions from community, non-state organisations and public sector bodies, leading to the 2017 standards shown in the adjacent figure by the [Scottish Community Development Centre](#) (2017) (18).



In Scotland, good-practice principles have been designed through consultation and dialogue to support and inform these interactions (18).

In Pomurje, Slovenia, improvements in health equity (or the distribution of health benefit) was used as the agreed criteria for prioritising and selecting actions from a range of options discussed (1;14). A [toolkit](#) was used to guide the process for applying the criteria, with review and [learning from its use in various processes](#) at local and [regional levels](#) (16).

In Ecuador, communities have a role in deciding on the certification of 'healthy spaces', for institutions

such as fresh food markets and schools. While the criteria for certification are currently developed by the local services, it is intended that in time this be delegated to the community health teams, as their experience grows. Certification provides an entry point for health improvement plans and for investment in healthy public spaces. Certification and the prioritisation of areas for improvement by community teams provides a voice for the administrators and users of public spaces to decide together how best to invest limited resources to promote health (22). Communities' *own* plans can also be given status and resource support, such as the experience in Chile below (19).

The Santiago CESFAM (family health centre) Madre Teresa de Calcuta developed through a participatory diagnosis a citizen participation plan to meet a new PHC performance goal for community participation. In a workshop working groups from 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." Using drawings and pictures, the groups identified their strategies and activities for the goals, building a plan for the CESFAM and community partnership. This included



A roadmap to strengthen participation ©CESFAM MT Calcuta, Santiago, Chile 2016

links and information exchanges together with specific initiatives, such as participatory public accounts, setting up an elected health council, citizen dialogues and consultations. The draft plan was discussed with and adopted by the wider community, with regular information dissemination on implementation and quarterly and annual evaluation mechanisms. (19 p14).

The experience in Chile also highlights the importance of *social accountability through communication back to communities on the implementation of decisions* (19). In PRA processes, communities are directly involved in choosing, implementing and reviewing actions. In more indirect forms of decision-making, social accountability is achieved in other ways. For example SSK in Varanasi, India, uses [social audits](#) and [report cards](#). Citizen leaders implement social audits through observation during visits to services and dialogue with communities. They hold follow-up public hearings on the results, to report the findings to communities and to discuss service performance with providers (21).

Processes that build co-determination on the use of public resources further deepen social power. They not only bring social voice into decision-making, but also provide the means to direct resources towards areas prioritised by communities.

[Participatory Budgeting](#) (PB) is one such process that has spread globally as one means of inclusive decision-making over the allocation of public funds. A growing network of sites and organisations implement it, including 20 cities in North America. [It is a democratic budget process](#) in which community members directly decide how to spend part of a public budget.

Aberdeen City Council (ACC) introduced PB in 2015, in line with the 2015 Community Empowerment Act (Scotland) and a government intention to allocate 1% of national budgets to PB. It was introduced to enhance participation in local service planning. Two rounds of PB have been held in deprived areas to date. The [first round](#) was introduced in schools as familiar community spaces. [Primary and secondary school pupils voted](#) on bids produced by community groups. The bids focussed on fitness, health, digital media, technology, citizenship, the environment and the arts, with a fifth of those funded on fitness and health. The second round expanded to three urban 'localities' through a web platform [UDECODE](#), publicised and administered online in a participatory platform, [Participare](#). Bids were made on digital skills, health, sports and exercise, food suppliers, cooking skills, hygiene and sanitation, community gardens and green spaces. The process concluded with a deliberative forum where voters could interact with bidders. The process is being further reviewed to address challenges such as its accessibility to less organised and more vulnerable groups (18).



Many experiences described in this report also indicate the range of ways communities are involved in **co-producing the agreed actions and health interventions**, especially when they are involved in their design and when the actions are embedded in their lives and settings. *Co-production has helped to align programmes and materials to local culture*, such as the co-design by adolescents from six high schools in Santiago of a sexual health manual: [Building Healthy Environments in Santiago: 100 Questions on Adolescent Sexuality](#) (19). The intense person-to-person approaches that often apply in these processes and peer-to-peer approaches that involve the affected community in care help to deal with stigma, such as that associated with mental illness (24;27).

Community roles in co-determination, design and implementation of health programmes has integrated health more directly within community life and processes. In [Santiago Sano](#), Chile, for example, community co-design of the content of initiatives on health has led to [a network of healthy food carts/kiosks](#) to increase availability of healthy products; a [Healthy Spaces in Santiago](#) programme to remodel public spaces; a [Let's make a deal for good treatment](#) campaign, and a communication strategy to promote child rights (19). In Vanuatu, WSB co-located community health services in places where there are creative activities and sports fields, encouraging uptake by youth. WSB have also worked with services and local farmers to introduce new drought resistant foods (26).

In Aberdeen, community food outlets sell affordable fruit and vegetables in deprived communities supporting improved nutrition (18). In Lusaka, health literacy and co-determination on plans have led to improved sanitation and solid waste management (20), while in Slovenia actions have been taken on social determinants such as healthy food production and use of renewable energy, as well as on social measures such as promotion of physical activity (16). *Community voice in decision-making is thus reported to have had a ‘public health pull’, raising the focus on such population health interventions.*

This engagement between communities and service providers often demands new skills and capacities for both. Health workers, especially those from outside the community, may need to build new competencies in communication, facilitation, cultural and language skills, teamwork, programme management and participatory methodologies.

