Annotated bibliography on country experiences of social participation and power in health systems

Sarah Simpson, Rene Loewenson
Training and Research Support Centre

May 2016

Table of contents

1. Background

There is growing recognition that health systems need to involve people in deciding, acting on and contributing to improvements in health and wellbeing and in organising the public information, relationships, leadership and capacities to support this. This recognition has raised interest in the conditions, mechanisms, processes and tools used in health systems for authentic participation by autonomous, competent and empowered actors. In 2016/17, Training and Research Support Centre (TARSC) is implementing work, with partners, to gather evidence on *promising practices in and models of* authentic community participation, power and decision making in health systems from selected high-, middle- and low-income countries; to identify and share learning for adaptation in local sites in the United States of America (USA). In the *process* of the work, it will connect sites in the USA with those implementing promising practices in other countries, to build dialogue and networking across institutions and enable ongoing peer-to-peer exchange and support on approaches and practices that can be adapted locally, in the USA and in other countries.

This annotated bibliography has been compiled as a resource and as one input for selection of country case studies. It organises evidence from published papers on measures for and experiences of social power and participation in health, health systems and social determinants of health internationally, through a desk search/review of largely but not exclusively peer reviewed published literature and reviews. As a resource to inform case studies outside the USA, it did not include papers on social power and participation in health, health systems and social determinants of health *in* the USA. Both 'community' and 'social' are used in referring to participation by groups of people in health systems. Community is a widely used term to describe people living and interacting in particular geographical locations or with common/shared interests, identity, goals or occupation. It can be used to refer to people living in the geographical/catchment area of a specific health centre. The term social is used to refer to society and its organisation, at a wide level. It is generally used descriptively to cover the generic inclusion of all levels of society, individuals, family, community and the general public. We recognise the use of both terms and have included both in our searches. In the introductory text these definitions are applied.

The evidence in the annotated bibliography aims to include available information on country experiences on:
a. The contexts for and the models, measures and resources applied in social power and participation in health, in health systems and in relation to the social determinants of health (SDH);
b. The mechanisms, methods and tools used for community participation and decision making at the level of primary care and local governance (local councils);
c. The enabling factors and challenges faced in implementing approaches for community participation, power and decision making in health and in the inclusion of the voice and agency in health systems decision making of those most at risk of poor health;
d. The process and health outcomes/impacts measured; and
e. The learning on what has supported or blocked promising practice, including in terms of meso-level measures and resources.

A separate paper produced in the project[1] from a desk review of relevant literature was used to outline the concepts and definitions applied and a framework for the organisation of evidence in the work. Initial evidence from key informants in sites of work on social power and participation in the USA also informed attention given to some focused areas of social participation in health systems in the bibliography.

---

[1] Loewenson R (2016) 'Understanding and organising evidence on social power and participation in health systems,' April 2016, Training and Research Support Centre

2. Methods

A search was implemented of published literature on social participation and power in health systems using the terms outlined below. The searches were implemented in three major online databases, viz PubMed/Medline; Google Scholar and SciELO. Searches included documents from 2005 to current in English, French, Portuguese and Spanish, for all countries (outside the USA). A template was developed for data capture drawing on the project framework (Loewenson, 2016) that included:

- Relevant context issues.
- The nature of the community and specific social actors involved in the work.
- The dimension of the health system within which participation is being organised, using as key areas: health information and health literacy; identifying and assessing health needs and priorities; health planning and budgeting; health policy deliberation; designing, implementing and co-ordinating health action; and oversight, monitoring, evaluation and review of health services/actions.
- The goals, form and organisation of participation.
- Impacts of factors affecting and meso-level mechanisms supporting participation.

The template was used to identify key words for the searches.

In search 1, combinations of the following terms were used:

- community OR social OR consumer OR citizen OR public OR civil society **AND**
- participation OR power OR involve OR voice OR agency **AND**
- health OR system OR service OR intersectoral action OR planning OR financing OR information **AND**
- internet OR m-health* OR online OR social media
- **NOT** hospital

(*m-health refers to mobile and e-health applications)

Responding to key areas of interest raised by key informants in the USA, search 2 focused on country experiences and practices on:

- community health workers/health promotoras*/village health workers/community health promoters in support of social participation in health systems;
- social participation and power in relation to mental health, opioid addiction and on integration of services (using 'participation' OR 'power' OR 'codetermin'* AND 'mental health' OR 'opioid addiction' AND 'services' OR 'systems' OR 'intersectoral action'); and
- social participation and power in relation to integrated health services (using 'participation' OR 'power' OR 'codetermin*' AND integrat* AND 'services' OR 'medical services' OR 'health services' OR 'health systems' AND 'social services' OR 'social sector').

(*promotoras refers to community health workers in Spanish)

The authors identified additional papers from citations relevant to the work included in the papers for review. Both authors reviewed the abstracts of the papers sourced for their relevance to the inclusion criteria. Papers were excluded if they were:

- not available in full in one of the included languages, viz: English, French, Portuguese or Spanish;
- on practice in the USA;
- duplicates already sourced from another online library; and
- earlier versions of an updated paper by the same authors already included, where the same concepts were already covered.

The full set of 1,772 papers from the searches was then sourced. The first author reviewed those for search 1 and the second author reviewed those for search 2. A final set of 255 papers was included at that stage (see *Table 1*). The template used for capturing evidence for the bibliography was developed from the separate background framework document for the project noted earlier. In the process of producing and editing the bibliography entries in the template, papers queried as not meeting the inclusion criteria or not yielding adequate evidence in the template were again reviewed by both authors and further exclusions made. A final set of 130 papers is included in the annotated bibliography, shown in the reference list in *Section 4.*

Table 1: Papers included in searches

Online Library	# papers included from the title search	# papers included after title/ abstract review
Search 1 for		
PubMed/Medline	412	88
Google Scholar	725	96
Scielo	319	28
Sub-total	1,456	212
Search 2 using specific terms		
PubMed/Medline	173	37
Google Scholar	88	5
Scielo	54	1
Sub-total	315	43
Total	1,771	255

The summaries included in the bibliography were prepared from a review of the full paper in line with the template described earlier. As drawn from the framework (Loewenson, 2016) the bibliography organised papers into sub-sections within the key health system dimensions below, based on their primary focus on participation. These and any other health system areas covered in the papers were noted in the summaries in a line on 'health system areas':

 a. Community health literacy, public information and the use of community knowledge on health.
 b. Assessment, identification and prioritisation of health needs.
 c. Health planning and decision making on spending priorities, resources and budgets.
 d. Policy deliberation and formulating strategic policy direction.
 e. Co-design, co-ordination and co-production/implementation of health actions, and
 f. Oversight, monitoring, evaluation, review and improvement of services/actions/quality, including measures of social outcomes.

