

shaping health



Exchanging on social power in health

Experiences of social power and participation in local health systems

Volume 1: Key features of the short case studies

Rene Loewenson and Sarah Simpson
Training and Research Support Centre

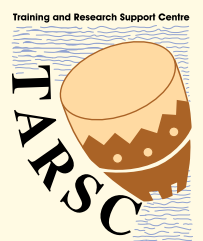
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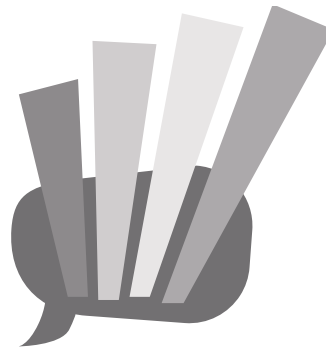
May 2017

Training and Research
Support Centre

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

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Training and Research Support Centre 2017

1. Background

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

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

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

systems, to promote population health. We gave particular attention to forms of participation that build autonomous and self-determined social power, confidence, capacities and understanding in communities to identify needs, set priorities for and engage in decision-making on the conditions, resources, services and governance arrangements that promote population health.

The project is led by Training and Research Support Centre (TARSC) and implemented with partners from the USA and from twelve countries internationally, with a grant awarded by Charities Aid Foundation of America from the Robert Wood Johnson Foundation Donor-Advised Fund. A community of practice involving five sites in the USA and sites of work in Australia, Brazil, Canada, Chile, Ecuador, India, Kenya, New Zealand, Scotland, Slovenia, Vanuatu and Zambia have in 2017 shared experiences, analysis and learning on social power and participation in local health systems, including in exchanges on a 'Shaping Health' web platform.

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

This document compiles in one volume a summary of key features of the six short case studies on social participation and power in local health systems in Australia, Canada, Ecuador, India, Zambia and Vanuatu. It draws on full case study reports, referenced and separately presented.

A separate document presents the summaries of the six deep scan case studies in the project, while a separate synthesis report integrates the learning and insights from the combined body of work and discussions in the *Shaping health* project.

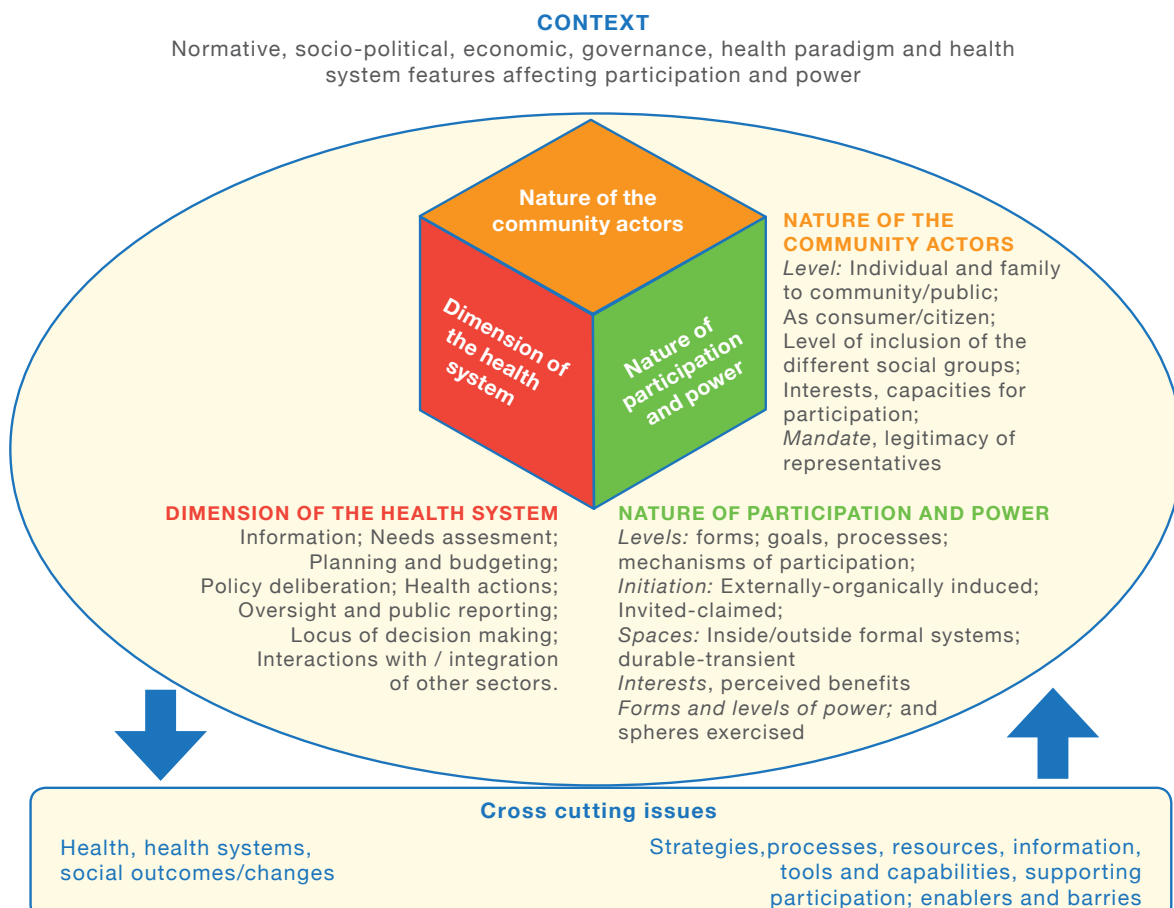
2. Methods

In the six selected countries the short case studies gathered and reported evidence on promising practices in and models of meaningful community participation, power and decision-making in local level health systems, included a focus on marginalised communities. They included innovative municipal/ local level models, even if not country-wide, with inquiry on the facilitators and barriers to and processes for wider application. The short case studies followed a framework provided by TARSC in Loewenson (2016), covering elements summarised in *Figure 1* below, taking into account prioritised areas of interest identified by sites in the USA. The short case studies thus:

- Focused on areas of social participation and power in the health sector, and in arrangements for inter-sectoral co-ordination between health and other sectors relevant to improving population health.
- Presented evidence from document review and key informant interview with a focal person from the site on the context for and purpose of the work; the practices and the mechanisms, tools and resources used; the enabling factors and the challenges faced and the meso-level measures facilitated or blocking these arrangements, and the health and other outcomes from the work.
- Presented insights and learning from the work, including areas that may be useful for wider application or adaptation in other contexts and in the sites in the USA.

The short case study reports were drafted and peer reviewed in February 2017 and finalised in March and April 2017.

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



3. The short case studies: key features

This section presents key features of the short case studies, drawing from the case study reports, with hyperlinks to further information, resources and video material. The full case study reports provide detailed information and sources.

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



3.1: Bridge for Health, Vancouver, Canada

For the full short case study report see: Simpson S, Ardiles P, Zappelli R (2017) *Short case study: Bridge for Health, Vancouver, Canada*, TARSC, April 2017, <http://tinyurl.com/yd5npaa9>



Key features

Bridge for Health is a grassroots network, using a co-operative model to build shared ownership and accountability for health promotion and population health, promote mentoring and youth engagement and mobilise inclusive and participatory models for realising population health and well-being.

Key features of the work that could potentially be adapted/adopted elsewhere include:

1. How to use the social and intellectual capital available to an organisation, as Bridge for Health has done, to bring about change and 'grow' the model of participation for improved population health and wellbeing.
2. Applying the Bridge for Health's co-operative model to enable organisational practices that are consistent with the network's underlying values and principles of participation and as a vehicle for social change.
3. The Bridge for Health Wellbeing @ Work model that is focused on strengthening workplaces as key arenas for citizen participation in health, through improved engagement and empowerment of working adults/employees.

The country and local context

Canada is a high-income country, with few formal vehicles for direct public participation in health system decision-making beyond general participation in the political system.

The work in this case study was centred in British Columbia with a population of more than four million people, and particularly in Vancouver, the largest city and metropolitan area in the province. The province is ethnically and linguistically diverse, and has 196,075 Aboriginal people, including First Nations, Inuit and Métis peoples. It is the healthiest province of Canada, albeit with rising prevalence rates and increases in non-communicable diseases such as for hypertension, cardiovascular disease and asthma (Provincial Health Services Authority, 2010), and a high and growing gap between gross

domestic product and wellbeing (Canadian Index of Wellbeing, 2016).

The 1984 Canada Health Act sets out standards for provincially administered health insurance and services, administered by regional health authorities. Local health authorities also have an Aboriginal health team and plan, and signed partnership accords with First Nations Health Council Regional Caucuses to facilitate greater collaboration (Aboriginal health directorate, no date).

Canada has a policy intention to ensure opportunities for meaningful input by citizens in health priorities, strategies and evaluation and Canadians generally have high voter turnout, although only 66% felt satisfied with how democracy works (Canadian Index of Wellbeing, 2016). Elected Regional Health Advisory boards are provided to extend participation,

although most members are appointed by provincial ministers or ministries of health (Marchildon, 2013). [Vancouver Coastal Health](#) has set up a range of ways for engaging communities, including the [community engagement advisory network](#), public advisory committees, patient and public consultations, community participation and capacity building for VCH staff for engaging with patients and families regarding their health care needs (Vancouver Coastal Health, 2014).

The site and its practices

Bridge for Health (B4H) was founded in 2013 as a self-organised Vancouver-based local and international volunteer network to foster collaboration, knowledge-sharing and social action to promote citizen engagement in health (B4H, 2016).

As a grass-roots network, its initial focus was on promoting, inter-sectoral action for health at local and national levels, including health policy engagement. It was founded by a local resident based on her [experiences](#) and work in health promotion, including as founding manager for a provincial multi-sectoral health literacy network on mental health and substance use, together with a small network of people with shared motivations and goals. It was motivated by a desire to incorporate a more holistic view of health and to provide greater opportunities for individuals and communities outside the health system to have a say and to be agents of change. It sought to move from top-down solutions to bottom-up solutions, to enable people to gain control over the conditions that impact their health, including by taking responsibility for engaging with other sectors (Ardiles, 2016).

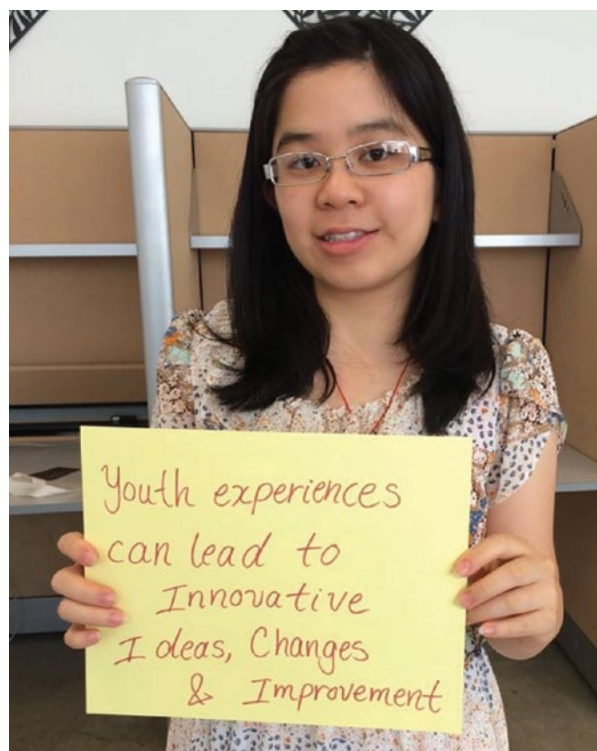
The network evolved organically over three years, taking time to identify where B4H can best contribute, working in collaboration with existing initiatives in a co-operative approach. It is guided by [principles of](#):

- Engagement i.e., actively involving individuals and collectives in the production and co-creation of opportunities, processes and outcomes;
- *Empowerment* i.e., accessing and realising personal and/or collective power to promote the psycho-social, political and cultural strengths of individuals and communities;
- *Enablement* i.e., creating connections and positive patterns of interaction that allow individuals and collectives to develop and grow by building on strengths; and

- *Ease* by supporting self-organising and organic contribution to B4H goals.