For communities, *health literacy processes can build community knowledge on health and health services in ways that strengthen collective capacities to organise and act locally on health and to engage with services and claim entitlements.* In Varanasi, India, SSK’s functional literacy programme with community members, women and adolescents builds their capacities to support local collective organisations, form CBOs and to know and claim entitlements (21). LDHO’s [health literacy programme](#) in Lusaka, Zambia, applies PRA approaches, bringing information and

new knowledge to support community analysis and actions in processes that are [now being scaled up to national level](#) (20). B4H Canada’s [Engaging the Leaders of Tomorrow](#) facilitated youth to engage in health promotion processes through participatory activities co-designed with youth B4H members (25). *Health literacy may be integrated within other skills building processes*, such as the inclusion of healthy nutrition in culinary skills training in Scotland (18), of health issues in [WSB Vanuatu theatre skills workshops](#) described earlier (26) or in the workshops of [Psircutopia in Ovalle](#), Chile, on circus, cinema, theatre, art therapy, and making musical instruments for youth involved in harmful drug use (19).

Formal training programmes also build capacities for representative roles and interactions with the health system. Biobío, Chile’s health service [Citizen Participation](#) Unit, works with health service teams to train community members and organisations for their roles in the design, implementation and evaluation of municipal health plans and programmes (19). After testing for cultural relevance, the [WHO mhGAP-IG](#) approach was used in Makueni, Kenya to train CHWs and traditional health providers on mental disorders. This built skills and helped to overcome communication and referral gaps that undermined mental healthcare (24). Training health workers and community members jointly, as in Lusaka (20), can strengthen mutual understanding of and respect for each other’s knowledge and roles.



Training of traditional health practitioners to detect mental illness Makueni, Kenya © D Ndeti 2017

4. But does participation make a difference?

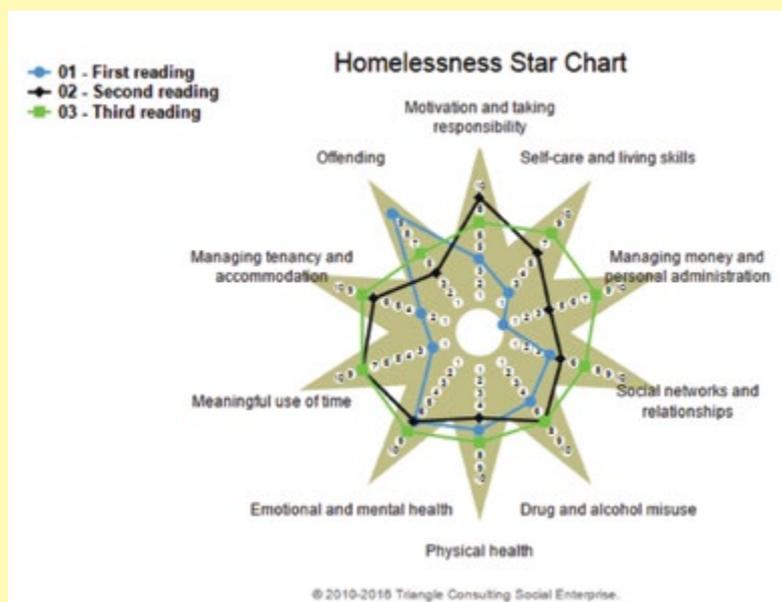
The literature on participation in health systems is often focused on what was done, with limited systematic consideration of what impact it had on health, health services or on its cost benefit (16). Despite this, there is documented evidence of impact in enhanced knowledge of, uptake, effectiveness, comprehensiveness and equity in health services, action on SDH and positive social perceptions of health (1;16). Various studies report improved self-efficacy and health-promoting behaviours and increased trust in and uptake of services when people are informed and involved in decisions about these interventions and services (1).

At the same time, cautions are raised about what is evaluated, when and how. Direct attribution of health impacts to participation is complicated by the context and time-dependent nature of these processes and by the many factors that lie between participation processes and potential outcomes. Routine information systems often lack the sort of disaggregated data needed to assess many of the

intended outcomes. Assigning a monetary value to the benefits misses the many qualitative impacts, but even more importantly may not recognise the inherent value of participation as a goal (1;28;29). *Evaluations should thus be able to track and monitor incremental change overtime, allow adequate time for outcomes to emerge and assess outcomes against the range of social, intellectual and material resources involved (1;16;20;25).*

Few sites in *Shaping health* have thus conducted formal quantitative *outcome* evaluations to assess the impact of their activities, but they have implemented *process* evaluations, strategic reviews and other reflexive research approaches. These are seen as more appropriate for review and accountability (15;16). Social Bite in Scotland and LDHO in Zambia both use participatory methods to directly involve communities in such review, as described below, complemented by quantitative evidence to support both internal review and external reporting (18;20).