Two further subsections included papers whose primary focus was on
 g. Impacts, enablers of and barriers to participation in health systems, and
 h. Measures and meso-level mechanisms supporting community and system resources and capabilities for participation.

The type of community was broadly categorised in a line on 'community', particularly noting whether the social involvement was as general public, residents of specific catchment areas (noting whether rural or urban), specific social groups (young people, people with a disability, women etc.), service users, community representatives, members of committees or as community volunteers or health workers.

It is acknowledged that much work on social power and participation is *not* published in the sources used, and the project is also using other sources of evidence from networks and key informants to identify countries for follow-up case study work. At the same time the annotated bibliography has compiled a useful body of published evidence. It provides url links to full papers for those that are open access and links to abstracts where the papers are not open access.

3. Annotated bibliography: Country experiences of social participation and power in health systems

3.1 Participation in health literacy and health information

Citation: Alazab R, Elsheikh R, Kamal I (2008) 'Child-to child health as a model of community participation for combating Avian Influenza in selected slum and rural areas, Egypt.' APHA 136th Annual Meeting October,25-29, 2008, San Diego, CA
URL:https://scholar.google.se/scholar?q=Childtochild+health+as+a+model+of+community+participationfor+combating+Avian+Influenza+in+selected+slum+and+rural+areas%2C+Egypt&btnG=&hl=sv&as_sdt=0%2C5
Country: Egypt
Community: Rural and urban residents, children
Health system area: Health literacy/promotion/information
Summary: Avian influenza (AI) (H5N1) is an emerging public health threat in Egypt, mainly affecting children and women. Urban slum and rural area households raise birds in cages, and sometimes in their houses and children play with the birds or sleep inside houses beside the birds. A child-to-child approach implemented since 1978 applies an educational process linking children's learning with taking action to promote health and wellbeing of themselves, their families and their communities. This approach was applied to control of AI with 650 children selected with input from community development associations from slum areas of Cairo and rural villages in Kalubia and Giza governorates, supported by community-based associations, universities and international non-governmental organisations. The children were trained on the definition, modes of transmission, prevention, symptoms, medical treatment for AI, what to do on finding a dead bird, sanitation methods, and contact with emergency units. The training also corrected common misconceptions. A train the trainer approach was used and child trainers used participatory games, drawing, stories and group discussion. In training implemented on three consecutive days every week for four weeks, children were invited to share their experiences and to make recommendations on their role. Quality assurance was regularly implemented to ensure that the children's knowledge was up to date. Surveillance of AI cases was established in selected areas. The intervention was reported to lead to a significant improvement in the knowledge, attitude and practices of the children involved and no AI cases were recorded in areas where the children were trained and had disseminated their health message to their communities. The quality assurance of this programme identified obstacles during intervention, managed in a follow up programme. The intervention indicated that children can play a role in AI prevention in rural and slum areas.
Keywords: Health education; children; Avian influenza; prevention; Egypt

Citation: Amerson R (2013) 'Contributing to family health using a promotora programme in Guatemala,' *Journal of Community Engagement and Scholarship 6*(1): 3.
URL: http://search.proquest.com/openview/63f714e04cfcbdef2ef3a43da835f291/1?pq-origsite=gscholar
Country: Guatemala
Community: Indigenous community; CHWs
Health system area: Health literacy/promotion/information; Implementing and co-ordinating health action; Enablers and barriers in health action
Summary: Pneumonia and diarrhoea can be addressed with early detection and education. However, low rates of literacy and high rates of poverty impact the ability of parents in rural Guatemala to recognise and seek treatment for their children. This article describes the health promotion programme implemented to address these and other common health problems in a highly, marginalised group, that is indigenous Mayan women in the Highlands of Guatemala. Both extreme poverty and a lack of education in a male dominated society prevent women from having voice or ability to make decisions which can positively influence the health of their family and community. A promotora ("promoter of health") programme involves indigenous women who are leaders within the indigenous community, in Latin American countries. This approach builds on cultural norms and expectations that women are care providers at home. The promotora understands the local dialect and recognises the cultural implications that influence how sensitive issues are discussed. Based on local health statistics and interviews with members of the community, a plan was established to teach women within the community about: basic hygiene, sanitation, vital signs, first aid for wounds and burns, signs and symptoms of dehydration,

directions for making oral rehydration solution, and how to differentiate between signs of pneumonia versus the common cold. Based on input from the local lay midwife and members of the community, 11 women were selected to attend the first health education class. The teaching programme was adapted to the women, such as to teach those women had never seen a watch before how to use it, so that they could count respirations. It included space for the women to teach the teachers e.g. they shared their knowledge about use of folk medicine to treat common ailments, building on the concept of reciprocity. The authors considered the programme to empower women in the community by giving them the knowledge and skills to improve their family and community health. They identified understanding the local cultural context and living conditions that influence healthcare decisions and involving community members in the decision-making process as important. Other research in the same region has demonstrated the effectiveness of promotora programmes, with an evaluation of a separate promotora provided education programme with 39,000 women finding a positive impact on health and social well-being. The authors recommend that the cultural aspects of the promotora programme be adapted to meet health needs of immigrant populations in the USA.
Keywords: Health education, promotion; promotora; community health worker; Guatemala

Citation: Batten LS (2008) 'Lady, is this civilisation?': a case study of community participation in a health development programme in Aotearoa New Zealand.' A thesis presented in fulfilment of the requirements for the degree of Doctor of Philosophy in Development Studies at Massey University, Palmerston North, New Zealand.
URL: http://mro.massey.ac.nz/bitstream/handle/10179/886/02whole.pdf?sequence=1
Country: New Zealand
Community: Indigenous community
Health system area: Health literacy/promotion/information; Implementing and co-ordinating health action
Summary: This paper explored participation within a small local health promotion programme – 'Grab a Bite That's Right' (GABTR) – in the New Zealand Ministry of Health primary health care strategy for healthy diets. The GABTR was unique to the Whanganui city and region, which has a higher than national level share of over 65 year olds, of those identifying as Maori (indigenous people of New Zealand), of unemployed, low income people, and lower than national averages of IT access and household spending on food. The programme aimed to increase the fruit and vegetable intake of Maori and Pacific peoples and those on low incomes by improving affordability, availability and accessibility. The authors noted the need to link with different and evolving understandings of the Treaty of Waitangi, biculturalism, the interaction of determinants of health, and the responsibilities of the health sector. Participation by Maori within the health sector is legislated by the government and necessitated by Maori. In 2005, the Ministry of Health released *Health and participation: An active agenda* providing strategic advice about the active participation of communities and specifically in relation to food and nutrition. Two projects were selected: a community-led project involving distribution of thousands of free heritage variety plants; and a health services instigated community gardens project. Community members' participation in both projects was voluntary, but differed greatly. The plant distributions had widespread appeal, but the community gardens faltered. In the plant distribution, primarily led and driven by the community, there was a perceived benefit in receiving free plants. The community garden project, led by the health sector, had less immediately apparent personal benefit and participation motivated by needs, values and interests. Both programmes faced challenges in defining and reaching target communities, in sustaining longer term engagement and in managing the different views of participation from health workers and community members. While the GABTR was well-resourced, bureaucratic delays in making or advising of decisions affected participation. For example, delayed decisions on funding for the gardens undermined community willingness to prepare gardens for planting.
Keywords: Health promotion; diet, indigenous communities; New Zealand