Three years later, and after consultation and review of experiences with a range of professionals, students, community members and non-state actors, B4H has evolved into a service-oriented social enterprise, as a co-operative association.

The co-operative model of B4H is a key feature of this case study. It is reported to enable collective leadership and shared ownership, to facilitate the generation of public health solutions within both informal systems (communities, schools and workplaces), and formal health and social-care systems; to enable its members to undertake socially innovative research, to consult with local businesses and organisations to co-design healthy social and built environments that promote wellbeing; to build confidence and skills through mentoring and knowledge sharing; and to offer varied levels of engagement via general and ‘worker’ memberships (Ardiles, 2016). B4H established a global expert advisory group and core team with skills in public health, equity, business administration, project management and evaluation, community engagement, IT, education and leadership development. It established links to academic partners and experts in various fields internationally, and aims to identify mechanisms for their formal inclusion as members.



Youth engagement © Bridge for Health 2016



B4H Co-op Launch © Bridge for Health 2016

B4H focuses on three core service areas: community capacity building; advocacy and influencing; and research and consulting. It has implemented a range of initiatives to foster engagement to date, most in an approach to health promotion that builds community and youth health literacy and that focuses on upstream health determinants:

- a. B4H's *Moving Health Literacy Upstream Project* (2014-2015) worked with under-served youth aged 15-21 years in Vancouver, specifically urban indigenous youth, newcomers and those living in poverty. Partnering with local community partners ([RedFox Healthy Living Society](#) and Big Brother Association of British Columbia), the project used [PhotoVoice](#), using participatory photography and digital storytelling. B4H integrated health literacy into an existing youth healthy living initiative, the *Youth Warrior Program*, where youth from lower socioeconomic backgrounds participated in activities via weekly 2-hour workshops on life and leadership skills. Icebreaker exercises engaged the youth on their definition of health and the factors, including social factors, they perceive as influencing their health and wellbeing. Workshops arranged by youth co-ordinators covered themes such as: personal health, community engagement and physical activity to stimulate critical thinking and dialogue. Using the concepts, youth used their cellphones to take photos in their communities of things that remind them of health, with a paragraph explaining each of their photos and what they say about their perception of health and wellbeing.
- b. B4H has built youth leadership in global health, working with the Public Health Association of British Columbia in participatory activities with a diverse group of student leaders to prepare input for the Scientific Conference for the 2016

Global Conference on Health Promotion about why it is important for youth voices to be heard in conferences.

B4H youth launched a social media campaign in September 2015 using the hashtag #EngagewithWHO to provide youth with a platform to share their opinions on health promotion. The campaign reached 6,601 individuals and the youth leaders chose the questions posed on the social media site, and supported the analysis of results and the discussion and recommendations. The process and results are captured in a [video](#) *Engaging the Leaders of Tomorrow* and B4H's [Engaging the Leaders of Tomorrow: a briefing report on youth engagement for the 9th Global Conference on Health Promotion](#). The campaign led to a youth symposium at the 2016 World Health Organisation international conference and the video was launched at the 22nd IUHPE World Conference on Health Promotion, Curitiba, Brazil.

- c. B4H developed a *Healthy Business Practice Framework*, further developed into a *Wellbeing @ Work* model, using a systems approach to understand how social and physical environments at work influence health outcomes. It conducted research and dialogue with business owners, managers, staff and professionals on the needs and gaps in the social and physical environments that promote health and wellbeing in the workplace. The interviews highlighted that ill-health at work stems not only from physical inactivity or poor diet, but also from a poor workplace culture and employee disempowerment or limited engagement. Workplace wellness programmes do not address these latter factors and discourage employee participation in wellness programmes.



B4H social impact prize © Bridge for Health 2017

B4H research thus supports identification of health problems and collaborative work with staff and management teams to find innovative solutions. In 2016, B4H developed a series of ‘wellbeing @work innovation labs’ for businesses to improve health and wellbeing in their workplaces. Individually tailored, based on the model and facilitated by B4H, the labs enabled workplaces to identify health-related problems and actions and test out solutions in their specific workplaces.

- d. B4H has also organised a range of forums to raise discussion on health and wellbeing, including a monthly speakers’ series in partnership with Burnaby Metrotown Library and a national ‘town hall’ with the Prevention of Violence Canada coalition and the provincial and national public health association in Ontario. Town halls. Town hall meetings include public health associations, researchers, educators, practitioners, government, nongovernment organisations and interested citizens to discuss health issues, including, in this case, progress and guidance for violence prevention.

B4H as a network was built on strong, pre-existing relationships and collaborations with a range of partners and associations locally, nationally and



Dancing as a way to health © Bridge for Health 2016

internationally, the technical and social credibility of its founders and the pre-existing trust present in strong existing partnerships. These relationships have enabled B4H to extend its reach, as have social media [blogs](#). The volunteer-driven status of the network has limited its capacity to track or measure outcomes and changes associated with its work.

However, as a newly formalised co-operative, a process is currently underway to develop a formal framework for evaluation, as a part of B4H co-operative’s broader organisational developmental processes.

Outcomes from the B4H work

While B4H has not yet developed a formal framework for evaluating its work, its contributors and partners have identified various benefits. These include: knowledge sharing on diverse health issues; the expansion of personal/professional networks; relationship building and social support among network members; innovative partnerships and funding opportunities; collaboration on research or training projects and tool development and recognition for their work, including for the young people and community members involved.

“What do I get out of being part of Bridge for Health? *“My spirit gets inspired by sharing with like-minded people my passion for creating a world healthier and happier for all its beings. Practically, I get the possibility of implementing sustainability projects that impact the communities I am close to.”* (Diana Leon, IT specialist working on workplace environments, in B4H, 2016). The work has led to invitations to speak in various local, national and international forums. In 2017, B4H was awarded a prize for social impact for its Wellbeing @ Work Innovation lab which works to create participatory approaches to promote wellbeing in workplaces.

BRIDGE FOR HEALTH

Wellbeing @ Work Model

SIX BUSINESS PRACTICES TO ADVANCE THE TRIPLE BOTTOM LINE: PEOPLE, PLANET AND PROFITS

PERSONAL GROWTH AND DEVELOPMENT

- Self-awareness and self-reflection
- Authentic leadership
- Communication skills

LEARNING AND WORKING ENVIRONMENTS

- Skills in collaboration and team building
- Building trust, relationships and partnership skills
- Inclusion in decision-making processes

POLICIES AND PROCESSES

- Living wage and/ or profit sharing
- Hiring and pay equity
- Flexibility in schedule/ work from home

PHYSICAL SPACES

- Décor and access to green spaces
- Designs that improve access to direct sunlight
- Shared open spaces to promote social connection

SOCIAL CONNECTION AND COMMUNITY ENGAGEMENT

- Community investments
- Participation in community (e.g., volunteer work)
- Opportunities for meaningful contributions to support others at work

SERVICES AND SUPPORTS

- Employee wellness programs
- Benefit plans
- Bereavement and sick leave

Adapted with permission from Health Promotion Team, Simon Fraser University.

bridgeforhealth.org

Areas for shared learning

The workplace framework, health literacy and health promotion efforts and the co-operative model may usefully inform other participation initiatives. The case study identified three specific areas for shared learning:

- i. First, while financial resources are important for enabling participation in health, having social and intellectual capital is essential. B4H drew on the existing connections, contacts, collaborations and values of its co-founders that enabled the network to grow in a self-determined manner and that attracted other people to join.
- ii. Second, there is need to invest time to let the model evolve. The network used three years of work and experience to identify where the network could best contribute, to understand the social and intellectual assets in the network, and the co-operative model described earlier that best suits its values, work and organisation.
- iii. Third, people should 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. This does not remove the requirement for health systems to have mechanisms for participation and engagement, but it starts a movement towards change, even if through incremental small social changes.
- iv. The space for participation may thus arise outside formal health systems and resources. Any evaluation should thus track and monitor subtle and incremental changes in the processes and outcomes that lead to positive health and wellbeing overtime, and the role of the social, intellectual and material resources that the members bring.

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3.2: Metropolitan District of Quito, Ecuador

For the full short case study report see: Loewenson R, Obando F (2017) *Short case study report: Metropolitan District of Quito, Ecuador*, TARSC, March 2017 <http://tinyurl.com/y9k3afas>



Key features

This case study reports the work of the municipality and communities in the Metropolitan District of Quito (DMQ) and the Municipality of Quito Health Department in the project Healthy Neighbourhoods - closing the gap in health inequality. The project involves community-led initiatives to integrate health in urban planning, decisions on local investment and public policy. Quito residents in community meetings and health teams use information on health and its local determinants to set local priorities and plans and to take actions to promote healthy physical, economic, and social environments. DMQ has also facilitated a community-led certification of 'healthy spaces' (such as in fresh food markets and schools).

While context needs to be considered, key features that may be adapted include:

- a. The processes used for information gathering, analysis and priority setting in the community;
- b. The measures used to encourage co-ordination across sectors, and the gathering, analysis and use of information to support community and cross-sectoral roles and actions in solving problems.

These measures are already being exchanged with other municipalities in Latin American countries.

The country and local context

The Metropolitan District of Quito (DMQ) is the second most populated city in Ecuador. It has grown rapidly in recent decades, with a 2010 population of 2.2 million in 65 districts called *parroquias*, 32 of which are urban and 33 rural, further sub-divided into 1,298 neighbourhoods. Quito residents are mainly mestiza-type, although with higher shares of indigenous, Afro-descendent and Montubio people in some areas. There are social differentials, in poverty levels, in education, and higher levels of illiteracy in poor, rural households and Afro-descendent and indigenous women (DMQ, 2016). Residents have a strong sense of belonging to their neighbourhood.

Ecuador's 2008 Constitution and its laws set an enabling legal framework for a more holistic rights-based approach to and for social participation in health, linked to the exercise of rights to water, food,

education, physical culture, social security, healthy environments and other areas that sustain good living (Asamblea Nacional del Ecuador, 2008). The *buen vivir* model in the Constitution conceives that personal wellbeing is reached when humans' basic needs are satisfied in harmony with the community and the environment, and the Ecuador National Plan for Good Living 2013-2017 locates health within *buen vivir* (wellbeing) in a holistic inter-sectoral perspective (Yanez, 2013). The DMQ is an autonomous local government with powers to plan and exercise control over various aspects of urban development and wellbeing through such inter-sectoral approaches, with municipal ordinances setting the duty to do so in ways that involve citizen participation, oversight and accountability (GoEcuador, 2010).

Quito households have good access to sewerage, drinking water and refuse collection. A 2016 DMQ health diagnosis ([Diagnóstico de Salud](#)) observed

a high burden of non-communicable diseases, with urbanisation associated with risk factors like alcohol consumption and physical inactivity, including in young people (DMQ, 2016; MSP, 2015). Young people are also affected by teenage pregnancy and its complications, harmful drug use and adolescent suicide; women are vulnerable to gender violence; and elderly people and people with disabilities are vulnerable given poor coverage of pensions, limiting access to health services and exposing them to informal employment and begging to survive (DMQ, 2016).

In the face of a fragmented system and a large share of privatised services, public health services have had increasing investment post-2007 as key to addressing such challenges. The health ministry has offices in each zone, co-ordinated with other government offices, local government and non-state and civil society organisations to provide health services. [The Ministry of Coordination of the Social Sector](#) (*Ministerio Coordinador del Desarrollo Social*) co-ordinates the policies and actions and resources of different institutions to implement these policies and has a social registry of beneficiaries of social programmes. Curative services are the responsibility of the national government while responsibility for health promotion and disease prevention are shared with municipal governments, including for DMQ.

Efforts towards replacing a reactive biomedical model by a proactive community-based and population health approach have led to a portion of funds being invested locally towards supporting this (Rasch and Bywater, 2014). A national Healthy Municipalities Program guides municipalities through a three-step process: for the mayor and council to declare their support; for participatory analysis of information on health; and to evaluate municipal performance in improving social determinants of health (SDH), culminating in a certification as a 'Healthy Municipality'. Positioning primary healthcare as a key strategy, the national government set up the [Comités Locales de Salud](#) (CLS) to facilitate public input to health services, with local community and social organisation representatives elected by the community. The CLS participates in a Health Situation Diagnosis, in health promotion and in forums such as the *parroquia* or municipal assemblies and in development of the health agenda in the Municipal Plan (MSP, 2012). DMQ is supporting the efforts of the CLS in Quito, building on these policy, legal and institutional provisions and basing its work on the culture of collective community work in areas of wider community benefit, such as in improving public spaces.