In Scotland, Social Bite is piloting an 'outcome star' to map needs and assess progress against goals, across up to ten dimensions, as shown in the figure adjacent. The star can be used internally as a visual representation for discussion and review of individual and collective progress and for external reporting. Social Bite also uses qualitative methods, such as stories. These are better at telling people's accounts of how the actions taken and support services provided have affected change in areas such as trust and dignity for those involved (18).



Outcomes Star © Triangle Consulting 2010-2016 in (3)

In Lusaka, Zambia, community and service personnel jointly set [progress markers](#) for their action plans to provide a framework for review. The method was adapted from an [Outcome Mapping approach](#) as a qualitative monitoring tool. Progress markers are identified by participants in relation to identified actions on what participants would

- 'Expect to see' (usual situation)
- 'Like to see' (improved situation)
- 'Love to see' (ideal situation) (see adjacent example).

While working on action plans those involved meet periodically to review their work against the progress markers. In early phases, they focus mainly on the like to see markers, as the 'love to see' progress takes longer to be achieved. Progress markers may be completed by other participatory methods to evaluate progress, such as a [wheel chart](#), plotting and reviewing changes against identified outcomes (20).

Problem: Inadequate Information And Communication On Planning Progress							
		Progress Monitoring					
		CLINIC A			CLINIC B		
		1	2	3	1	2	3
<i>EXPECT To See Progress Markers</i>							
1	HC staff meetings with CMs having schedules, agendas & minutes		■	■	■	■	■
2	HC staff & CMs disseminating or sharing information on planning and any other current issues		■	■			■
3	HC giving CMs feedback on planning activities and any other current issues as soon as it is received		■	■	■	■	■
4	HWs & CMs respecting each others views during meetings & discussions		■	■	■	■	■
5	Participants who attended the 2007 PRA orientation workshop sensitizing or sharing the information with their immediate workmates and colleagues.		■	■	■	■	■
<i>LIKE To See Progress Markers</i>							
1	HC providing necessary materials & simplified guidelines to CMs on planning process		■	■			
2	HCs & CMs beginning the planning cycle activities without being prompted by higher level						
3	HC providing & sharing information to CMs on budget allocation & expenditure for HC			■	■	■	■
<i>LOVE To See Progress Markers</i>							
1	75% of HWs conversant with planning process						

Key: Done ■ Started/Ongoing ■ Not Started/not done □

Source: Modified from Mbwili Muleya et al., 2008

Despite the caveats noted earlier, the sites noted **a range of social outcomes** associated with their work, including:

- Exchange and use of information, knowledge and skills of those involved (18;21;22;25;26), and a growth in a range of capabilities for improved health and empowerment, especially in disadvantaged communities. This includes increased health literacy and a growth in leadership and skills for facilitation, teamwork, communication, financial management, negotiation of benefit claims, and for engaging and auditing services (18;22;26;27).
- A growth in community and professional networks, partnerships, collaborative work teams and relationships that facilitate or provide social support (18;21;22;25), improvement in the interaction between health workers and community members (17;19;20;24) and more effective use of safe spaces for vulnerable groups to meet, obtain information, dialogue and engage on their health-related needs and ideas (20;26;27).
- A shift in community perceptions of health and of their roles in improved health: "Community members have become part of the change process.... and see health as not just about taking medication but about having healthy environment and health relationships" (20 p9).

- Change in institutional governance and more inclusive and participatory governance, with
 - ▶ increased teamwork, links with and inclusion of voice from marginalised communities (21;22;26;27);
 - ▶ partnerships and links with other sectors (28;29);
 - ▶ strengthened community representation and roles, bringing local communities into decision-making, design, implementation and oversight of services (28;29).
- Communities feeling valued and empowered, more self-confident, with a greater sense of ownership of plans and budgets, and actively defending the services they value (28;29).

“We now have positive representation of all the groups inside the communities, for youth, women, chiefs and children...Now there are groups responsible for the different areas, which makes it easier for people to report their problems, for it to be raised with the representative group” (Pastor Lulu Fula, Sarete Village, Santo in (26 p8).

Sites report **improved outcomes in health determinants, services and in health status**, in:

- Investment in information systems and data analysis, including in interactive electronic versions and ways that give public access to health information (16;22).
- Use of participatory processes across different health system functions (28;29).
- Actions to improve health environments and practices in communities and to improve the experience and performance of health services; in relation to healthy dietary practices, community environments; recreational and healthcare infrastructure, and in access to rehabilitation for older people and shelter for disadvantaged groups (28;29).
- Improved local employment, particularly for youth and disadvantaged groups (16;19;23;26).
- Improved service uptake, including out-of-school youth returning to school (Vanuatu; 26); health insurance uptake, school enrolment, institutional deliveries (Varanasi; 21) child and family health service consultations (NPH New Zealand, 23) and primary care service coverage (Sao Paulo, Brazil, 17). At the same time, other factors are also noted to contribute to these improvements in service uptake.
- Service priorities shifting from being largely clinical towards social and cultural components and social dimensions of health (17;23), supporting CHWs, household visits and service uptake in excluded communities (17;21;22;26); with improved care and family support for people with mental illness: “...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 Kenya, 2017, in 24 p16).
- Service practices and protocols integrating community voice, with improved collaboration between formal and informal providers and communities for mental healthcare, in Kenya (24) and NPH guidelines for genomic research informing national guidelines in New Zealand (23).
- Increased recognition and application of resources by authorities for these roles and interventions and significant levels of social security entitlements claimed (21;25).
- Participatory practices contributing to health status improvements, including a fall in cholera incidence, in Lusaka (20) and in common mental illness symptoms in Makueni, Kenya (24).