Citation: Bryant J, Saxton M, Madden A, Bath N, Robinson S (2008) 'Consumer participation in the planning and delivery of drug treatment services: the current arrangements,' *Drug and alcohol review* 27(2):130-7.
URL: www.tandfonline.com/doi/abs/10.1080/09595230701829397
Country: Australia
Community: Health service users

Health system area: Health literacy/promotion/information; Enablers and barriers in health action

Summary: This is a study of consumers (*term used*) and providers from pharmacotherapy, residential rehabilitation or residential detoxification services in 3 Australian states New South Wales (NSW), Victoria and Western Australia. Although participation has been broadly endorsed by government at state and national levels in Australia, there are few examples of consumer participation policies in Australian drug treatment services. The 2004-2009 National Drug Strategy refers to consumer involvement but does not outline a framework to guide the implementation of consumer participation. Certain consumer participation activities can be required for service accreditation but this is not consistent across Australia. The NSW government is an exception with its "Guide to Consumer Participation in NSW Drug and Alcohol Services" encouraging consideration of consumer participation in such services. Consumers and service providers from pharmacotherapy, residential rehabilitation or detoxification services were interviewed. The study applied a typology of participation drawing on Arnstein's 1969 ladder, using examples of participation activities in service planning and delivery in Australian health services. Types of activities are organised by degree of participation ranging from low-level information provision and consultation to high-degree shared decision-making. The study found that existing consumer participation activities were largely 'low'-involvement activities, providing information to or receiving information from consumers. Activities where consumers participate by shared decision-making with providers were uncommon. Many service providers reported participation activities, but consumers reported very little knowledge of these activities at the service they attended: only half of the consumers attending the service knew about the service's complaints process and fewer knew of the existence of suggestion boxes. A large proportion of services reported having a consumer charter of rights that a large proportion of consumers knew. This may be because services require people to sign an agreement on entering treatment programmes that lists consumers' rights and responsibilities. A minority of services included a consumer representative on decision-making committees, demonstrating consumer involvement in shared decision-making to be feasible in drug treatment settings. Despite the limited number of high-level participation activities, the findings were viewed as encouraging given the limited State or Commonwealth policy directive and funding allocated to participation in drug treatment services. It was noted that meaningful participation needs to include measures to inform consumers of available opportunities for participation.
Keywords: Health information; consultation; Australia.

Citation: Gray K, Elliott K, Wale J (2013) 'A community education initiative to improve using online health information: participation and impact,' *Informatics for health & social care* 38(3):171-81.
URL:www.tandfonline.com/doi/abs/10.3109/17538157.2012.705201?journalCode=imif20
Country: Australia
Community: General public
Health system area: Health literacy/promotion/information
Summary: In 2008, a team of clinicians and consumer (*term used*) representatives from a large metropolitan hospital initiated a project to provide free interactive workshops for the public at a public library in Melbourne, with groups of up to 15 people participating for 2 hours in a computer training room. The workshop aimed to increase participants' ability to find and use online evidence-based health information. The long-term outcomes were to improve participants' communication with healthcare providers and their participation in healthcare decision-making. Australia is among the top five nations using major health information websites although online health information use is reported to vary from 17-79% of Australians depending on socio-economic status. Prior to the workshops, 85% of participants had sought online health information and assistance in dealing with health or medical issues. Evaluation of the workshops found that they made a strong positive difference to participants' online health information knowledge, skills, attitudes and behaviours and to their perceptions of the impact of using online health information on future health. Women reported finding the workshops more relevant than men. The greatest anticipated behavioural change was on asking a doctor new questions, followed by an overall approach to maintaining health, and coping with a chronic disease or managing pain. Participants born in Australia and or on middle incomes were more likely to anticipate changes in using online health information than those born overseas or in lower income groups. The study suggests, however, that the level of education may predict online health information use more powerfully than income level. Educational initiatives need to be

customised to make a difference to different socioeconomic, age and or cultural groups. The results suggest that community education about online health information has the potential to contribute to better health. However, further in-depth research in natural settings and longitudinal studies are needed to identify the residual effects of workshop participation and the impact of online health information on the health behaviours of other social subgroups.
Keywords: Health literacy; online information; internet; Australia

Citation: Findley SE, Uwemedimo OT, Doctor HV, Green C, Adamu F and Afenyadu GY (2013) 'Comparison of high- versus low-intensity community health worker intervention to promote newborn and child health in northern Nigeria,' *International Journal of Women's Health 5*: 717-728. 10.2147/IJWH.S49785 [doi]
URL: www.ncbi.nlm.nih.gov/pubmed/24194649?dopt=abstract
Country: Nigeria
Community: Women and children; CHWs
Health system area: Health literacy/promotion/information; Implementing and co-ordinating health action
Summary: In 2008, a high-intensity programme to improve maternal, new-born, and child health (MNCH) was trialled in three states of Northern Nigeria. The 3 programme intervention zones received government-supported health services *plus* integrated interventions at primary health care posts and development of community-based service delivery with a network of community volunteers and community health workers (CHWs). This study looked at the relative effectiveness of the low-intensity volunteer approach versus the more intensive approach with CHWs before scaling up. CHWs or volunteers educated women about signs of and responses to their or their infants' health problems. Community volunteers were recruited and trained for outreach and social mobilisation in each community. They used community discussion groups, jingles and other audio-visual cues for education. A cascade model of community based training involved core trainers training community volunteers, who in turn trained new volunteers. Community discussion groups addressed barriers to access and affordability of MNCH services and set up strategies such as blood donor groups, community emergency transport schemes and a mother's helper system involving peer exchange. In 2010 the programme developed a small cadre of CHWs who provided primary health services directly to families through rotating visits or by living in the communities. The CHWs were recruited from unemployed but previously trained Junior Community Health Extension Workers, who were given an additional 2 weeks training and toolkits. In 2011, they were active in 25 communities, all of which also had community volunteers supporting their work through community education and mobilisation. The study assessed the relative effectiveness of a low-intensity volunteer approach versus the more intensive community-based service delivery and CHW approach, using stratified household surveys at baseline (2009) and follow-up (2011) of new-born and ill child care practices. The evaluation found that community volunteers and CHWs together improved new-born and sick child care. The low-intensity approach with community volunteers appears to have been as effective as the higher-intensity community-based service delivery and CHW approach for several health outcomes, such as for home care for children with fever or cough. The main difference in high-intensity sites was in mothers learning to care for sick children from the CHWs.
Keywords: Health education; maternal and child health; community volunteers; CHWs; Nigeria