The site and its practices

This case study reports work of the municipality and communities in the Metropolitan District of Quito and the neighbourhoods that have emerged as the city has grown and changed. The [Health Department of the Municipality of Quito](#) has since 2015 led implementation of a *Healthy Neighbourhoods - closing the gap in health inequality* project, starting in Ponceano, Centro Histórico, and Chimbacalle districts, with a combined total of 130 000 people. While these districts have poorer health status than others in Quito, they have administrative capacities to support the work. The project aims to improve health and well-being by integrating health into urban planning, local investment and local public policy, by promoting community-led initiatives and sharing them with other cities. DMQ seeks to achieve this change through three intermediate pathways:

1. Local public policies generated and implemented with the participation of Quito residents taking desegregated health data and SDH into account.
2. Citizen participation in action on community health and its determinants to improve healthy environments.
3. Sharing knowledge and best practices in urban health for local governments in the region.

To support the work, DMQ Health Department set up a multi-organisation steering committee to resolve local issues and keep communities informed on the work, a technical health committee of sectors involved with health, and community health work teams at city and neighbourhood levels to bring local community voice to the processes. These teams include representatives from the community, community institutions or organisations; local healthcare services; primary and secondary schools and workplaces; and opinion leaders of their sector (education, health, etc.) within the *parroquia*.

The city is gathering and analysing information on health and SDH to engage with residents on their priorities in the different neighbourhoods. Existing databases of various departments, and implementation of surveys are used to collect and analyse information relevant for population health, using the [WHO Urban Health Equity Assessment and Response Tool](#) (Urban HEART), the United States Centers for Disease Control [Healthy Communities program](#) and the Ecuadorean Ministry of Public Health (MSP) National Program for Healthy Municipalities (See *Appendix A1 and A2* and the Ministry [programme guide](#)).

DMQ has trained staff for this and is developing a virtual platform to display health data and health determinants disaggregated by district to make the information publicly accessible, including for slum neighbourhoods. Residents carry out their own awareness raising and local 'priority setting' workshops facilitated by DMQ in local neighbourhoods, using a combination of the evidence gathered by DMQ and issues perceived by the communities. Residents use the information and priorities to develop a road map with activities for the neighbourhood and city level.

The responses are organised in an intervention proposal that is presented to the mayor for approval and implementation. DMQ supports the capacity of residents to generate these intervention plans, or Community Health Plans. As a pilot scheme, DMQ provides incentive funds of between US\$2 000 and US\$5 000 on a competitive basis to promote community involvement in the development and implementation of the plans. These funds support community-led initiatives to improve health that benefit the wider community, rather than a small group of individuals, and aim to target and stimulate participation in those with higher health need.

DMQ is also facilitating a community-led certification of 'healthy spaces', where institutions such as fresh food markets and schools within the municipality that meet certain criteria are certified. The criteria for certification are developed by the DMQ Health Department in collaboration with relevant sectors and with the Ministry of Health and PAHO. In the longer term, responsibility for certification of these healthy spaces will be delegated to the Community Health Teams. For food markets, community teams, administrative staff, workers and the municipality assess the markets and develop workplans for health improvements on prioritised gaps in the standards. Similar work is done in schools and for healthy public spaces selected by community teams such as equipped parks or streets in residential neighbourhoods.

In all cases, the participatory action plans are implemented in co-ordination with relevant actors, with participatory review of how well they worked. The certification process aims to support the administrators and users of spaces like markets and schools to prioritise how best invest limited resources to address those issues that preserve and promote health and to address any gaps identified.



Community identifies the main health and determinants of health issues in the Parroquia Centro Historico of Quito. © LJ Cárdenas 2016

It is expected that the initial effort around receiving a certification will forge a working relationship between the relevant actors in the improvement of these spaces, which will continue after the space meets the criteria for certification.

These processes are designed to empower and guide the different community sectors (education, health, community institutions) to act within their area of influence, so that they have the power to implement these changes, but also to identify tasks for the municipal government. These tasks are put on the agenda of the Secretary of the Health Department, who will negotiate with the mayor, other secretaries and the council on behalf of the community. Over time, the DMQ plans to share knowledge and local best practices that improve health with other neighbourhoods in Quito and with other cities.

The practices do face challenges, such as to ensure that the mechanisms adequately represent specific groups like youth, women or children, to encourage areas where the culture of participation is weaker, to ensure that private actors, like companies, play their role and that all actors get the necessary capacity support to play their role. The process

raises expectations from community members that need to be managed, especially given that they take time and given the limited resources DMQ has for the work. The co-ordination across sectors is also challenging. Historically, sectors have had separate administrative procedures and resources. These siloes need to be broken to generate shared planning, shared indicators of success and shared results for inter-sectoral action in a way that does not compromise the individual goals of each sector. This too needs time and to progress step by step. The evidence being gathered intends to build confidence of the sectors and communities involved and of others in the links between health and SDH, in the relationships built and in the outcomes from the work.

Outcomes from the work

The city has identified the programme and health equity outcomes it hopes to achieve. In addition it has set up an interactive electronic system to store, update and give public access to the health information included. As outputs, it has identified participatory health diagnoses; technical reports; awards to implement initiatives; dissemination and training workshops and wider exchange workshops in the country and the region.



Students explaining perceived health problems in their neighbourhoods. Quito © LJ Cárdenas 2016

As outcomes, over the next two years the work aims to set up a DMQ representative health work team to carry out high-impact actions in health policies and environments; community health work teams representing the selected districts taking high-impact actions in health policies and environments; 20 neighbourhood health action plans, elaborated in a participative way with implementation and financing involving relevant departments of DMQ; fourteen schools implementing health promotion activities;

and fifteen markets taking health promotion and food safety into consideration. Further, the programme aims to have built awareness and capacities in 100 DMQ staff and 3,300 people, including the district's leadership.

While investments have been made in the processes and information needed to support assessment of these outcomes, it is still too early to see changes in outcomes.

Areas for shared learning

In any discussion of adaptation of practices the context needs to be considered, such as Quito's recognition of the role, orientation and competencies of the municipality in population health, the culture of collective work for common goals, and a supporting legal and policy framework. This has been critical for engaging other sectors and for the participatory processes. The work is in progress, but there is some indication of practices that could be adapted elsewhere, including:

- a. The systematic and participatory steps and processes in Quito for information gathering, analysis and priority setting in the community, combining local information with that collected by the services.
- b. The use of information and team approaches for encouraging co-ordination across sectors and for ensuring that the information gathering and analysis supports both community and cross-sectoral roles in solving problems.
- c. The focus on and work to map, incentivise and certify healthy public spaces.

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Links to information materials about the work of the Secretaría de Salud, Quito

- a. News from the Secretaría de Salud MDMQ: http://www.noticiasquito.gob.ec/index.php?module=Noticias&func=news_user_category&category=10159&umt=Salud
- b. News related to "Barrio Saludable" and Health Change: http://www.noticiasquito.gob.ec/index.php?module=Noticias&func=news_user_view&id=22662&umt=Municipio%20de%20Quito%20promueve%20el%20programa%20Barrios%20Saludables
- c. http://www.noticiasquito.gob.ec/index.php?module=Noticias&func=news_user_view&id=23531&umt=Quito%20participa%20en%20iniciativa%20global%20en%20salud
- d. Youtube Channel of the Secretaría de Salud - Municipio Metropolitano de Quito <https://www.youtube.com/channel/UCB7jXEtZtdFKBCUzpDzED5w>
- e. Cotocollao Community Health Team. <http://bit.ly/2tEXmCY>

3.3: Youth participation in a local mental health service, Gosford, NSW, Australia

For the full case study report see: 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>



Health
Central Coast
Local Health District

Key features

This case study presents the development and practice of a model for youth mental health services in New South Wales (NSW), Australia, for youth participation in governance, planning and implementation, termed the Youth Alliance (YA), and for improving families and carers participation in the mental health service.

Key features of the work that could potentially be adapted elsewhere include:

1. Employment and pay of youth consultants (YA model) and youth peer workers (CHOICE pilot).
2. Processes applied to select and recruit YA consultants/peer workers, ensuring diversity in the representation of young people.
3. Approaches to enable youth participation and empowerment, particularly for youth from disadvantaged backgrounds, including having a paid youth co-ordinator for the YA; having mentors for peer workers; flexible models of participation (2013 YA) and providing initial and ongoing training and development.
4. The approach to ensuring system and staff readiness for young people's participation and engagement in a Youth Mental Health service, including awareness and information sessions, in-service training and formal feedback mechanisms.
5. The 2010 carer strategy empowering families to be actively involved in the young person's care.

The country and local context

The Central Coast Local Health District (CCLHD) provides public health services to the communities of Gosford City and Wyong Shire Local Government Areas, located between Sydney and the Hunter Valley in New South Wales (NSW), Australia. It had a population of 333,119 in 2015, with a higher than average population growth and relative disadvantage compared to other parts of NSW, particularly in the Wyong Shire (NSW Health, CCLHD 2013). Aboriginal people were 2.9% of the population in 2011, with 40% living in the Gosford Local Government Area. They too are a disadvantaged population (Yerin Aboriginal HS Inc. et al., 2013). The area has higher levels of health risk related to education, physical

activity, diet, obesity, smoking, alcohol/drug use and psychological distress than NSW, and higher average death rates than NSW from all causes. Aboriginal people experience higher levels of mortality and morbidity from mental illness and from related injury and suicide than the non-Aboriginal population (Yerin Aboriginal HS Inc et al., 2013).

Local Health Districts are responsible for managing public hospitals and health institutions and for providing health services to defined geographical areas. CCLHD is served by two acute hospitals - Gosford and Wyong, two sub-acute facilities and ten community health centres and other community-based services. The population has relatively

poor access to general practitioners and hospital specialists and limited support services for the ageing community (CCLHD, 2015). CCLHD plans and policy approaches emphasise population health and expansion of community-based services, but a slow growth in resources, workforce and physical space limits this in the areas of population growth and demand (NSW Health, CCLHD 2013).

There is policy support for patient, public or community participation in health services. In NSW, each local health district has a board of between six and thirteen members appointed by the Minister, on the basis of their understanding of the community and of Aboriginal health. Amongst its duties, the board is seeking the views of providers and communities on health services and district policies, plans and initiatives and advising providers and community members about the district's policies and plans. Local health districts must have appropriate consultative and communication strategies involving community and staff, as well as a Local Partnership Agreement with Aboriginal Community Controlled Health Services and Aboriginal community services. Districts have a duty to publicly report annually on their performance. Communities can contribute through formal and informal mechanisms to health service plans, operations and programmes; dialogue on meeting community health needs; obtain and disseminate public health information; participate in actions, in forums, in budget planning and resource allocation; in service reviews and setting service standards; in quality and accreditation processes; and in advisory and other processes (NSW MoH, 2012). CCLHD has a [Consumer, Community and Engagement Committee](#) that helps to facilitate and oversee the community involvement in the local health district's plans, policies, care design and service provision.

A 2014 strategic plan, [Living Well: A Strategic Plan for Mental Health in NSW 2014-2024](#), emphasises the importance of people-to-people support and self-agency in mental health. It seeks to shift from specialist clinical services to community-based support for people with mental illness, including through the involvement of a wide range of stakeholders and people with mental health issues. The NSW Mental Health Commission has a commitment to employ people with lived experience of mental illness. It has developed a framework for a peer workforce in mental health services across NSW for people with experience of mental illness to support others, as shown in the [video](#) and in the [peer work hub](#) site and discussed in a [Peer Work Forum](#) (Mental Health Commission NSW, 2015).