In Pomurje, Slovenia, more [comprehensive efforts were made to assess the impact of the participatory interventions](#) on health and development, using evidence from national health monitoring surveys from 2001 to 2008. They found positive changes in the region in terms of: increased consumption of fresh fruits and vegetables; reduced use of animal fats in cooking; reduced smoking and consumption of unhealthy foods (fried foods, sweets, beverages and salt), and an increase in physical activity. This was backed by qualitative reports from services and community members of improvements in awareness and practices in both local people and policy makers, and perceived changes in institutional practices towards intersectoral co-ordination and participatory planning and decision-making in the RAG (16).



Producing food in a sustainable way. © CHD 2014

5. What shared learning and common principles?

The contexts of the international case studies in *Shaping health* vary, as do the organisation of their health systems. However they have all responded to socio-political, institutional, health and health service factors that motivate demand for strengthened social participation in health. Many countries have policies that usefully explicitly support social participation. These may, however, not translate to lower levels and may waiver under resource constraints (23) or changing political conditions. Social participation thus depends greatly on what connections exist and what happens at local level. Many of the experiences described have been sustained over relatively long periods, weathering or growing in both favourable and harsh contexts. As context-dependent approaches, it is not possible to simply transplant practices from one site to another. The processes and tools described earlier, and the insights and learning can, however, be shared and, where relevant, adapted. Without repeating the detail in prior sections on these approaches, processes and tools, this section outlines ten broad insights or principles of practice that have emerged from the work and discussions in *Shaping health* that may inspire or inform efforts to strengthen social participation and power in health.

5.1 Participation is intrinsic to peoples identity, a reflection of values, rights and justice and integral to health

Social participation and the growth of social power in health are both a means to improved health and an end in themselves. Social participation is intrinsic to people' identity, a right and a democratic goal of society, and a means to improve action on and services for health. Whether rooted in historical culture or a result of socio-political activism, this understanding motivates and underpins many of the experiences described in Shaping health. It draws from and reinforces a sense of belonging and collective identity in communities. It challenges discrimination and exclusion, positions community members as rights holders and promotes social rights, equity and solidarity. It underlies the significant levels of voluntary health activism that community members contribute to health and the claim people make to participate in decisions that affect their lives.

In health services, it is made evident in explicit policy intentions of services to deliver health entitlements as duty bearers, to overcome unfair disparities in health and in access to services. It involves a commitment to strengthening democratic functioning *within* services, including engaging community-level and primary care personnel previously disengaged from planning (20;22;23;24). The case studies suggest that *the more embedded and claimed the processes are within the community, the more those involved are able to sustain, defend and strengthen them over time*, supporting service personnel and yielding stronger models than when participation is organised primarily as a functional need of the health services.

As noted in Zambia: “The processes take time and need to be sustained by values, commitment, and persistence, especially during less conducive times, so they can advance when windows of opportunity exist” (20 p9).

This raises a range of strategic issues for participatory practice: How to build solidarity when some groups are discriminated against? How to avoid a response to demands for immediate support for vulnerable communities displacing longer term measures that build social autonomy? How to manage conflicts and resistance when communities claim rights? How to organise the consistency of interactions needed to shift social norms or build trust in a context of insecure funding? (28;29).



Community reviewing Neighbourhood health committee guidelines Lusaka Zambia, A Zulu 2017

Many sites make these issues explicit, share information and discuss them with those involved to build collective solutions. *Having or building through the processes a shared recognition of participation as intrinsic to people and to health; shared values and vision across community, political and service actors and dialogue on how to overcome challenges are thus important factors in initiating, supporting and sustaining participatory practice (7;9;11).*

5.2 Community experience and knowledge, community activism and leadership are drivers of participatory practice

Participatory practice starts from or engages early with community experience, knowledge, culture and perceptions as an input to the evidence, analysis and priority setting for decision-making and design of service interventions (13;28;29). Community-level activists from affected groups play a key role in this and in bottom-up, organic forms of participation. They thus need to be identified and nurtured. They are often already active within civil society and communities. They may also be encouraged by new processes, whether as youth peers in mental health services, as actors in theatre groups, as citizen leaders, councillors, or health literacy facilitators (28;29). Community health workers (CHWs) may also take on these ‘activist’ roles, if elected by the community and trained for it. Whatever their ‘label’, the connection these community leaders and activists have in the community and in local socio-political and civil processes, their election by

communities in any representative processes and their perceived legitimacy, experience and capability are key assets in their roles (17;19;20;21;27).

This calls for investment in activist and leadership capacities, such as facilitation, communication, convening, negotiation and advocacy skills and diverse functional skills, such as in art, theatre, food production or marketing and in literacy on health, health determinants, services and benefit claims systems (28;29). This may be, but is not always, provided in ‘workshops’. Exchanges, networks and forums also provide a means to meet, share and discuss experience across areas, as do community based organisations and civil society associations.