Citation: Kieler B (2008) 'Community Participation in Health, Safety, and Development Projects in South India.' Final report for Fulbright-sponsored research project in India, Fulbright Programme, New Delhi.
URL: www.researchgate.net/profile/Bruce_Kieler/publication/271504559_Community_Participation_in_Health_Safety_and_Development_Projects_in_South_India/links/54c91e800cf25087c4ec6474.pdf
Country: India
Community: Rural residents
Health system area: Health literacy/promotion/information; Assessing health needs and priorities; Implementing and co-ordinating health action;
Summary: Gaining the participation of multiple communities with varying levels of understanding of disease processes by facilitating active community participation in coalitions and advisory groups is identified to foster a "culture of prevention" in southern India. The paper presents several examples of community participation in southern India used in the formulation of health plans, safety plans, and community development projects. A number of examples are detailed,

one of which is the YR Gaitonde Centre for AIDS Research and Education in Chennai, which aims to respond to the needs of people not currently receiving care and support on HIV, and to prevent and reduce domestic violence in slum areas. Community participation takes place through review and advisory boards and in the training (in 2003) of men and women in different aspects of reproductive health and domestic violence, who graduate as Community Popular Opinion Leaders and support further community engagement. India's Disaster Management Authority is developing a set of guidelines to create public awareness, evaluate risk and vulnerability and involve the community in planning evacuation and post-disaster management structures. This includes community involvement in preparing hazard maps, escape routes and evacuation plans. Other projects reviewed were LAMP NET job skills training for people with disabilities, the Village Development Society community development in the Dalit communities, the Servites Net for empowering people with disabilities, and the Hope Foundation HIV/AIDS care and education. Community participation is extensively used in various health, safety, and community development projects in southern India, is apparently well accepted and is reported to have improved health and safety. While community participation was found to be successfully used for HIV prevention, care and treatment, and in health promotion, it was also identified as having potential in malaria control, environmental safety, TB, diabetes and bird flu education and control. The authors recommend establishing citywide and regional public interest groups to advocate for community participation in health, safety and development planning.
Keywords: Health promotion; public health; participation, volunteers; planning; India

Citation: Llovet I, Dinardi G, De Maio FG (2011) 'Mitigating social and health inequities: community participation and Chagas disease in rural Argentina,' *Global public health* 6(4):371-84
URL:www.tandfonline.com/doi/abs/10.1080/17441692.2010.539572?journalCode=rgph20#.Vpjsp5PhDGl
Country: Argentina
Community: General public
Health system area: Health literacy/promotion/information
Summary: Chagas disease causes 12,500 deaths annually in Latin America, and is associated with poverty and health inequality. Primary transmission is through an insect that colonises poor housing and rural areas with close contact between humans and animals. After relatively unsuccessful vector control in 1960-1990, Argentina launched a large national vector surveillance initiative (1992-1998) based on community participation, training community leaders and members for detection and house spraying. Seventy-seven participatory workshops were organised by the National Chagas Programme (NCP) with local support in Avellaneda. From 2002-2003 social networks in Avellaneda with 300+ participants were established to support interventions and sprayings with active community involvement. From 2003-2004, the NCP sprayed dwellings with the involvement of social networks and designed a framework for a bottom-up notification path, supported by serological surveillance. After 2004, political instability bought community participation to a standstill, and no further control actions took place until 2006. A cross-sectional survey in 2006 found that greater awareness of the disease and its transmission, along with community mobilisation and spraying, may bring about more self-reported Chagas disease, and a reduced vector population. The authors suggest that such community participation strategies may be effective in reducing the burden of disease, even in poor areas, but that this should not remove responsibility for state provided health services to marginalised populations.
Keywords: Health literacy; community mobilisation; Chagas; prevention; Argentina

Citation: Magnezi R, Bergman YS, Grosberg D (2014) 'Online activity and participation in treatment affects the perceived efficacy of social health networks among patients with chronic illness,' *Journal of medical Internet research* 16(1):e12.
URL: www.ncbi.nlm.nih.gov/pmc/articles/PMC3906665/
Country: Israel
Community: Health service users
Health system area: Health literacy/promotion/information
Summary: "Camoni" the first online non-profit, health-related social network in Hebrew language was established in 2009. "Activation refers to having the capability and the willingness to take on the role of managing one's own health and health care". "Patient activation" describes the extent to which individuals are able to manage their own health care. Camoni offers medical advice, including blogs, forums, support groups, internal mail, chats, and an opportunity to consult with

medical experts in the 16 communities. Registration is required for active participation. Medical online support groups are designed to improve individuals' understanding of their health conditions, change their health behaviours, and enhance their ability to manage a chronic health condition. They can enhance self-confidence by providing emotional support and by enabling members to better manage their diseases. A 2012 evaluation sought to determine predictors of perceived site usefulness, while examining patient activation. The study focused on the site's five largest and most active communities: diabetes, heart disease, kidney disease, spinal injury, and depression/anxiety. The evaluation found that those more likely to search online for health care information included women, those with a higher education, a chronic health condition, more years of internet experience, and those with broadband access. Associations between income and age with online health-related information seeking are less consistent. Men aged 30-39 years scored significantly higher in *active involvement* than those aged 40-49 years; individuals aged 20-29 years of age had significantly higher *perceived usefulness* scores than those aged over 50 years, with older adults having difficulty accessing relevant information online. Individuals with low patient activation still reported that the website provided them with useful information on their ailment, but those at an early stage in their illness were possibly less ready to actively participate in their self-care and comply with medical advice. Younger people may experience greater perceived usefulness because they use the internet more and may prefer immediate health information online over waiting for a physician consultation.
Keywords: Health literacy; promotion; online information; internet; Israel