The 2016/17 NSW Government budget allocated US\$1.35 million to fund reforms in mental health, including for a state-wide rollout of a *CAMHS GOT IT!* programme for early mental health intervention in schools. While late adolescence and early adulthood is a peak period for onset of mental illness, young people usually receive services in adult mental health settings. In 2007, the federal government established the National Youth Mental Health Foundation called *headspace*, aiming to deliver improved mental health and wellbeing of young Australians aged 12–25 years (Howe et al., 2013).

The site and its practices

The CCLHD approach to mental health service provision is one of person-centred care, managed within the community in community based treatment and support programmes that focus on prevention and early intervention. This model relies on service integration within Mental Health Services ('One Service'), on the inclusion and involvement of other service providers, sectors, non-state organisations and community and consumer groups (NSW Health and CCLHD, 2013).

In 2006, Children and Young Peoples Mental Health (CYPMH), CCLHD was chosen as the 'prototype' Youth Mental Health (YMH) service for NSW Australia. Funding from NSW Health enabled the development of an integrated YMH service platform (*ycentral*) in Gosford for young people with moderate to severe mental health problems.

As a first step a set of key principles were developed based on a literature review and feedback from 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 and a common set adopted, shown overleaf. The principles were endorsed by the *NSW Mental Health Program Council* in 2008 and used for reporting on service performance (Howe et al., 2013).

With this funding, CYPMH established a YMH Clinical model for the Central Coast region; a co-located 'one stop shop' (the *ycentral* physical site); a [YMH specific website](#); primary care level YMH initiatives and a YMH consumer participation model. The YMH clinical team is a mobile service providing support to young people at locations in the community that suit them, including schools, emergency departments, community health centres and in the home.

Principles for youth and mental health 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. Focus 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 (Howe et al. 2013)

It is supported by a consultation and assessment team within CYPMH, including general practitioners, secondary-level services (headspace), private allied health workers (psychologists and social workers). In 2007, Commonwealth funding for a headspace site was allocated to develop a headspace site on the Central Coast (one of the first 10 headspace Centres in Australia). In partnership with [headspace](#) Gosford in 2007-2009, CYPMH established the Youth Alliance (YA) model for participation.

In this model sixteen young people aged 15–24 years were employed on a casual basis, supported by a full-time paid coordinator. They were involved in informing the development of youth mental health services at the site and in training, consultations, working parties and community awareness activities. They ensured collectively that services developed as youth-friendly and developed a [virtual tour](#) of [headspace](#) Gosford. Services could request the YA to hold consultations with youth in Central Coast.

They reached more than 4000 young people with peer support on areas such as sexual health, violence and abuse; and chronic illness. They contributed in the NSW Consumer Advisory Group on improvements for young people in the mental health system (Howe et al., 2010). ... *when the young people from more disadvantaged backgrounds could attend meetings of the YA, their contribution was of incredible value* (KI interview , Simpson and Howe, 2017).

To improve the participation of families and carers, CYPMH developed a carer strategy, where clinicians were trained to work with carers and families, a carer's library and a number of carers' forums were set up, and carers were involved in service feedback (Howe et al. 2013). Given their specific needs, the [ycentral website](#) includes links to national resources such as [yarnsafe](#), a [campaign](#) to increase awareness of headspace for Aboriginal and Torres Strait Islander youth to seek information, help and support. The website also has a dedicated area for [families and carers](#) which includes tailored information and resources for parents, family members, friends or carers and resources for [workers/schools](#), including opportunities for training and online training. In May 2015, the CYPMH and [headspace](#) Gosford organised the 2015 [Believe, Share and Connect](#) Forum with the education sector for secondary students, providing information and an opportunity for dialogue on mental health and wellbeing. The YA engaged young people from diverse backgrounds as 'consultants', including indigenous young people, those from different cultures and languages and from low socioeconomic groups (Howe et al., 2011).

A review of the model in 2013 drew lessons from previous work to build a [Youth Reference Group](#) that includes, on a voluntary basis, young people 16-25 years with experience of mental health issues from diverse backgrounds, including from minority and marginalised populations. In 2014-15, with national funding, *headspace* Gosford developed a [CHOICE project](#) to explore the role of peer workers and to develop a tool for shared decision-making in youth mental health services. The flexible participation model provided a continuum of opportunities for and levels of participation. It was affected by the availability of human and financial resources, with funds having to be found from within existing budget and or new project allocations. A decline in youth participation when funding declined indicated the need to pay young people appropriately for their time or to engage them as employees. The experience underlined the importance of a paid co-ordinator to supervise and support participants and of training and information tools.

Challenges were faced in the availability of the YA consultants; in the balance between support and autonomy; and in the involvement of youth from more disadvantaged backgrounds (Howe et al. 2011). Staff did not always hold positive attitudes and beliefs about the benefits of youth/peer participation and meetings were held to discuss their concerns and measures taken to increase their role in YA consultant training and supervision (Coates and Howe, 2016).

Outcomes

The YA 'consultants' in 2007-2009 indicated that they had gained skills in teamwork, communication, presentation, public speaking and time management and in consultancies. They reported feeling valued and empowered by their participation in the project, which also helped them to access and keep accommodation (Howe et al., 2011). An evaluation of the later YA model found that the consultants felt that it gave them a safe space to make new friends and build social skills (Coates and Howe, 2016).



ycentral site waiting room © D Howe 2017

Areas for shared learning

The experience offers insights and learning on participation for young people in a mental health service, including:

- a. Reimbursing the contribution that young people and their carers make, putting them on an equal footing with professionals and others, and ensuring resources for this and for a youth participation coordinator.
- b. Having a flexible model for different levels and forms of participation and getting the right balance between professionalising young people who participate and empowering them, particularly when, for most, they are vulnerable due to their age, experience of mental illness or inexperience of workplaces.
- c. Ensuring a diversity of young people with experience of service contact and mental illness by including participants from diverse backgrounds, screening out those without personal experience with mental health and providing support from a youth participation co-ordinator to better understand and help to address barriers to their participation, including transport and hours of events.
- d. Ensuring that the system and staff are ready for change and for implementation of participatory approaches, with communication in email updates and presentations at staff forums, communication between staff and the YA coordinator and measures to hear and address staff concerns.

A range of features of the work could be adapted in other settings, including

- a. Employment and pay of youth consultants (YA model) and youth peer workers (CHOICE pilot), and ensuring diversity in the representation of young people.
- b. Approaches to enable youth participation and empowerment, particularly for youth from disadvantaged backgrounds, including having a paid youth coordinator; mentors for peer workers; flexible models of participation and providing initial and ongoing training and development.
- c. Ensuring system and staff readiness for young people's participation and engagement including awareness and information sessions, in-service training and formal feedback mechanisms.
- d. The 2010 carer strategy empowering families to be actively involved in the young person's care.

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3.4: Sahbhagi Shikshan Kendra, Varanasi, Uttar Pradesh, India

For the full short case study report see: Loewenson R, Mohanty R, Lal U (2017) *Short case report: Sahbhagi Shikshan Kendra, Varanasi, Uttar Pradesh, India*, March 2017 <http://tinyurl.com/y9mzhbby>



Key features

This case study reports the work of Sahbhagi Shikshan Kendra (SSK) and communities in Varanasi, Uttar Pradesh. SSK supports citizens and builds citizen leaders and collective and community based organisations (CBOs) to make claims on the state, especially amongst women. It supports the formation of women's and adolescent groups, provides information on government schemes and builds functional literacy skills and capacities. The communities implement social audits, hold public hearings and dialogue with local authorities, and work with community health workers and panchayats to improve healthy environments, to make claims on services and benefits and to improve health service performance.

While context-specific, there is potential to adapt the bottom-up strategies and measures used by SSK to:

1. Encourage and organise participation of socially excluded people;
2. Carry out sensitisation meetings and disseminate information;
3. Build local individual and collective citizen leadership and social organisation in CBOs through functional literacy and training;
4. Carry out participatory audits and create multiple spaces for engaging local providers on services;
5. Build partnership with CHWs and frontline providers;
6. Manage conflict and power imbalances.

The country and local context

Uttar Pradesh (UP) is one of the most populous states in India, with a population of 199.6 million in 2011. Varanasi, the case study area, is in the Eastern region of the state. UP is divided into districts, villages and blocks. Panchayats are clusters of villages, a block is a cluster of panchayats and a district is a cluster of blocks. UP's population is diverse, primarily Hindu and Muslims, with scheduled castes (SC) (low castes called Dalit) a fifth of the state's population. There are social and income differences across the different social and religious groups in UP, with lower socioeconomic status amongst Muslims and SCs (GoUP and UNDP, 2008). Varanasi, the study district, is primarily non-agricultural with low rates of employment, and the work in the case study largely

takes place in the villages around the city, where poverty levels are relatively high, particularly for SCs, Muslims, agricultural labourers and artisans.

These economic conditions are reflected in social conditions that affect health including: poor living conditions, low levels of literacy and life expectancy and high infant mortality (GoUP and UNDP, 2008). Varanasi has better than state averages for literacy (79.2% in 2013) but higher infant mortality at 72/1000 in 2013 (ORGCC, 2013). About a fifth of rural households are headed by women, who are responsible for family survival, but are vulnerable to abuse, domestic violence, and lack information and face poor recognition for their economic role. Premature death and disability are largely caused by communicable diseases, malnutrition, and prenatal

conditions, together with reproductive morbidity, malaria, tuberculosis, leprosy, AIDS, blindness, diarrhoea, measles, diabetes, hypertension and heart disease. While Varanasi generally has better health outcomes, it has a high prevalence of HIV. SC, Muslim and other marginalised groups have higher morbidity and face barriers in access to services.

The public health system in UP provides services at three levels: urban district hospitals; community health centres for every 100,000 people; and primary health centres in remote rural areas and sub-centres for every 5,000 people. Public health services play an important role in health improvements, such as through immunisation campaigns (GoUP and UNDP, 2008). While widespread and free at point of care, public services often have poor sanitation and electricity and staff, specialist and medicine shortfalls in some services contributing to poor service delivery and poor sensitivity to patient needs (GoUP and UNDP, 2008). There are wide social differentials in access to and uptake of key services, although Varanasi district has better coverage data than state averages (ORGCC, 2013). Various measures have been implemented to improve access, including community healthcare and community health workers (CHWs). Each village has one Anganwadi worker (AWW) and helper who provides nutrition, pre-school education, and health services to children under-6 years of age. Accredited Social Health Activists (ASHA), are women selected by local

villagers, who are trained, deployed, and supported to function in their villages to improve health and access to services. They get fixed incentives from government for defined tasks, and are responsible for maternal and infant care, including nutrition, communicable disease prevention and community health.

India's Constitution formalises villages as self-governing bodies through Panchayati Raj institutions. 'Panchayat', means assembly (*yat*) of five (*panch*) wise and respected elders chosen and accepted by the village community. In the Panchayati Raj system, gram panchayats are publicly funded units, supporting improvements in infrastructure and public assets, meeting halls and markets; communicating with local communities, collecting prescribed taxes and fees and reporting on their use of these funds. The public elect the members and participate in and monitor the programmes and activities. The gram panchayats control the local medical, health, family welfare and mother and child welfare centres, and the school, sport, welfare, and other development programmes and infrastructure (Mishra et al., 2011). They facilitate the appointment of CHWs, hire and pay primary health centre staff and organise land for local healthcare centres (GoUP and UNDP, 2008). While women have faced barriers in political participation, they have also increased their presence as elected representatives to the Panchayati Raj Institutions in UP (GoUP and UNDP, 2008).



Discussion with women and health service providers in a SC hamlet, Munari-Burkaini, SSK 2017

The site and its practices

This case study reports on the work of the nongovernment organisation (NGO) Sahbhagi Shikshan Kendra (SSK) in villages adjacent to Varanasi city, Uttar Pradesh, India, to support citizen leadership and participation in making claims on the state, by forming women's groups, providing information on government schemes, providing training for capacity building and facilitating interface with and support around claims for health-related inputs. It reports on how the community works with village health workers and local mechanisms (panchayats) to secure their health needs, ensure healthy environments, make claims on services and benefits and improve performance of health services, as shown in various [videos](#). SSK initiated its work in Varanasi in 2005 with capacity building of rural communities to strengthen the decentralised panchayat governance, and it has since expanded in scope.