*While many community health activists perform voluntary roles, they also need to see benefit, given that many come from disadvantaged groups. The benefit may be economic, from the health sector as an economic actor and employer in its own right (16;22;23;25), through pathways to employment, such as in the emergence of [Vanua Fire](#) from WSB health activities (26), or from social enterprise activities in Scotland (18). However, benefit is not only seen in economic terms. It is also perceived in achieving and gaining recognition for changes, as, for example, in the formal funding of Pomurje’s RAG plans (16), the government scale-up of Lusaka’s health literacy activities (20) or the state endorsement of Gosford, Australia’s youth co-developed mental health services principles (27). In all these cases *higher level recognition followed, rather than led, local activism and evidence of successful local practice, suggesting that it does not trigger or initiate community activism, but it does help to sustain it.**



Nutrition centre outreach workshop ©WanSmolbag 2016

5.3 Participatory processes in health are more likely to flourish within community settings...

Interactions with community-level activism and processes appear from the international experiences to be best supported and to be more likely to overcome inhibiting power imbalances when service and others interact within community settings and processes, such as schools, markets, workplaces, sports grounds and traditional gatherings including funerals. *This centres processes on the community rather than the services.* These familiar and more accessible local processes include 'safe spaces' for discriminated or vulnerable groups, such as 'social suppers' for homeless people. It takes service personnel outside their traditional roles and terrains, but provides opportunities to understand community conditions, perspectives, processes and resources, given that these are key assets for population health approaches. While it does not negate communities coming into service settings in representative and other roles, discussed later, the value of engaging within community settings for participatory practice makes this a common feature of many sites, including as formalised in law, such as Scotland's 2015 Community Empowerment Act, providing that processes start in familiar community spaces (18).

5.4 ... supported by and eliciting more holistic models of health

The experiences reported in *Shaping health* indicate that *social participation is more likely to be nurtured and flourish when health systems are organised around holistic, people-centred, population health and comprehensive primary health care (PHC) approaches.* This appears to enable health services to be more receptive to and competent in engaging with communities. Examples include Chile's biopsychosocial approach (19) or the comprehensive family health team approach in Brazil (17). Support for public health interventions and interactions with other sectors on the social determinants of health, as in Quito and Pomurje, also facilitate social roles (1;14).

A key task of services is thus to strengthen their orientation towards these approaches, including in terms of the capacities and readiness of their personnel and their ability to facilitate and respond to community roles and processes (5;11;23). This implies teamwork, engaging primary care and community-level personnel in participatory planning and decisions, investing in and providing incentives for social and cultural competencies and processes and, as discussed later, setting and monitoring feasible indicators of change to build support (28;29).



MDMQ steering committee meeting, Quito LJ Lurado 2016

These approaches often imply co-location of services and joint work with non-state organisations and other sectors, with shared planning and indicators of success that do not compromise the goals of each (16;22;28;29). Leadership for this often comes from (and needs to be encouraged in) local government. Even sites with promising experience in these holistic, multi-sectoral approaches report challenges of inadequate and vertical disease-specific funding, administrative siloes between sectors, competing health personnel commitments and capacity gaps at primary care level (16;17;19;20;24). Local service personnel have thus found creative ways to mobilise the resources and incentives from routine budgets or external funders and to build the partnerships, evidence base and political support to implement innovations (14;15;28;29), while noting the positive feedback loop social participation brings for these efforts and holistic approaches.

5.5 Informal and formal spaces and processes are both key and their two way interaction enriches both

The case studies profile diverse forms of formal and informal spaces (mechanisms/ forums) and processes within which social power and participation are organised. Both are important for social power and participation in health.

Informal spaces and processes take place outside legally or state defined mechanisms. They are wide ranging, including forums, drama, art, festivals, meals, peer-to-peer processes, literacy and skills-building activities, hearings, social media, campaigns and protests. They may be ad hoc and transient, but may also be organised, structured and sustained, and may build social networking and organisation.

Informal spaces are often more flexible, more inclusive, more able to use media and forms that are accessible to communities. They open opportunities for social dialogue and peer-to-peer exchange and approaches for inclusion of groups excluded from or disempowered in formal processes. They can set their own rules and processes in ways that build trust and collective power and confidence, including as a basis for more formal interactions (28;29). In building the collective power and capacities of rights holders to make claims, including in social audits and public hearings, they strengthen rights-based approaches (21).

At the same time formal spaces, such as health service or local government boards or committees at local level upwards, are constituted by laws or guidelines. *Formal spaces provide a means for dialogue, co-determination and oversight of policies, plans, budgets, resource allocation and management practices between community representatives and services, as forms of social power to transform systems.* They enable practice to be institutionalised, including through certification and budget processes (28;29). How far they actually do this depends on their mandate, given that some are only advisory and not decision-making; how representative they are, as some appoint rather than elect representation; how inclusive they are of different social groups, the evidence, processes and procedural rules they use, and how far they report back to constituencies.