Citation: Molale MG (2012) 'Community participation in health education programmes: A case of study of a tuberculosis programme in the rural communities of Thabana-Morena, Lesotho.' Dissertation submitted to the Department of Sociology, Anthropology and Social Work in Partial Fulfilment of the Requirements for the Degree of Master of Science in Sociology, National University of Lesotho; Roma.
URL:http://repository.tml.nul.ls/bitstream/handle/123456789/231/the20120900.007.002.mol.pdf?sequence=1
Country: Lesotho
Community: Rural residents
Health system area: Health literacy/promotion/information; Implementing and co-ordinating health action
Summary: Tuberculosis (TB) control remains one of the biggest challenges for Lesotho, including among people with HIV. Heath education has faced difficulties including a lack of technical assistance for health educators, inappropriate ways of involving people, poor allocation of resources for implementation of comprehensive programmes and fear of stigma in communities. In 2007, a TB health education programme was implemented as part of the disease control initiative by the Ministry of Health and Social Welfare (MOHSW) in rural Thabana-Morena. The programme was administered by nurse-trained village health workers (VHWs). The training aimed to build the capacity of TB patients to participate in problem analysis, planning, implementation, monitoring and evaluation in the programme. Community participation was, however, limited to implementation. During implementation, the VHWs paid home visits to TB patients who could not attend the education sessions. Community members including traditional healers were learners in the programme. Other groups such as teachers, chiefs and priests that were credible to communities were were also trained to deliver messages about TB programme. Chiefs tracked those not cooperating with educators. Participant TB patients were reported to have obtained skills on how to improve their health, with skills that were seen to have wider benefit in other development interventions. Key informants and VHWs noted challenges in the health beliefs/myths about TB, lack of payment of workers, illiteracy of workers and learners, a lack of resources, access barriers in the physical environment, exclusion of other members and lack of motivation by rural community members. A top-down approach was observed to deny the communities the chance to engage and have a say in every stage and level of the programme.
Keywords: Health education; literacy, case-tracing; CHWs; Lesotho.

Citation: Murakami JK, Petrilli Filho JF, Telles Filho PC (2007) 'Conversando sobre sexualidade, IST e AIDS com adolescentes pobres' [Talking about sexuality, STI and AIDS with poor adolescents] *Revista latino-americana de enfermagem* 15 Spec No:864-6.
URL: www.scielo.br/pdf/rlae/v15nspe/22.pdf
Country: Brazil
Community: Urban adolescents

Health system area: Health literacy/promotion/information

Summary: An education action on sexuality/STI/AIDS was implemented with adolescents in a context of poverty by a Family Health Unit (FHU) located in a city in São Paulo, Brazil. In 2007, Brazil was seeing a significant increase in HIV among heterosexuals, particularly women and individuals with low education. Adolescents living in poverty appeared to be more susceptible to transmission of sexually transmitted diseases. In this context, six female adolescents living in poverty participated in an educative initiative about sexuality/STI/AIDS. It involved five meetings of an average of 70 minutes. A nurse specialised in using the Systemic Thought and the Operative Group, a nursing undergraduate, and a nurse from the Family Health Unit took part in the educational sessions. The adolescents discovered the power of being in the group, and the researchers visualised other horizons for work with highly vulnerable groups.
Keywords: Health education; information, adolescents; HIV; Brazil.

Citation: Perestelo-Perez L, Perez-Ramos J, Abt-Sacks A, Rivero-Santana A, Serrano-Aguilar P (2013) 'Promoción de la participación ciudadana en cuidados de salud a través de PyDEsalud.com' [Promoting citizen participation in healthcare through PyDEsalud.com,] *Gaceta sanitaria* 27(5):466-7.
URL: www.sciencedirect.com/science/article/pii/S0213911113000149
Country: Spain
Community: General public
Health system area: Health literacy/promotion/information; Implementing and co-ordinating health action
Summary: PyDEsalud: participate and decide on your health (PyDEsalud.com), launched in 2012, is a web platform aimed at people with chronic diseases with a high socioeconomic impact, such as breast cancer, depression, and diabetes, with a plan to expand to other conditions. The platform contains three information service modules (*Patients' experiences, Shared decision making*, and *Research needs*), aimed at promoting health education for patients and families and aims to be updated regularly. The *patients' experiences* module aims to communicate experiences of people with the condition to new patients, using also audio or video recordings from household interviews, so new patients can feel more included, deal with their disease better or reinforce their decisions. The *Shared decision making* module aims to increase patient knowledge and participation in their health, and promote exchange between patients and professionals on diagnostic or therapeutic options. It includes *shared decision making aid tools* providing valid and reliable information about a given disease, the advantages and disadvantages of possible treatments, and an exercise to clarify patient values and preferences. The *research needs* module seeks to identify and prioritise, patient perspectives in identifying research needs using the Delphi technique. The platform was developed by a multidisciplinary research team (doctors, psychologists, anthropologists, sociologists, technicians of health assessment services, computer and graphic designers). It included information from discussion groups, interviews and focus groups with patients and their families and from scientific literature. It was tested and revised after further discussion groups with professionals and semi-structured interviews with people with depression or breast cancer. Most participants reported increased knowledge about their disease after visiting the website, considered it useful to deal with their health problem and would recommend it to other people. Some expressed some barriers to its use, such as not having sufficient computer knowledge to manage it. It is being used in and beyond Spain, with 46% of visits in its first month from Spain and over 40% from Latin America.
Keywords: Health services; co-design; online information; internet; Spain

Citation: Rahmawati R and Bajorek B (2015) 'A community health worker-based programme for elderly people with hypertension in Indonesia: A qualitative study, 2013,' *Preventing Chronic Disease 12*: E175. 10.5888/pcd12.140530 [doi]
URL: www.ncbi.nlm.nih.gov/pubmed/26469948?dopt=abstract
Country: Indonesia
Community: Rural older residents
Health system area: Health literacy/promotion/information
Summary: Hypertension is prevalent in people aged 65+ years in Indonesia. The Integrated Health Service Post for the Elderly (IHSP-Elderly) is a national CHW-based programme for healthy ageing, implemented since 1997 to screen and manage disease in low-income social groups. A community-based programme in a rural village involves CHWs as volunteer

community members trained to serve in the programme to address hypertension. Each community member in the programme pays 1,000 Indonesian rupiah IDR (<USD$0.10) to attend a meeting, compared to the standard patient fee for a consultation in the community health centre of 9,000 IDR and about 50,000 IDR in a private clinic. Relative to the average resident income, the programme fee is said to be affordable. CHWs organised weekly physical exercise and monthly meetings, with a venue, refreshments, materials and speakers, and reported the IHSP-Elderly programme to the community health centre. CHWs played a prominent role in supporting uptake and as co-ordinators of health care in the community. They facilitated blood pressure checks, physical exercise and provided monthly public education on healthy ageing. Members reported feeling healthier, and having peer support and access to affordable health care. They noted infrequent routine blood pressure screening (in part due to CHW skill and equipment deficits) and inadequate referral to other health care services, due to distance barriers. The findings highlight the need for adequate training and supervision of the CHWs, to help members develop self-care management plans and refer patients to other health services. The study highlighted the potential of CHWs to liaise between rural communities and the health system, particularly if strengthened by improved delivery of health care services.
Keywords: Health education; chronic conditions; NCDs; older people; CHWs; Indonesia