In SSK sites in Varanasi, people express their demands and views on health issues and healthcare

- directly - through community-based organisation (CBO) meetings, citizen leader meetings, panchayat meetings, capacity building trainings organised by SSK and government departments, interface meetings with government officials organised by SSK, social audits and public hearing meetings; and
- indirectly - through SSK representation at the block, district and state levels.

Even with these formal mechanisms in place, further measures were needed for meaningful levels of participation within them, particularly in the health sector, where decisions over resource allocation are concentrated at central level and where decisions do not use lay evidence. This, and the marginalisation of women, left women alienated from these mechanisms and CHWs dissatisfied (Sinha et al., 2002).

SSK has mobilised and supported women for over a decade to engage with panchayat institutions, government departments and health care providers in 54 villages around Varanasi city. It involves socially excluded, low caste (Dalit) and Muslim women, directly and in groups. The work aims to strengthen a chain of change agents and women CBO leaders to enhance women's literacy and life skills and to promote their links with and engagement of the Panchayati Raj Institutions and government departments to claim entitlements. This is based

on the understanding that improved health and services for marginalised women depends on their being able to organise collectively to claim these rights. SSK strategies cover four areas: effective information dissemination; strengthening local-level organisation and cadreship; strengthening links between people, their representatives and local-level leaders and creating platforms to interface with services and for service accountability (SSK, 2015b). SSK understands that power is negotiated, diffused, claimed or overcome in formal and informal ways and uses these participatory processes and negotiation to break power imbalances around health issues that are important for socially excluded groups.

The actions SSK and the communities have taken include:

- a. a. *Building functional literacy and lifelong learning skills* through an Adult Functional Literacy Program for marginalised Muslim and SC women leaders chosen by SSK and communities. The programme has established 10 functional literacy centres and run 20 courses on functional literacy. SSK holds refresher workshops on tutor and counselling skills for women leaders for their literacy work in the community, so they can initiate and sustain community action in other spheres. Periodic dissemination events at district level facilitate the sharing of work-plans and support and input for interventions.
- Excluded communities are *collectively organised in CBOs* to facilitate information on their rights and entitlements and on local programmes. Under the *Our Rights, Our Voice* programme, SSK has organised CBOs in a number of areas. The CBOs provide information on government schemes and engage state departments on services. While not formally recognised entities, CBO members include panchayat members and service providers, giving them legitimacy and influence in formal spaces. They have thus successfully taken up issues relating to: the functioning of schools and the provision of nutritious locally prepared midday meals to schoolchildren; facilitating weavers' groups/federations to strengthen their voice, their awareness of available government schemes and to enable training for improved value added products and links with public and private agencies, including credit agencies. The CBOs have also facilitated farmers' access to compensation grants after crop failure (SSK, 2015a).



Discussion with SC and Muslim women, (c) U Lal R and Mohanty 2017

- *Facilitating adolescent girls' groups.* Kishori Samuh tackles adolescent vulnerability, including early marriage, reproductive and other health risks and school dropouts. The interventions have supported their education and discussions of their futures, and strengthened their literacy, networks and leadership. Female school dropouts were supported with collective learning in the school syllabus, in vocational skills, music, sport and in health, and in accessing adolescent health services. A forum for parents and guardians was formed, and the adolescents met with and secured the support of health service personnel for their entitlements in other areas, such as safety and sanitation in schools.
- *SSK's Citizen Leadership Programme* is building citizen leaders in villages to ensure effective implementation of such schemes. Two citizen leaders are selected from each village and with CBOs engage with panchayats, government departments and healthcare providers, local CHWs, school personnel, ration shops and others. Citizen leader groups federate and meet as forums at block and regional level to network and share strategies on common issues.

CHWs have played a key role as link-workers (facilitating access to healthcare facilities), health workers (treating minor ailments), and health activists (creating health awareness and mobilizing communities on health). In Varanasi, with SSK support, *the CBOs, citizen leaders, ASHAs, AWWs and Auxiliary Nurse Midwives (ANMs) interact with front-line service providers* directly and through the

panchayats on health service performance (SSK, 2015a). SSK has also supported social accountability in service provision in Varanasi through *social audits and report cards*. Citizen leaders trained by SSK implement the social audits through visits to services and dialogue with communities and hold follow-up public hearings using the results, to discuss service performance with providers.

These processes have common mechanisms, tools and resources. They build individual and collective leadership, engagement between communities and the panchayat; define key constituencies and organise village-level CBOs and regular community meetings from village to block level to enhance the community interface with government service officials and providers. SSK has played a strategic and consistent role of credible, competent organiser, facilitator, trainer, and negotiator, building trust and confidence in communities. It has facilitated good working relationships with state officials and strategic alliances with non-state actors. The first issues taken on were those where there was a greater likelihood of early results, such as claiming entitlements to widows' pensions. Successes at the onset created confidence and an understanding of leadership and process that could be built on for more complex issues. While this demands time and challenges existing marginalisation and dominant power structures, the processes are reinforced by capacity inputs, by CHWs and local level leaders, by exchanges across areas, social recognition and alliances with wider actors, and by a growing community belief in their ability to bring about positive change.

Outcomes

The work described in the case study is reported to have led to a range of outcomes, including:

- Collective organisation of excluded groups, adolescent girls, women and men citizen leaders; strengthened and sustained leadership and networks for female literacy and community awareness and sensitisation on health and service entitlements and on women and adolescent girls' issues;
- Strengthened networking, sharing of practices and support among local village committees, and between communities and CHWs, and increased household visits in excluded communities;
- CBO involvement in school development plans, strong linkages between the education

department and community; and improved outcomes in school midday meals, in school enrolment in excluded groups and in retention rates in primary and middle schools;

- Increased uptake of health insurance and institutional deliveries, especially in SC and Muslim communities (SSK, 2015a).

The programmes are reported to have improved the effectiveness of CHWs; led to more informed communities on health; and improved health actions and service uptake and service performance. A 2016 SSK evaluation of the adult literacy programme in Varanasi found an increased community role in decision-making, increased awareness of rights and actions on gender bias, increased female school enrolment; opening of bank accounts and attendance of panchayat meetings (SSK, 2016).

Areas for shared learning

Various features of the work could be applied in other settings, taking context into account, including:

- Encouraging, strengthening and organising poor and socially excluded people to enhance their participation in processes for their development;
- Building bottom-up participatory models that build capacities, strengthen individual and collective leadership and social organisation for engaging local providers on effective service delivery;
- Engaging in ways that build partnership with governance agencies and health systems at the community level and that involve and work closely with CHWs and frontline providers;
- Creating multiple formal and informal spaces to articulate interests and demands for negotiation and to voice and manage resistance, and multi-layered channels for interfacing with service providers;
- Strengthening information to communities as a resource for social power and engagement on issues;
- Identifying mechanisms for managing conflict and power imbalances, such as NGO intervention to enable resolution and power shifts in ways that build community leadership, capacity and strength;
- Innovating and adapting new participatory approaches, methods, strategies, and technologies.

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3.5: Lusaka district health office, Zambia

For the full short case study report see: Loewenson R, Mbwili Muleya C, Zulu Lishandu I (2017) *Short case study: Lusaka district health office, Zambia*, TARSC, March 2017 <http://tinyurl.com/yaasxj8k>



Key features

The work by the Lusaka District Health Office tells the story of sustained participatory approaches used since 2005 in urban Lusaka. Participatory approaches were used in priority setting, planning and budgeting and in health action by communities and frontline health workers in local health committees and in a community health literacy that is now scaling up to national level.

Features of the work that could potentially be adapted elsewhere, include

- The use of participatory reflection and action (PRA) approaches to organise community experience, analysis and action in health literacy and in dialogue between communities and health workers.
- Facilitating PRA in health committees for joint community and service planning and action.
- Building joint health services and community identification of needs and actions, with support for voluntary community roles and for community champions and voice to sustain the process.

The work has sustained and spread due to various factors, including the social power and confidence built within communities from the PRA processes; a horizontal, rather than top down, spread; facilitating participation mechanisms that involve elected community members and frontline health workers; providing forums for wider sharing of experience across localities; accessible online reporting of the work; and a committed leadership able to sustain and advance the processes.

The country and local context

Zambia is a lower middle income country, with a growing economy largely from mining, but also with persistently high levels of poverty, unemployment and socio-economic inequality. Lusaka province has the fastest population growth in the country, with 85% of its population urban and 1.7 million people in Lusaka, the capital city (UNDP and GoZambia, 2013). The adult literacy rate among women and men in the province is 68% and 83% respectively. While infant and child mortality in the province declined in the past decade, maternal mortality remained high, there were deficits in access to safe water and sanitation and a mixed profile of communicable and non-communicable diseases (UNDP and GoZambia, 2013).

The national health strategy gives priority to improved environments and food safety, control of epidemic outbreaks, health promotion and primary health care services for family health, communicable and chronic conditions (MoH Zambia, 2011).

The public sector dominates in health services, but cultural and religious beliefs mean that communities often visit traditional healers before going to allopathic health providers and some religious sects do not allow their members to attend health care services, preferring spiritual healing. The presence of extended families and traditions can, however, also facilitate community networks for health activities.

Lusaka city has all levels of health services from health posts to the University Teaching Hospital. The Lusaka District Health Office (LDHO) mandate ends at district hospital level, and it collaborates with non-state actors, other public sector and private health providers, especially at health centre level, to provide health services and public health programmes for prioritised conditions and for maternal and child health and environmental health. LDHO identifies needs and delivers services, although staff recruitment and allocation of funds are largely decided at central level. Lusaka's district administration co-ordinates the operations of government departments' and other organisations in the district. A District Development Coordinating Committee carries out integrated planning and a district council with elected representatives from civic leaders integrates community inputs into plans.

Zambia has a policy commitment to participation in health service planning and delivery. Neighbourhood health committees (NHCs) were set up in the 1995 National Health Services Act as a link between the community and the health system. In 2006, as part of wider health reforms, this Act was repealed removing the legal mandate of NHCs but they continue to function as set in national health strategic plans and budgeting handbooks (LDHMT and TARSC, 2015).

According to government guidelines, NHCs identify health needs in the community, collect community evidence and plan and work with the health centre staff on shared concerns, together with community based organisations. They support information exchange between health services, communities and community health volunteers. The community elects community members from the neighbourhood of a health centre into the NHC, excluding politicians or health service workers / employees. The NHC elects a chairperson who becomes a member of a health centre committee (HCC) at the health facility, which involves community members and health staff, and is chaired by the community with the nurse-in-charge the secretary.

The site and its practices

The case study describes the sustained participatory approaches used in [Lusaka urban](#), institutionalised to [national level](#). These include work on health literacy and with [health centre committees](#) involved in participatory priority setting. [Participatory methods were used in comprehensive primary health care \(PHC\)](#), linking with other sectors and with community health workers (CHWs) and health literacy facilitators.

The work used appropriate approaches, including to track and support uptake and to raise policy/political attention and support.

Participatory reflection and action (PRA) methods have been used since 2006 to support these processes, as described in an online [video](#).

LDHO has used PRA approaches for over a decade to strengthen primary care level health service delivery, also working internationally with the [Regional Network for Equity in Health in East and Southern Africa](#). In 2006, the growing level of public health problems in Lusaka motivated community members, health workers and LDHO to strengthen information sharing, partnership, joint decision-making and accountability on resources and actions.

Various [participatory tools](#) were used to identify needs, system barriers and areas for change. The issues raised included poor communication between and within health workers and community members, poor understanding of roles; health workers' perception of low health knowledge in the community and community members feeling powerless and unappreciated by health workers.

In the PRA process community members and health workers identified shared priorities and actions to remedy these problems, improving information sharing and mutual respect between them, and community confidence in engaging health workers. They addressed an impending cholera outbreak, reducing cholera cases and deaths, and mobilised resources for local health improvements (Mbwili Muleya et al., 2008).

In 2008/9, applying the iterative spiral PRA model shown in *Appendix A3*, the approach was spread with health workers and community members to new health centres in the district and consolidated at existing ones.