Whether formal or informal, various practical measures affect whether their procedures and processes overcome power imbalances and build meaningful participation, including:

- Mapping social groups and networks and dialogue on plans within communities to ensure that key communities and stakeholders are included.
- Providing community-level activities (workshops, theatre, suppers, cafés) as safe, non-stigmatising entry points for engaging under-represented groups; embedding processes within community processes, settings and culture; with shared language, local terms and visual methods to facilitate the different culture, experience and voice of those involved.
- Defining with communities and personnel involved the composition, role, mandates, objectives, procedural rules, timings, location and intended results of forums, ensuring that they do not inhibit or bias against participation of particular groups.
- Supporting the capacities of those involved.
- Taking a community- and area-based, rather than a facility-based, approach to issues.
- Recognising, enabling and using different forms of knowledge and evidence, combining community evidence (narratives, social and family mapping, participatory reflection and action learning, social audits) with service data; and establishing with those involved agreed criteria informing decision-making on priorities, actions and resources; and
- Linking representative forums with activities in the community, including online, to involve and build accountability to the wider community (28;29).

Participatory practice involves a two-way dynamic between formal and informal mechanisms, enabling dialogue and relationships, analysis and action to be built across different realities and lenses of communities and services. The opportunities to share information, build social power, propose and innovate on actions in informal processes can assist to support inclusion, and address the barriers and power imbalances that exist for communities in formal processes. As noted by CEBRAP in Brazil, “the interplay between institutionalised and non-institutionalised forms of citizen participation and joint professional activities helps to create a zone of dialogue and mediation between two quite different realities and experience” (17 p14). Further, as noted in Varanasi, a multiplicity of formal and informal spaces are likely to be needed “...to articulate interests and demands for negotiation and to voice and manage resistance, through multi-layered channels for interfacing with service providers” (21 p11).

5.6 Information sharing and organising community evidence are necessary, but not sufficient for meaningful participation

At the most basic level, participatory processes share information within and between communities and services, through drama, radio and other media, within existing and special meetings, through online platforms and social media, in materials developed with communities, in joint training activities and in peer-to-peer processes. This two-way communication supports transparency and trust between those involved. Involving community members in the development of this media has enabled the format (often visual), language, messages to be relevant and appropriate for the constituency they are intended for and facilitated outreach.

Beyond basic level of exchange, which may alone have little impact on empowerment, the evidence and diverse forms of knowledge that are brought to decision-making play a key role in more meaningful forms of participation. They drive problem definition and priority setting, inform how claims on entitlements are judged and inform decisions in planning and allocation of budgets and oversight of progress. The under-reporting of stigmatised conditions on health in excluded communities, the demand for evidence on social determinants, assets and entry points for improvements call for different forms of evidence (10;13;24).

A range of methods, such as participatory, social and family mapping, photojournalism, community and online surveys and narratives, are used to collectively gather and organise community experiences, conditions and perceptions. While communities are often asked to identify their health needs, meaningful participation goes beyond this. *Collective, reflexive participatory processes ranging from discussions of drama and problem trees, to ‘ranking and scoring’ to identify problems, analyse causes, and prioritise those to act on, involve communities in analysis of evidence to prioritise interventions.* These findings can be reviewed together with service evidence through tools described earlier, like Urban Heart. This implies that the criteria for choices and decisions – such as what will best achieve joint health and economic improvement or most effectively improve health equity – are also co-decided.

5.7 Participation calls for accessible processes for co-determination linking decisions to actions and resources

Joint decision-making (co-determination) is central to meaningful social participation in health. The processes for information sharing and review of evidence, the spaces and organisation of actors feed into processes that decide how problems will be addressed, entitlements delivered, services organised and resources distributed to support improvements in health. It is also the point of contestation of different interests and power. The assumptions, rules and procedures that govern decision-making may thus enable or block social participation and power. Building on the features in the first seven principles, various features of and practices in co-determination facilitate meaningful participation:

1. Inclusive and representative voice, where indirect community representatives are elected by, accountable to and communicate plans back to communities for feedback before adoption.
2. Transparency on the commitments, rules, criteria and principles that govern decision-making, agreed where feasible with communities, with transparency on where decisions are actually made and guidance and capacity support for those involved.
3. Processes for decision-making that:
 - a. are accessible to all, such as visual road-maps, enabling collective decisions;

- b. define goals and set measures for assessing progress, such as progress markers, to align the different actors to shared outcomes;
 - c. set stepwise processes for change, with short-term wins to build confidence;
 - d. are backed by monitoring and reporting of improvements to widen community and service support.
4. Methods to link decision-making to actions that involve communities and the resources for this, such as certification, community grants, incentive funds and participatory budgets.
 5. Investment in processes for social accountability on decisions, such as social audits and public hearings, with participatory monitoring and evaluation to track and report on progress and support strategic review, discussed later (1;7;9;11;13;28;29).

While co-determination is often conceived of as taking place in formal spaces and rational processes, in reality decision-making is also influenced by the informal processes described earlier, whether dialogue, negotiations, campaigns, media or protest, further reinforcing the understanding that social participation involves multiple strategies, spaces and processes.