Citation: Ribeiro SM, Bógus CM and Watanabe HA (2015) 'Agricultura urbana agroecológica na perspectiva da promoção da saúde' [Agroecological urban agriculture from the perspective of health promotion] *Saude e Sociedade 24*(2): 730-743.
URL: www.scielo.br/pdf/sausoc/v24n2/en_0104-1290-sausoc-24-02-00730.pdf
Country: Brazil
Community: Urban residents
Health system area: Health literacy/promotion/information; Implementing and co-ordinating health action
Summary: Urban and peri-urban agriculture whether for personal consumption or sale in local markets can improve local food and nutrition security, while also reclaiming household backyards and vacant lots as healthy spaces from the accumulation of rubbish. A project "Achieving Sustainability: community practices of food security and urban agriculture" (PCS), was implemented in Embu das Artes, São Paulo metropolitan region, 2008-2011, an area of significant population growth. The first community vegetable garden in Itatuba initiated an awareness and mobilisation process, that involved intersectoral collaboration at the technical level between social workers, community health agents, nursing assistants, nine basic health unit staff and other technicians. The sites made use of available natural resources and reduced waste, raising ecological awareness among participants that reinforced community actions. The project involved new social networks and increased the development of solidarity and cooperative processes for those inside and outside the PCS. The project had a ripple effect with people interested in vegetable gardens visiting the PCS vegetable gardens. As a result of the project, urban agriculture was incorporated as a health promotion activity at municipal level. The PCS experience gave new opportunities for civic participation using popular education and collaboration among individuals and communities to promote health and nutrition, with benefits reported in mental health and physical activity. It contributed to an expansion of gardens in vacant lots, day care centres, schools and other 'inactive spaces', that were also used for other cultural and artistic activities seen as conducive to health. While the results highlighted the potential for expansion, the local government did not renew the partnership with the NGOs. The vegetable gardens were incorporated into health services but land sales by the local government and lack of sites for implementation of new vegetable gardens affected its sustainability.
Keywords: Health promotion; urban agriculture; nutrition; Brazil

Citation: Silva EC, Pelicioni MC (2013) 'Participação social e promoção da saúde: estudo de caso na região de Paranapiacaba e Parque Andreense' [Social participation and health promotion: a case study in the region of Paranapiacaba and Parque Andreense] *Ciencia & saude coletiva* 18(2):563-72.
URL: www.scielo.br/scielo.php?script=sci_arttext&pid=S1413-81232013000200028&lng=en&nrm=iso&tlng=en
Country: Brazil
Community: Urban residents
Health system area: Health literacy/promotion/information
Summary: This study analysed the perceptions of residents of areas of St. Andrew springs, São

Paulo in relation to health education activities and environmental education developed by the municipal government, and community participation in these processes. The municipal government undertook a number of health education and environmental initiatives in the area to ensure environmental conservation and health promotion. Ensuring community participation in these processes was noted to have been a major challenge. A study was done of the measures in Santo André used to encourage social participation in health promotion through structured and semi-structured interviews with government officials and local residents. The results showed that the health measures adopted in the study region are still seen predominantly through the prism of prevention rather than as an educational process capable of supporting and achieving health promotion goals, the development of personal skills and strengthening community action. The data showed the importance of intersectoral co-operation and emancipatory educational activities in participatory processes for the "empowerment" of the population.
Keywords: Health promotion, environmental health; social participation; Brazil.

Citation: Silveira AC, de Rezende DF, Nogales AM, Cortez-Escalante JJ, Castro C, Macedo V (2009) 'Avaliação do sistema de vigilância entomológica da doença de Chagas com participação comunitária em Mambaí e Buritinópolis, Estado de Goiás,' [Assessment of an entomological surveillance system for Chagas disease with community participation in Mambai and Buritinopolis, State of Goias] *Revista da Sociedade Brasileira de Medicina Tropical* 42(1):39-46.
URL: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0037-86822009000100009
Country: Brazil
Community: Urban residents
Health system area: Health literacy/promotion/information
Summary: Surveillance of Chagas in the 1980s in Mambaí and Buritinópolis included the involvement of the communities to notify public health authorities of the presence of insect vectors in houses that were then sprayed with insecticide. The public were also provided with plastic bags for the collection of the vectors, after the treatment of homes with insecticide. The numbers collected did not match that expected, leading to an investigation of the knowledge, attitudes and practices of the population with respect to Chagas disease and vector control through a 2004 cross-sectional study in these municipalities. The results show a social disinterest in *Chagas disease*, attributable to the reduction in the magnitude of the disease burden, the lack of involvement of schools in surveillance, the small importance of secondary vectors and limited control services interventions in response to notifications. The study found low levels of knowledge about the disease and vector control measures among children aged less than 15 years compared to those aged 15-50 years. It is proposed that direct search activities and spot checks are periodically carried out and that Chagas disease and vector control be included in the health education curriculum.
Keywords: Surveillance, vector control; community involvement; Brazil.

Citation: Soe HHK, Somrongthong R, Moe S, Myint KT, Ni H (2012) 'Assessment of community participation in safe motherhood health education programme in Shan State, Myanmar,' *European Journal of Scientific Research* 73(3):373-81.
URL: www.researchgate.net/profile/Kay_Myint/publication/266486572_Assessment_of_Community_Participation_in_Safe_Motherhood_Health_Education_Programme_in_Shan_State_Myanmar/links/5474402d0cf2778985abcc1d.pdf
Country: Myanmar
Community: Rural residents
Health system area: Health literacy/promotion/information.
Summary: Pa-Oh is the second largest ethnic group in Myanmar. The safe motherhood health education programme was implemented in three Pa-Oh villages during 2010 and included health education on maternal health care covering breastfeeding, family planning and HIV/AIDS. Sessions were provided by village health volunteers using a pictorial handbook that integrated the social and cultural context. In addition to improving women's knowledge, attitudes and practices, the programme aimed to enhance the participation of village leaders, village development committees and community members in health and in the design, implementation and evaluation of the intervention. None of the three villages had a health facility. The only health resource was the midwife working in rural health centre – 45-60 minutes' walk away. Community members were purposively involved in a needs assessment using participatory learning and action tools such as village mapping, seasonal calendars, daily timeline, problem tree, and

planning tables. Community meetings held twice monthly were used to design, implement and review health education activities. The meetings and actions involved village leaders, health committee members, education committee members, business loan fund and income generation committee members, traditional birth attendants, village health volunteers and villagers. At least one representative from each group attended every meeting. A tool was developed to assess community participation in needs assessment, leadership, organisation, resource mobilisation and management, categorising the level as narrow, restricted, fair, or open and wide. The assessment scores reflected the view of the representatives of the community such as village health leaders, rather than the villagers as a whole. Resource mobilisation was rated as the most participatory activity, in part due to the presence of a village development fund, followed by leadership, organisation and management while needs assessment was the lowest. The participatory learning and action tools used for needs assessment, while appropriate for people with low literacy, were new for the women. While community involvement in planning and implementation of activities was encouraging, the monitoring and evaluation was seen as largely driven by health professionals.
Keywords: Health literacy; participatory learning and action; evaluation; Myanmar.