The model starts with local experience, builds shared analysis of problems and their causes, identifies and takes action on prioritised problems and reviews the learning from the actions taken. LDHO and NHC facilitators held combined workshops of health workers and communities, followed by implementation of planned activities and regular review meetings to reflect on activities and outputs. A pre- and post-intervention questionnaire administered to participants reviewed the impact, complementing participatory review (MoH Zambia et al., 2012).



HCC chairpersons planning at district level © M Daka 2013

The actions included clean-up campaigns, with local government support; improving sanitation, housing and maize milling; and solid waste management. They took a wide lens on health and wellbeing and involved many other sectors and actors. Other actions more directly focused on service performance and uptake, such as HCCs supporting mobile phone appointments and follow up of HIV positive mothers, or distributing and monitoring use of mosquito nets. The HCCs mobilised local resources for these actions, including from their own activities, and from public funding (LDHMT and TARSC, 2015).

These approaches strengthened community and health centre partnership and accountability and included community voice in planning and budgeting and supported the functioning of the NHCs and HCCs. The planning and budgeting decisions made by the NHCs and HCCs were binding on the participating communities, local stakeholders and health facilities and, through this, the district and MoH. LDHO has since 2005 further formalised the role of its HCCs by consulting with and preparing an HCC constitution, training HCCs in planning and budgeting, and facilitating exchange over the past nine years in an annual general meeting of all NHCs in the city (LDHMT and TARSC, 2015).

The PRA approaches were complemented by other participatory methods, such as community photography, or [photovoice](#). LDHO trained community members and health personnel in HCCs in photography, provided them with cameras and facilitated their sharing and analysis of the

environmental, service and social issues raised in the photographs. HCC members used the photographs in local clinic and district health meetings, to stimulate discussion on solutions to problems identified, including with other sectors, provoking action on the problems raised (LDHO and TARSC, 2016).

In 2010 a wider community-level health literacy (HL) process, also using PRA, was institutionalised within the city. HL shares information and builds skills for health action, using the PRA spiral. It facilitates community level diagnosis, provides relevant health information and stimulates action and engagement to shape health programmes and services. Zambia specific materials were developed and HL facilitators trained. HL sessions were held in communities involving the NHCs, church, youth, businessmen, civic leaders, residents' development committees, police, teachers, TV and print media and the local council authority. In a series of repeated meetings and training sessions with the communities,

HL facilitators stimulated community interactions with frontline health workers on health needs and service gaps or barriers and used this information to set shared action plans for prioritised issues. These were initially on more visible priorities, like community environments and service performance, but widened over time to less well-recognised issues, such as non-communicable diseases. Monthly reporting and regular review meetings were used to assess and discuss progress and baseline and post surveys implemented to evaluate the impact on service performance.

The HL programme addressed role confusions and miscommunication between communities and health workers that was raising distrust in services. It identified areas of shared interest to raise jointly to higher levels of the system. The engagement of a range of actors in a common process facilitated cross-sectoral actions and the mobilisation of resources for the actions from different local stakeholders. The information brought by service workers helped to inform actions. For example, making clear the ways mosquitoes breed helped to direct actions towards addressing the open potholes and long grass facilitating mosquito breeding. Most importantly the activities positioned the communities as change agents. Every three months those involved met to review and evaluate their progress, using a wheel chart and progress markers (described in *Appendix A4*). The positive feedback from the HL programme and its impact on improved SDH and health led to its recognition by Ministry of Health and subsequent launch of HL as a national programme in 2012 by the then Minister of Health, Hon Dr. Joseph Kasonde, and roll out to all nine provinces of the country.

The experience showed that sustaining participatory approaches progressively de-mystifies and increases community involvement in planning and budget processes, building trust, transparency and accountability. *Community members have become part of the change process themselves.* It did not require significant resources, but did need feedback and review, time and mentorship, formal responsibilities to co-ordinate and follow-up on activities, good facilitation capacities and leadership and management support to institutionalise the

process (MoH Zambia et al., 2012). Given the competition for attention from curative programmes and target-driven strategies that did not prioritise participation, the support from political and policy levels, national and international exchanges and the growing support from communities and local health teams was critical to sustain the work.

Outcomes

Pre- and post-intervention surveys and reports from health workers and communities of the initial 2006-8 PRA work found improved interaction between health workers and community members and increased confidence of community members to participate in planning, contributing to increased local ownership of plans and budgets. HCC members are now themselves presenting health centre plans and budgets. There is some evidence of the effect of these activities on health outcomes, in a reduction in cholera incidence after 2010 in part due to the removal of waste sites and the measures for community health literacy and action (LDHMT and TARSC, 2015; MoH Zambia et al., 2012). The processes also led to a range of system and social outcomes. They provided organised spaces, processes and capacities for communities to express, shape and monitor their health programmes and local services and to negotiate for the resources for improved health. The ‘bottom-up’ approach has supported conflict resolution and improved relationships between health workers and communities. It has shifted community perceptions of health as *not just about taking medication but about having healthy environments and relationships.*



Health literacy training, Zambia 2014 © Shana

Areas for shared learning

In the initiation of new processes, it was noted that the changes take time, especially in complex processes like budgeting and planning. Their design needs to address potential challenges, like the adequacy and turnover of health personnel in primary care services; competing demands on people's time; poor understanding of different roles; and service providers' fear of shifting control to communities. This called for processes that change mind-sets on what meaningful participation involves; and to integrate the processes into formal roles and functioning of health centres, supported by leadership, capacity building, information sharing, mentoring and resources for the activities involved. After more than a decade of implementation, further *learning and insights on the more mature process*, and on what has enabled it to deepen, sustain and spread, indicate that:

- *Social power and the confidence in communities* to articulate the processes and their benefit become sustaining factors, keeping the demand for the processes alive in changing contexts.
- *PRA empowers communities* by drawing on their experience and generating collective learning in an accessible way. Inclusion of health officials has strengthened their understanding and support.
- *Horizontal spread*, rather than top down spread, has been a sustainable and more legitimate strategy for reaching new communities, spreading the processes through those with experience of it.
- *Formalising the role of the mechanisms for social participation* (NHCs and HCCs) enables dialogue between communities and health services, especially formalised, such as in a constitution, with community members elected by the community and with mechanisms for exchange across local areas, like the NHC AGM, for sharing experience and for collective analysis.
- *Documenting the work, including online, and being part of a regional network* has helped to build trust in, transparency of and respect for the work by different institutions.
- *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.

Features of the work could potentially be adapted elsewhere, include:

- a. health literacy training using PRA approaches;
- b. using participatory mechanisms to strengthen capacities for and a clearer understanding of the role of mechanisms for dialogue between communities and services (such as HCCs and NHCs);
- c. working with teams from health services and communities;
- d. supporting voluntary community roles;
- e. building community champions and voice to sustain the process.

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3.6: Wan Smolbag, Port Vila, Vanuatu

For the full short case study report see: Simpson S, Dorras J, Walker P (2017) *Short case study: Wan Smolbag, Port Vila, Vanuatu*, TARSC, April 2017 <http://tinyurl.com/y7xre294>

WAN SMOLBAG THEATRE

Key features

This case study tells the story of sustained participatory approaches used by the Wan Smolbag (WSB) Theatre, a non-profit organisation based in Vanuatu, since 1989, to raise awareness of health and social issues. Key features of the work that could potentially be adapted/ adopted elsewhere include:

1. The WSB participatory approach to developing the scripts and content for plays, radio, or television, together with workshops and publications;
2. Using creative media as a focus for youth centres, in a way that provide spaces for nutrition and reproductive health services, literacy and computer classes and for a range of sporting activities;
3. WSB approaches to building individual and community capacity for change beyond awareness raising, such as for improving food security and providing education on nutrition;
4. Fostering partnerships with external funders, encouraging long term commitment from staff to the organisation and creating employment opportunities for youth;
5. Having a long-term commitment to poor communities near WSB through youth centres and outreach services in agriculture and nutrition;
6. Promoting an indigenous presence in contemporary theatre and film.

The country and local context

The population of Vanuatu was 234 023 in 2009, primarily Melanesians, spread across six island provinces with 80 islands. A quarter of the population is urban and many rural people are geographically isolated. Vanuatu has a young population, with 40% under the age of 15 years, and increasing life expectancy. Although it has had positive economic growth, unemployment is common and poverty and inequality persist. Vanuatu has high rates of early pregnancy, high fertility and poor reproductive health status. Sociocultural norms and traditions make it difficult for young people to obtain information on reproductive health from family members. Increasing non-communicable disease with existing communicable disease pose a double burden, and the country has amongst the highest diabetes rates globally (WHO WPRO and MoH Vanuatu, 2012). Frequent natural disasters, such as Tropical Cyclone

Pam in 2015, and climate change impact on health and increase food insecurity and malnutrition (WHO WPRO and MoH Vanuatu, 2012).

The government provides health services through referral hospitals, health centres, dispensaries and community-supported aid posts, the latter as the first level of care. Village health workers with limited training work with communities to promote hygiene, good sanitation and disease prevention. Each province comprises several islands divided into zones and health facilities are distributed among the zones. Provinces provide community and preventive services and employ health promotion officers (WHO WPRO and MoH Vanuatu, 2012). Vanuatu's [Health Sector Strategy 2010-2016](#), emphasises equitable access to health services at all levels and locates quality primary health care as the central strategic health priority for the country (MoH Vanuatu, 2010).

Limited availability and accessibility of health services and a lack of a trained health workforce and equipment, however, pose barriers to achieving this, particularly in remote rural communities and outer islands. A *Healthy Islands* approach seeks to improve the health and quality of life of people in island settings, by establishing more effective working relationships between health and other sectors and organisations, including WSB, with peoples' participation.

The site and its practices

Wan Smolbag (WSB) Theatre is a non-profit organisation based in Vanuatu, operating across the South Pacific. It was formed in 1989 as a small development theatre group with fifteen voluntary actors. The group called itself *Wan Smolbag*, meaning 'One Small Bag' in Bislama (Vanuatu's language), to show that a theatre group could go anywhere. Initially the group toured the country with one small bag of costumes, helping nurses, teachers and theatre groups to use drama to address social issues. It has grown over 25 years and expanded its activities to include environmental conservation, sports, reproductive and sexual health services, youth centres and more. WSB employs more than 140 people (full- and part-time) and more than 400 volunteers in Port Vila, Luganville and North Pentecost (WSB, 2016). WSB's participatory practices create community awareness, dialogue

and empowerment to tackle current and emerging social issues, including health and its social determinants. A 2015 [video](#) tells the WSB story and its evolution over 26 years from a community theatre group to a not-for-profit organisation, well known throughout the region.

WSB's mission involves:

- a. Creating awareness, dialogue and empowerment in using theatre, media, publications and open engagement and discussion with communities to enable open dialogue about issues such as discrimination due to gender, sexual orientation and disability.
- b. Providing direct assistance and support to people to improve their lives and wellbeing and to support them in making a positive contribution to society, such as in the youth centre services, through literacy, sports, arts, drama, dance, agriculture and nutrition.
- c. Facilitating and fostering collaboration and engagement among citizens and stakeholders, through activities such as community waste management for improved environments (WSB, 2016).

WSB uses creative activities, including drama/theatre and radio, TV and film media, publications (informative booklets, books, comic books and



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

DVDs), participatory workshops and peer education to communicate information, create awareness, build capacity and knowledge for action on key social issues in Vanuatu. These creative media activities facilitate discussion and reflection on sensitive and contentious issues, and help provide a platform for change (WSB, 2016). The actors involved in WSB plays undertake capacity building workshops as part of the preparations. With core group members, this includes interviewing people on the topics before playmaking starts and experts in the field briefing actors so that they can lead post-play workshops. In the youth drama, out-of-school youth come together for a play project. In a week or two of drama games, youth improvise around issues and experiences from their own lives, while a WSB writer present uses material from this in the final script. The youth also attend sessions with reproductive health nurses in WSB health services (described later) on the same premises as youth recreational and artistic services.