Revising the Standards Infographic, (c) Community health exchange, Scotland 2016

5.8 Institutional and individual facilitators play a critical role

Whatever their origins, *the international experiences suggest a critical role for one or more strategic, consistent facilitators and supporters of these processes, seen as credible, competent and trustworthy by communities, local services and authorities.* This institution may be in the local public sector health services (17;19;20;22;23;27), other local authority or state institutions (16;18); or it may be a non-state service, social enterprise or institution (18;21;24;25;26). It takes on the roles of secretariat, facilitator, trainer, and broker, mediator and communicator. In the case studies they have a number of features that enable this role: a visionary and enabling management, having adequate personnel as staff or volunteers; an experience of joint work with other agencies, a funding base or resource strategies that enable and sustain programmes, support from other levels of services or other institutions, and a degree of organisational freedom to test, develop and sustain new practice (28;29).

The role brings opportunities for new learning and practice in creative social and institutional interactions. It also demands strategic reflection and management, including navigating local and vertical relations. It takes time and commitment to “...walk beside people who struggle to navigate systems seen to be hostile to them...” and facilitate their power (18 p10).

This catalytic and mediating role facilitating the interaction between communities and services may also be contributed to by people who cross these institutional/ constituency boundaries. It may be achieved by health workers who live and work in their own communities (23), by traditional health practitioners (24), community health workers (*promotoras*, ASHAs, Kaiawhinas) (9;12;21), expert patients (27), or by leaders of community-based organisations working in health. They facilitate communication and exchanges between services and the community, with a caution that in disabling conditions they may delink from communities and use their role to build their own power as local ‘elites’ (17;25).

Setting achievable goals and monitoring and making visible to all involved stepwise progress in addressing shared concerns play an important role in contributing to a growing belief and trust in the credibility of the process and in the ability to bring about positive change.

[Documenting and drawing attention to good practices and achievements](#) not only positively influence participants' self-perception, but can provide ideas for other areas and build recognition from higher level authorities, expanding and sustaining the work (16;20;27).

5.9 Deepening participation takes time and capacities

Whatever the practices, building a participatory system and interface between communities and services in a manner that is empowering for communities are not achieved in a single step or two. It takes time to let models evolve, to identify where and how best to contribute, for work to remain grounded and to spread horizontally and to understand and work with the social assets that are present (20;22;25;28;29).

The various forms of capacity building that support participation are usually embedded within implementation processes. It means that those involved must plan for how to manage, resource, sustain and expand the processes and changes over time (7;9). This is a challenge! For example, there is a common preoccupation with unpredictable and scarce resource flows in a context of community expectations. *A key way of dealing with this has been to have participatory discussions with those involved, including employees and community members, on how to manage challenges, building collective strategies and approaches to sustaining processes through strategic review (16;22;26).*



Community garden activities with teens © 11th St Family health services, Philadelphia 2016

While social participation may demand time and wide and sometimes intensive interaction, the growth in social capabilities, ownership and involvement also increase the means and support to sustain the work: *“Social power and the confidence in communities to articulate the processes and their benefit itself becomes a sustaining factor. In Zambia, it has often been the communities themselves who explain the nature and value of the process to other communities and districts and to local and national leaders and health authorities. They have kept the demand for the processes alive in changing institutional contexts” (20, p9).*

5.10 Tracking diverse forms of progress builds learning from action and demonstrates the benefit to health

The processes described in *Shaping health* have grown through strategic review and learning from action and experience. *They thus demand opportunities for all involved to reflect on the progress achieved and what this means for their analysis, methods and actions.* Some tools that support this, such as the progress markers, wheel charts and outcome stars, discussed earlier, track and review changes against expected defined outcomes, factoring in the timing of when change is expected, and giving enough time for changes (18;20). *At the same time, there is need for evidence that builds policy and management support, noting from the outset that this includes social, system, service and health outcomes, that all of these matter and that they are measured in different ways.*

The case studies show evidence of the contribution of social power and participation to a range of positive health and social outcomes. These may not be measured through quantitative indicators, calling for recognition from the outset of the value of qualitative evidence and participatory methods, including for strategic review.

Finally, this work demands an openness to constructive criticism (23; 26): *“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)” – KIs New Zealand, 2017 (23).*