Other publications which also include information about social participation in *health literacy and health information* and listed elsewhere in this document include:
1. Micikas et al (2015); and Siriliang (2013) in *Section 3.2*;
2. Karwalajtys et al (2013); Kema et al (2012); South et al (2012) and Tallo et al., (2008) in *Section 3.5;* and
3. Ruano et al (2014) in *Section 3.7.*

3.2   Participation in identifying and assessing health needs and priorities

Citation: Hassan MM (2005) 'Arsenic poisoning in Bangladesh: spatial mitigation planning with GIS and public participation,' *Health policy* 74(3):247-60.
URL: http://www.healthpolicyjrnl.com/article/S0168-8510(05)00013-8/abstract
Country: Bangladesh
Community: Rural residents
Health system area: Assessing health needs and priorities
Summary: A PPGIS (Public Participatory Geographical Information System) in combination with PRA (Participatory Rural Appraisal) and GIS (Geographical Information Systems) methods were used in 2001 to assess the needs and perceptions of rural low income communities regarding arsenic mitigation in a local government administrative unit in Bangladesh. The intervention aimed to integrate socially differentiated local knowledge through cognitive maps and embed 'community perceptions' within a GIS for deep tube-well planning and management. In Bangladesh 95% of districts are reported to have groundwater contaminated with arsenic and more than 30% of the tube wells were contaminated with arsenic. Hand-pump deep tube wells are identified as one of the sources of arsenic-free safe drinking water. The participatory and PPGIS approaches encouraged public participation in spatial decision-making and integrated local knowledge with GIS to institutionalise and legitimise outputs. They used a combination of digital mapping and local sketch mapping by members of the public, individual or grassroots groups. PRA surveys, social meetings and focus groups provided an overview of the physical and social conditions of the area and an initial impression of arsenic problems, linking participatory evidence to using GIS maps. The PPGIS led to improved knowledge about arsenic-free safe drinking water; and identification of the number and where to locate the deep tube wells. Integrating people's opinions in GIS was found to be a valuable measure but with a need for a for well-constructed process so that it does not value some people's views over others.
Keywords: geographical information; participatory appraisal; environmental health; Bangladesh

Citation: Jeffery V, Ervin K (2011) 'Responding to rural health needs through community participation: addressing the concerns of children and young adults,' *Australian journal of primary health* 17(2):125-30.
URL: www.publish.csiro.au/index.cfm?paper=PY10050
Country: Australia
Community: Rural and urban residents

Health system area: Assessing health needs and priorities; health policy deliberation

Summary: A 12 month, self-funded project was undertaken in two rural communities in one of the most disadvantaged local government areas of Victoria using participatory rural appraisal, to analyse the communities perceived needs as an input to health service planning. The project was seeded by community health staff in 2008, and presented to the health service management board. The project sought to: identify consumer needs; develop community health plans; and improve collaborative approaches to health service delivery. Participants from a major town and thirteen small rural townships were identified by a community health worker. Key stakeholders were identified from telephone directories, health workers and other organisations and their participation invited. A situation analysis of health and its determinants was compiled. Communities were engaged through face-to-face meetings with key personnel or community forums for service and sporting clubs. Participation was voluntary. Two major priorities were identified for immediate action: (i) Youth friendly health services, given the above average adolescent pregnancy rate and (ii) speech pathology services given a decline in language and reading skills in primary school children. The findings led to improved collaborations and networks; to the establishment of a clinic to provide screening, advice and health support for young people in a building identified in consultation with local young people to provide an acceptable and attractive environment that afforded greater confidentiality than the mainstream medical clinics. The clinic was well utilised by young people and early feedback was positive. Poor performance in the Australian Early Development Index (AEDI) was reviewed with key stakeholders and a collaboration established between the shire and the health service for a 0–8 year-old shire group aligned with a successful Best Start programme in neighbouring area. Local initiatives have been adopted at other similar health organisations throughout the local government area, and collaborative partnerships have supported other health service developments, supporting planning and policy at many levels.
Keywords: Needs assessment; participatory appraisal; youth-friendly services; Australia

Citation: Mubyazi GM, Mushi A, Kamugisha M, Massaga J, Mdira KY, Segeja M, Njunwa KJ (2007) 'Community views on health sector reform and their participation in health priority setting: case of Lushoto and Muheza districts, Tanzania,' *Journal of public health* 29(2):147-56
URL: http://jpubhealth.oxfordjournals.org/content/29/2/147.full
Country: Tanzania
Community: Rural residents; committee members
Health system area: Assessing health needs and priorities; Health policy deliberation; Meso-level supporting mechanisms
Summary: Decentralisation of health planning to regional and district levels was a crucial element of the national Health Sector Reform process in Tanzania beginning in the 1960s. Focus group discussions were held with village household members, and members of Ward Development Committees (WDCs) and Village Development Committees (VDCs) in two districts in north-eastern Tanzania to explore: community knowledge of the Health Sector Reform process; communities' participation in health priority setting; how community priorities correspond to those set at higher decision-making levels; and how the VDC and WDC responsible for community health programmes performed their duties in relation to community desires or expectations. The VDC and WDC include members elected by the local residents to represent them in key subcommittees at village and ward levels for finance and planning, defence, security and social welfare, water, health and works. The village committees automatically include village chairperson and the village executive officer and the ward committees the ward executive officer and the elected ward councillor. In focus groups, a number of challenges were identified: Participants expressed low trust local representatives and perceived their priority needs to be ignored by higher district level authorities. Delays in or poor feedback from district level authorities on claims presented from grassroots level were reported to disappoint local people and lead to leaders being blamed for not presenting their concerns to the district level. Local leaders saw higher authorities to be initiating health programmes without consulting them or sensitising the local population. District level officers indicated scepticism in the ability of local community leaders to represent people in priority-setting. The authors recommended awareness raising of communities about the purpose of participation, continuous sensitisation and more training of professionals and technical people on what participation means and how to facilitate it.
Keywords: needs assessment; priority setting; committees; Tanzania