Local plays are usually followed by a discussion of the issues raised, as shown in a [video of the work](#) and publications distributed to communities after a play performance, or at the WSB clinics or in schools and other or educational facilities (WSB, 2016). WSB actively promotes social inclusion in its activities. In the Rainbow Disability Theatre, for example, community actors with a disability give performances on topics such as living with a disability, raising awareness and engagement on disability and related rights. The theatre company seeks to lead by example in its own practices, in employing a large number of female staff, in core actors having a right to vote on management issues and strategies around funding. The full-time professional group is selected by audition and members remain in their communities.

WSB developed a radio series, *Sarah's family*, to increase public knowledge on sexual and reproductive health, women's health and as a teaching tool for schools, nurses, aid post workers and rural training centres. Research in the community to assess attitudes and knowledge levels was used in storylines. Given the sensitive nature of the issues in *Sarah's family*, the first ten episodes were used to enable the audience to bond with characters and did not discuss sexual health (Walker, 2001). Initially, Radio Vanuatu rejected the proposal for the radio drama, because of the sensitivity of the issues. WSB then played it to focus groups in different villages who had no difficulty with it, which persuaded the local station to air it. It has since run for more than 300 episodes over eight years. As a follow-up, a

television series, '[Love Patrol](#)' produced by WSB is a soap opera. Initially intended to educate viewers about AIDS, it was first televised in Vanuatu and Fiji in 2007. Over time it has covered sex work, drug and alcohol abuse, corruption of authority figures and other issues. It is popular and is shown in Papua New Guinea and Australia, and in Fiji, where it is an official part of their Family Life syllabus in secondary schools (WSB, 2016).

The organisation complements these activities with *three WSB clinics* (Port Vila, Haulua and Luganville), community outreach and a *school-based peer education programme* in three Port Villa secondary schools on reproductive health. The clinics, all located at WSB youth centres, provide free and confidential family planning and testing and treatment of sexually transmitted infections. The youth centres run by WSB Theatre first started in 2006. WSB called a meeting of youth from surrounding settlement areas and asked what activities would youth like to see at a youth centre. Suggestions included 'elegant dancing' and training to be an airline pilot! WSB took what was feasible and popular, such as music, sport and hip-hop, and what they saw as useful work skills, such as computer classes and literacy work, and purchased land that enabled the construction of a sizeable multipurpose sports field adjacent to the youth centre. Having the clinics at the youth centres means that the youth access educational workshops through nurses and peer educators who provide information and outreach on family planning and reproductive health.

Much of WSB's participatory activity takes place outside the healthcare system. The youth centre activities build skills in sports, art, performance and creativity, literacy, computing and nutrition. Computer classes give young people access to computers that they would not ordinarily have (WSB, 2016). Several youth have gone on to jobs in the organisation. Twelve unemployed youth were trained in fire dancing and have for six years now been a leading tourist attraction in many hotels ([Vanua Fire](#)). WSB involves communities in acting on social determinants of health, such as waste disposal and sanitation, employment and education.

Following Cyclone Pam in 2015, the WSB youth centre prioritised agricultural activities to support the recovery of livelihoods in neighbouring communities. This involved distribution of over 4,200 seedlings, agriculture tutoring sessions on planting fast-yielding foods and providing free lunches. A breakfast programme for the WSB kids

literacy class introduced drought-resistant, protein-rich vegetables and legumes not commonly eaten in Vanuatu, including ochre amaranth, chick peas, pigeon peas and lentils (WSB, 2016). The Urban Nutrition Program is supported by a demonstration growing site that communities can visit, and WSB has worked with two communities to start similar sites with them. A resilience programme after Cyclone Pam made a portion of project funding available for the communities. Each community has a resilience committee which meets with all groups in the community to assess priorities that are brought to a full community meeting facilitated by WSB to agree on priorities for action (WSB, 2016).

Continuity of support has built trust, while consistency of work, strong relationships, a large number of staff and volunteers and joint work with a range of other agencies in Vanuatu have been a resource base and opened possibilities for a range of areas of work. WSB has sustained continuity through multiple funding sources and links across interventions. WSB's use of a variety of media and techniques create safe spaces for people to discuss sensitive issues, particularly as media are based on real experiences. At the same time cuts in aid funding and limited payment from media houses using WSB products raise insecurity of funding and demand for new avenues of funding.

Outcomes from the work

Beyond the immediate benefits such as those related to the services, meals, performances and environmental improvements, the work has also yielded full or part time work for youth inside and outside WSB, safe spaces for youth at a vulnerable time in their lives; and writing and reading instruction for out of school youth. WSB has been able to influence institutional and social change within the health sector and other institutions, in youth reproductive health services, food offered in school stores; support for turtle monitoring; recognition of gay rights; and in water and sanitation practices (WSB, 2016). The literacy program has resulted in youth returning to school, and efforts to improve livelihoods have focused attention on upstream factors, such as sustainability of crops grown and household agricultural practices. The programme has led to changed social structures for village participation in some villages:

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 WSB, 2016:48).



Areas for shared learning

One key insight is the role of drama and places like the youth centres to create safe spaces for raising awareness, enabling dialogue and reflection on sensitive and potentially stigmatising issues, especially using WSB's participatory approach to developing scripts based on community experiences and concerns.

- Linking spaces, like the youth centres and the clinics, opens opportunities to engage around wider health and wellbeing issues and personnel.
- A flexible approach in awareness raising and adaptability has enabled social participation, responding to issues prioritised by communities, including after emergencies like Cyclone Pam. Being flexible in responding to new community circumstances, has enabled new activities and resources.
- A sustained presence has built community trust. This has been possible because of the innovative approaches used, linking resources from different sources to emergent opportunities, like the purchase of land for the sports field and youth centre site.

WSB's inclusive and participatory approach to developing scripts and workshop materials for any activity could be adapted elsewhere, noting that flexibility in terms of when and how health messages are introduced is a key part of the success. Plays that are only seen as 'messages' are, in contrast, alienating. Its focus on root causes linking health problems like malnutrition or diabetes to solutions like fast-yielding crops could also be adapted elsewhere.

Many enabling factors for change are, however, beyond the communities' control and demand support from a more equitable government. Further, the practices of the organisation are also important. Efforts to support staff retention work better when employees are involved in strategic discussions and decisions, by applying a participatory approach to planning, decision-making and organisational growth. The organisation has given much needed work in poorer communities and has enabled WSB to draw on a pool of people to respond to requests for different areas of work in communities. Many of the jobs created by WSB are within the arts industry, generating not only communication on health and governance, but also a power that comes from role models in local communities rather than foreign artists.

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Links to videos

- a. <https://www.youtube.com/watch?v=n0DEo2ykpPs> - Sef Haos (TCPam doco)
- b. <https://www.youtube.com/watch?v=EEYCsC-G2kc> - Wasen Han (Sanitation Play)
- c. <https://www.youtube.com/watch?v=Zeixy82r--s> - Yumi Go Kale Trailer
- d. <https://www.youtube.com/watch?v=7CUe7opPPs8> - Yu no save ronwei long lav
- e. Love Patrol <http://www.youtube.com/watch?v=OvqLBJKSOy4&list=PL63FC35F79E236009> (note all 7 series available on you tube)
- f. <https://www.youtube.com/watch?v=GCQdkpQRvfw> - Ae blo hem i blaen (Rainbow Theatre)
- g. <https://www.youtube.com/watch?v=dwaWBmiHJAw> - Kakae Rat (Recorded live at Santo)
- h. <https://www.youtube.com/watch?v=jeiGbkZOAmA> - Tijim Hem (Violence verbatim play)

Appendices:

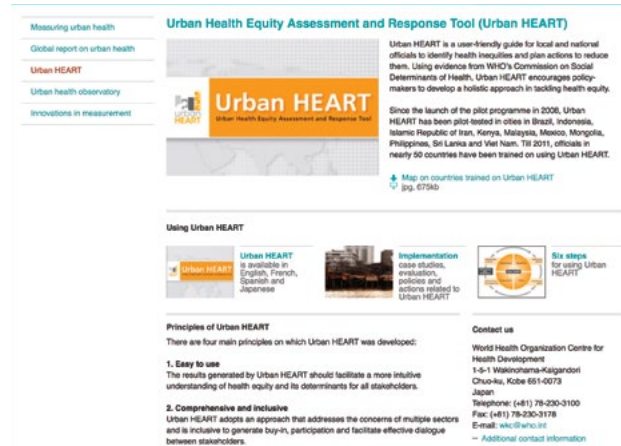
A1: Urban Health Equity Assessment and Response Tool (Urban HEART)

Urban HEART is a user-friendly guide for local and national officials to identify health inequities and plan actions to reduce them. The tool enables local communities, programme managers, and municipal and national authorities to:

- better understand the unequal health determinants, unequal health risks and unequal health outcomes faced by people belonging to different socioeconomic groups within a city;
- use evidence when advocating and planning health equity interventions;
- participate in inter-sectoral collaborative action for health equity;
- apply a health equity lens in policy-making and resource allocation decisions.

Using evidence from WHO's Commission on Social Determinants of Health, Urban HEART encourages policy-makers to develop a holistic approach in tackling health equity. Since the launch of the pilot programme in 2008, Urban HEART has been pilot-tested and used in numerous cities globally. There are four main principles on which Urban HEART was developed:

1. **Easy to use:** The results generated by Urban HEART should facilitate a more intuitive understanding of health equity and its determinants for all stakeholders.
2. **Comprehensive and inclusive:** Urban HEART adopts an approach that addresses the concerns of multiple sectors and is inclusive to generate buy-in, participation and facilitate effective dialogue between stakeholders.
3. **Operationally feasible and sustainable:** Urban HEART should be implemented through existing institutional mechanisms where possible. As much as possible, data should be collected from existing information systems and regular reports.
4. **Evidence linked to actions:** Evidence generated by Urban HEART should clearly link to feasible strategies and actions to reduce health inequities.



Urban HEART can be implemented in [six simple steps](#). The steps are designed to be followed in order. Some steps may need to be revisited and repeated as Urban HEART is intended to be a cyclical process:

STEP 1: Build an inclusive team

STEP 2: Define your local health equity indicator set and benchmarks and targets for evaluating performance

STEP 3: Assemble relevant and valid data relying as much as possible on use of available datasets.

STEP 4: Generate evidence in easy-to-read charts (the MATRIX and the MONITOR) to illustrate health inequities in your city.

STEP 5: Assess and prioritize health equity gaps and gradients through participatory careful and deliberative discussion with all stakeholders that integrate their perceptions and concerns, including on the causes and consequences of inequities.

STEP 6: Identify the best response, taking into account the relative strengths of potential interventions, their potential impacts on equity, community preferences, available resources and alignment with existing government priorities and finalize a response plan.

A [user manual](#) (in diverse languages) supports users to implement the steps.

See also the Ecuadorean Ministry of Health [Programa de Municipios Saludables Program Guide](#).

A2: CDC's Healthy Communities Program: Community Health Assessment and Group Evaluation (CHANGE). Building knowledge to prioritize community needs

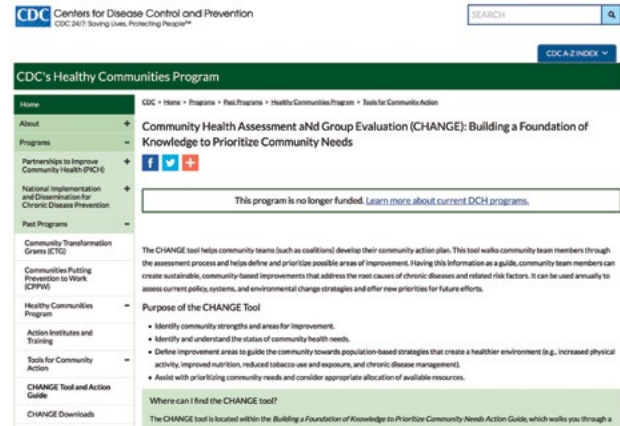
The CHANGE tool helps community teams (such as coalitions) develop their community action plan. This tool walks community team members through the assessment process and helps define and prioritize possible areas of improvement. Having this information as a guide, community team members can create sustainable, community-based improvements that address the root causes of chronic diseases and related risk factors. It can be used annually to assess current policy, systems, and environmental change strategies and offer new priorities for future efforts.