6. References

1. Loewenson R (2016) '[Understanding and organising evidence on social power and participation in health systems](http://tinyurl.com/ya7jzrc)', TARSC, April 2016. <http://tinyurl.com/ya7jzrc>.
2. Simpson S and Loewenson R (2016) '[Annotated bibliography of literature on evidence on country experiences of social participation and power in health systems](#)', TARSC, May 2016.
3. Training and Research Support Centre (2016) 'Exchanging learning on social participation in health: Project meeting report', Henley on Thames, UK, September 30-October 1 2016, TARSC with support from RWJF and CAFA.
4. Dudding R (2016) 'Site brief', Athens City-County Health Dept (ACCHD): ACCHD: Ohio.
5. Dudding R (2017): 'Management of change: Site brief', ACCHD: Ohio.
6. Gerrity P (2016) 'Site brief: 'Stephen and Sandra Sheller, 11th Street Family Health Services (11th St)' Drexel University: Philadelphia.
7. Gerrity P, Green M, Kirby J, Monroe D, Ballard A (2017)): 'Management of change: Site brief', Stephen and Sandra Sheller, 11th Street Family Health Services: Site brief', Drexel University: Philadelphia.
8. Ivie V (2016) 'PIH Health (PIH): Site brief', PIH Health, Whittier, CA.
9. Ivie V with PIH team (2017) 'Management of change: site brief', PIH Health: Whittier.
10. Tanzman B, Gilbert M (2016) 'Site brief', Blueprint for Health' Burlington Health Service Area, University of Vermont Medical Center Family Medicine, Dept of Vermont Health Access (DVHA): Burlington.
11. Tanzman B, Gilbert M, Farnham P (2017) 'Management of change: Site brief', Blueprint for Health: Burlington.
12. Wagner B (2016) 'Site brief', Centro Sávila: Albuquerque/South Valley.
13. Wagner B (2017) 'Management of change: Site brief', Centro Sávila: Albuquerque/South Valley.
14. Loewenson R (2017) 'Strengthening social power in health: Reflections from US site work', mimeo, TARSC, June 2017.
15. Simpson S (2017) 'Brief: Summary of issues raised by US sites on managing change towards strengthening social participation', mimeo, TARSC, June 2017.
16. Beznec P, Maučec G, Nemeš S, Nemeš D (2017) '[Case study: Pomurje Region, Slovenia](http://tinyurl.com/y9q74yc4)' 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>.
17. Coelho VS, Calandrini A, Waisbich LT (2017) '[Case study: Voices from Cidade Tiradentes, São Paulo, Brazil](http://tinyurl.com/yaddlr74)' 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>.
18. D'Ambruso L, Abbott P, Douglas F, McPherson E, Okpo E (2017) '[Case study: Empowerment approaches to food poverty in NE Scotland](http://tinyurl.com/y7s55jeh)' 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>.
19. Frenz P, Alfaro T, Mazzei M, Sgombich X (2017) '[Case study: Citizen participation and co-management for health in Chile](http://tinyurl.com/y78y6jvn)' in the *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>.
20. Loewenson R, Mbwilli Muleya C, Zulu Lishandu I (2017) 'Short case study: Lusaka district health office, Zambia', TARSC, March 2017. <http://tinyurl.com/yaasxj8k>.
21. Loewenson R, Mohanty R, Lal U (2017) 'Short case report: Sahbhagi Shikshan Kendra', Varanasi, Uttar Pradesh, India, March 2017. <http://tinyurl.com/y9mzhbby>.

22. Loewenson R, Obando F (2017) 'Short case study report: Metropolitan District of Quito, Ecuador', TARSC, March 2017. <http://tinyurl.com/y9k3afas>.
23. Matheson D, Matheson K (2017) 'Case study: Ngāti Porou Hauora, New Zealand' in the *Shaping 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>.
24. Ndetei D, Musyimi C, Musau A, Matoke L, Mutiso V (2017) '[Case study: Mental health in Makueni County, Kenya](#)' in the *Shaping health programme on Learning from international experience on approaches to community power, participation and decision-making in health*, AMHF, TARSC, July 2017. <http://tinyurl.com/yaq97rxg>.
25. Simpson S, Ardiles P, Zapelli R (2017) 'Short case study: Bridge for Health, Vancouver, Canada', TARSC, April 2017. <http://tinyurl.com/yd5npaa9>.
26. Simpson S, Dorras J, Walker P (2017) 'Short case study: Wan SmolBag, Port Vila, Vanuatu', TARSC, April 2017 <http://tinyurl.com/y7xre294>.
27. Simpson S, Howe D (2017) 'Short case study report: Youth participation in a local mental health service, Gosford, NSW, Australia', TARSC, April 2017. <http://tinyurl.com/y9lnmdkj...>
28. Loewenson R, Simpson S with Ardiles P, Zappelli R, Obando F, Howe D, Mohanty R, Lal U, Mbwili-Muleya C, Zulu-Lishandu I, Dorras J, Walker P (2017) *Experiences of social power and participation in local health systems-Volume 1: Key features of the short case studies*, Training and Research Support Centre (TARSC), June 2017. <http://tinyurl.com/y8w8tu9b>.
29. Loewenson R, Beznec P, Coelho V, D'Ambruoso L, Frenz P, Matheson D, Ndetei D et al., (2017) *Experiences of social power and participation in local health systems- Volume 2: Key features of the deep case studies*, TARSC, August 2017. <http://tinyurl.com/y8yauy8l>.
30. Robert Wood Johnson Foundation (RWJF) (2015) '[From vision to action: Measures to mobilise a culture of health](#)', discussion document, RWJF: New York.
31. Magnussen L, Ehiri J, Jolly P (2004) 'Comprehensive versus selective primary health care: Lessons for global health', *Health affairs* 23(3):167-176, doi: 10.1377/hlthaff.23.3.16.
32. Loewenson R, Laurell AC, Hogstedt C, D'Ambruoso L, Shroff Z (2014) '[Participatory action research in health systems: A methods reader](#)', TARSC, AHPSR, WHO, IDRC Canada, EQUINET, Harare. 9999999

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

TARSC 2017