The CHANGE Tool aims to

- Identify community strengths and areas for improvement.
- Identify and understand the status of community health needs.
- Define improvement areas to guide the community towards population-based strategies that create a healthier environment (e.g., increased physical activity, improved nutrition, reduced tobacco use and exposure, and chronic disease management).
- Assist with prioritizing community needs and consider appropriate allocation of available resources.

It allows local stakeholders to work together in a collaborative process to survey their community; offers suggestions and examples of policy, systems, and environmental change strategies and provides feedback to communities as they institute local-level change for healthy living.

The CHANGE tool is located within the Building a Foundation of Knowledge to Prioritize Community Needs Action Guide, which walks you through a step-by-step process for completing the tool. In addition, this Action Guide provides resources for team building along with worksheets, templates and Excel Files to support the data collection and review processes. For each sector, this tool includes specific questions to be answered in the areas of demographics, physical activity, nutrition, tobacco, chronic disease management, and leadership. In addition, the school sector includes questions related to the school district and after-school program.



- Community-At-Large Sector includes communitywide efforts that impact the social and built environments, such as improving food access, tobacco use and exposure, or personal safety.
- Community Institution/Organization Sector includes entities within the community that provide a broad range of human services and access to facilities, such as childcare settings, faith-based organizations, senior centers, boys and girls clubs, YMCAs, and colleges or universities.
- Health Care Sector includes places where people go to receive preventive care or treatment, or emergency health care services, such as hospitals, private doctors' offices, and community clinics.
- School Sector includes all primary and secondary learning institutions (e.g., elementary, middle, and high schools, whether private, public, or parochial).
- Work Site Sector includes places of employment, such as private offices, restaurants, retail establishments, and government offices.

CHANGE is a data-collection tool that allows community team members to track progress across a five-point scale, so incremental changes can be noted. As problem areas are identified, health-related policies are implemented, and systems and environmental change strategies are put in place, team members can document the community-level changes.

A3: Participatory reflection and action approaches

Processes of participatory reflection and action (PRA) or participatory action research (PAR), imply that those most directly affected by conditions affecting health and health service performance actively participate in data gathering, analysis and in debating policy reforms and monitoring their implementation. Participatory action research (PAR) has several key features:

- Those who are usually the subjects of research or those who experience a problem are the active researchers and agents of change in PAR. Those affected by a problem are the main source of information and the lead actors in producing and using the knowledge for action and change. The PAR facilitator is a trusted person who can facilitate the process.
- Secondly, it involves developing, implementing, and reflecting on actions as part of the research process to build new knowledge. PAR seeks to understand and improve the world by changing it, where those affected by problems collectively act and produce change and learn from it to produce new knowledge. PAR is transformative.

PAR does this through a spiral of repeated cycles, where the experience of, and learning from action and transformation of reality becomes the input to a new round of collective self-reflective inquiry. The PAR process follows steps to:

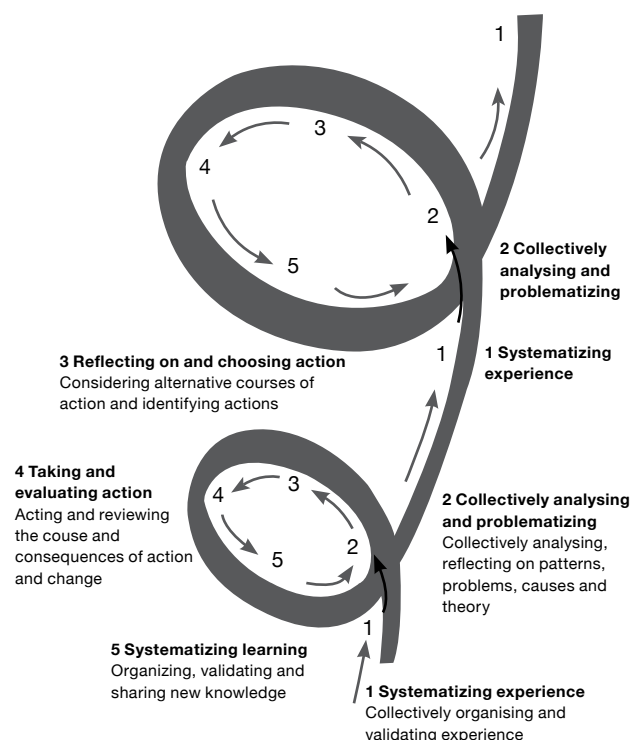
1. Systematize local experience, to organize people's own shared lived experience and situation.
2. Collectively analyse this experience and identify problems and their causes.
3. Reflect on the experiences and views of problems and their causes to choose actions that will address the problems.
4. Take action, and review the changes produced to learn from the actions.
5. Use the learning to produce new knowledge.

Each repeat of the spiral draws in wider relevant knowledge to further inform analysis and action. In doing so, we construct knowledge from lived experience and action; and bring this into a collective domain. This needs to be done with rigour so that the learning and knowledge can be systematized and shared

Health systems are complex social systems that reflect and affect the values, norms, and institutions in society. Participatory action research (PAR) draws on the paradigms of critical theory and constructivism, enhances people-centred health systems and may use a range of qualitative and quantitative methods. Participatory approaches seek to transform the role of those usually addressed as the subjects of research, to involve them instead as active researchers and agents of change. Participatory approaches have been used to study and act on a range of health systems issues -from action on social determinants of health, through community health outreach, to improving quality of services.

See for further information Loewenson R, Laurell AC, Hogstedt C, D'Ambruso L, Shroff Z (2014) *Participatory action research in health systems: a methods reader*, TARSC, AHPSR, WHO, IDRC Canada, EQUINET, Harare, www.equinet africa.org/bibl/docs/PAR%20Methods%20Reader2014%20for%20web.pdf

Figure A3: The cyclical and spiral process of participatory action research



Source: Loewenson et al., 2014

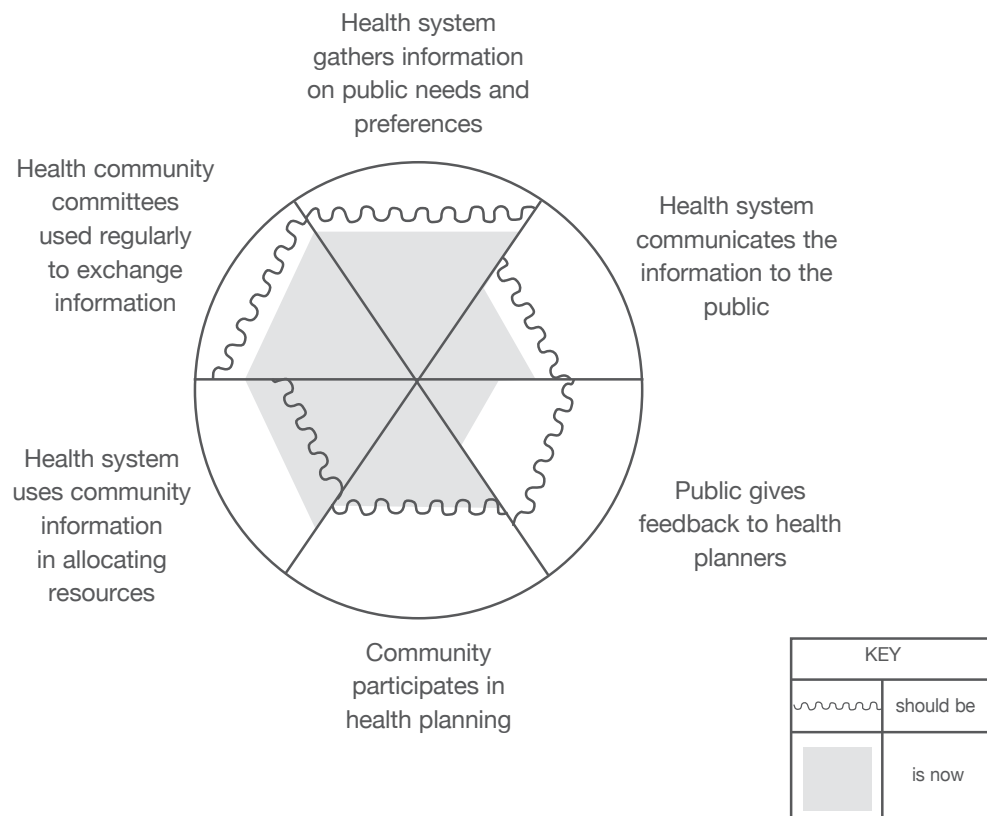
A4 Methods used for participatory evaluation of progress

Text quoted from Loewenson R, Laurell AC, Hogstedt C, D'Ambruso L, Shroff Z (2014) *Participatory action research in health systems: a methods reader*, TARSC, AHPSR, WHO, IDRC Canada, EQUINET: Harare www.equinet africa.org/bibl/docs/PAR%20Methods%20Reader2014%20for%20web.pdf

The wheel chart can be used to collectively review a range of dimensions in situations, processes or outcomes that provide a quantitative means of assessing change when repeated over time. Participants work in groups as relevant to the process. These may be social groups with different experiences of the process or outcomes, for example. They draw a blank wheel chart on flipchart paper and mark each 'spoke' on the wheel with points from 1 to 5, with 1 nearest the centre. Each segment is labelled with the feature under inquiry, such as the outcomes or process changes intended, dimensions of participation, and so on. Participants collectively assess the level of the outcome. For each segment of the wheel, they discuss the situation or outcome and decide on the level.

Once they've decided, they shade the area of the segment to show this. The wheel chart can also be used to reflect the level they intend for an outcome, or what the situation should be. This can be marked in each segment with a squiggly line (as in the diagram). The space between the two markings creates a clear visual picture of the gap between what the situation should be (squiggly line) and what it is now (shaded area). The levels may also be quantified, to give a measure of the difference. After the chart is completed it is 'interviewed'. This involves the groups discussing the differences and similarities between each of the wheel charts or, if the charts are repeated over time, the differences over time and what is driving – or blocking – the change. If the wheel chart is used to measure progress over time, the shaded area would reflect the situation at the start and future squiggly lines or new charts would document any changes. In all cases the chart is used as a basis for discussion to explain what changes have taken place, what is causing them and what can be done about them. The ratings and interpretation of the collective group are recorded.

Figure A4: Example of a wheel chart:



The 'progress marker' method was adapted locally from an Outcome Mapping approach (Earl et al., 2001) 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' (higher level or improved situation) and
- 'love to see' (more ideal situation).

As shown in the example below, these markers are used to monitor and discuss progress and review the strategies used, particularly for the like to see markers, noting that the 'love to see' progress markers would probably take longer to be achieved.

Table A4: Example of progress markers from Lusaka

Problem: Inadequate Information And Communication On Planning Progress							
EXPECT To See Progress Markers		Progress Monitoring					
		CLINIC A			CLINIC B		
		1	2	3	1	2	3
1	HC staff meetings with CMs having schedules, agendas & minutes		Started/Ongoing	Done	Done	Done	Done
2	HC staff & CMs disseminating or sharing information on planning and any other current issues		Started/Ongoing	Done			Done
3	HC giving CMs feedback on planning activities and any other current issues as soon as it is received		Started/Ongoing	Done	Done	Done	Done
4	HWs & CMs respecting each others views during meetings & discussions		Started/Ongoing	Done	Done	Done	Done
5	Participants who attended the 2007 PRA orientation workshop sensitizing or sharing the information with their immediate workmates and colleagues.		Started/Ongoing	Done	Done	Done	Done
LIKE To See Progress Markers							
1	HC providing necessary materials & simplified guidelines to CMs on planning process		Started/Ongoing	Done			
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			Done	Done	Done	Done
LOVE To See Progress Markers							
1	75% of HWs conversant with planning process						

Key: Done Started/Ongoing Not Started/not done

Source: Modified from Mbwili Muleya et al., 2008

Reference:

Earl S, Carden F, Smutylo T (2001), *Outcome mapping: building learning and reflection into development programs*, International Development Research Centre: Ottawa.

See for further information Loewenson R, et al. (2006) *Participatory methods for people centred health systems A toolkit for PRA methods*, TARSC, Ifakara: Harare

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

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

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

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

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



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