Citation: Otieno CF, Kaseje D, Ochieng' BM and Githae MN (2012) 'Reliability of community health worker collected data for planning and policy in a peri-urban area of Kisumu, Kenya,' *Journal of Community Health 37*(1): 48-53. 10.1007/s10900-011-9414-2 [doi]
URL: www.ncbi.nlm.nih.gov/pubmed/21769730?dopt=abstract
Country: Kenya
Community: General public
Health system area: Assessing health needs and priorities; Health planning and budgeting.
Summary: CHWs collect health status data at the household level in Kenya, which is then used for dialogue at all the levels to inform decisions and actions towards improvement in health status. The use of CHWs to reach out to the community has contributed to the successful implementation of many health interventions. This study assessed the validity and reliability of the data collected by CHWs for use in planning and policy formulation. Ten percent of the data that CHWs register and update twice a year for of all households visited was recollected and tested by a technically trained team. The team also undertook verbal autopsies in households experiencing mortality to establish possible causes of death. For indicators on latrine availability and antenatal care there was good correspondence between the two sets of data. This was also true for exclusive breast feeding indicator. Measles immunization coverage showed less consistency than the rest of the child health indicators. The study concluded that given the 90% concurrence between the research team and CHW collected data in all the variables, CHWs can accurately and reliably collect household data which can be used for health decisions and actions, especially in resource poor settings where other approaches to population based data are too expensive. The study also indicates that other factors such as CHW's education level and the number of training sessions need to be further investigated to see how this influences the accuracy of the data.
Keywords: Health information; needs assessment; CHWs; Kenya

Citation: Robinson L, Newton J, Dawson P. Professionals and the public: power or partnership in health research? *Journal of evaluation in clinical practice*. 2012;18(2):276-82.
URL: http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2753.2010.01572.x/pdf
Country: United Kingdom
Community: Older service users
Health system area: Assessing health needs and priorities
Summary: The quality of life of an older person can be dramatically reduced following a fall. To better understand the factors influencing uptake and adherence of strength and balance training, a series of focus groups were held with older people attending services, relatives and local physiotherapists. Participants were asked to propose strategies to promote long-term participation in an exercise-based programme for prevention of falls. Public involvement was conceptualised as a product of the degree of collaboration throughout the research process and the extent of top-down or bottom-up approaches, characterising the public as: ignored, acknowledged, advised or engaged. At each key stage of the research, the researchers reported room for improvement, even as they moved towards a more collaborative approach. The team shared early findings with service users and their relatives, integrating public advice in research design and implementation. A decision to not involve service users and relatives in dissemination of research findings was identified as a missed opportunity for the study to impact on local service delivery. The conceptual model encouraged researchers to move into the public acknowledged and public advised quadrants as the study progressed and to critically reflect on how their research practice can be improved for greater public involvement.
Keywords: older people; public advice; research; UK

Citation: Siriliang R (2013) 'People's Health Development in Tambon (Sub-district) Administrative Organization, Responsible Areas by Emphasis on Community Participation in LOEI Province, Thailand 2012,' *Journal of Biology, Agriculture and Healthcare*. 2013 (15):47-54.
URL: http://iiste.org/Journals/index.php/JBAH/article/view/8211/8719
Country: Thailand
Community: General public
Health system area: Assessing health needs and priorities; health planning and budgeting; health literacy/ promotion/ information
Summary: A community based planning project using a creative brainstorming process was undertaken in the Tambon (sub-district) Administrative Organizations (TAO) in Thailand. The

project aimed to assess the contribution of social capital to community physical, mental and social development; to encourage community participatory planning for health; and to assess continuity in the implementation of participatory community health development. Volunteers in the village, village health volunteers and other groups participated in a 2-day brainstorming process coordinated with the district head of health promotion at the hospital, the head of the village and research assistants. From this, six projects were identified: an anti-drug campaign for youth; an aerobic exercise programme; an aegypti eradication programme for dengue prevention; a health promotion programme for diabetes and high blood pressure; a village environmental management initiative; and training for community mental health. The village broadcasting system was used to renew and maintain people's interest in advancing the plan. Respondents participating in the health development plan were mainly female (71%) aged between 40-60 years. The projects were implemented but with delays in continuity due to villagers needing to do other important activities in their daily life.
Keywords: needs assessment, community volunteers, health promotion; Thailand.

Country: Colombia
Community: Urban residents
Health system area: Assessing health needs and priorities; health planning and budgeting; Implementing and co-ordinating health action.
Summary: In Bogota comprehensive primary health care (CPHC) aimed to improve access to health services and address inequalities in health outcomes. The municipal government established the CPHC in consultation with the social security agency, the community and the city's political forces. The policy used family and community-oriented approaches, organising comprehensive health care teams in geographically defined areas to meet population health needs and act as a gateway to the system. It used social mapping, health promotion, intersectoral action and social participation as a right, creating conditions for autonomous social organisation and mobilisation. Comprehensive Social Action used a community survey made by Health at Home (SASH) team to assess needs, develop, implement, monitor, and evaluate comprehensive action plans. The survey was a form of social mapping and local health diagnosis undertaken with community participation to build consensus in identifying priorities. The CPHC included new organisational methods to encourage community participation and foster community management and representation in the planning and decision-making processes. Management centres were used for communities to identify local needs and present them to the government. Government policy proposals to coordinate collaborative actions at the local level were discussed in these management centres, to set action plans and monitor family and community projects. Hospital representatives in the local government councils and local Social Policy Councils provided another channel to communicate community needs to higher government levels, directing political attention to locally identified problems. An online information system incorporating information from the household surveys and community assessments was used for strategic planning and to foster social participation. It enabled local analysis of health conditions and the auditing required by the Bogota Municipal Health Department to monitor providers and insurers. There has been improvement in selected health indicators since the implementation of the CPHC. Community participation was, however, still organised by the rules of individual institutions and the financing of health care markets given the overall social security framework, limiting wider participation and intersectoral action.
Keywords: Comprehensive primary health care; needs assessment, urban health; Colombia

Other publications including information about social participation in *assessing, identifying health needs and priorities* listed elsewhere in this document include:
1. Murray (2010) in *Section 3.3*; and
2. Eftekhari et al (2014); and Galaa (2008) in *Section 3.5*.

3.3   Participation in health planning and budgeting

Citation: Andrade GR, Vaitsman J (2013) 'A participação da sociedade civil nos conselhos de saúde e de políticas sociais no município de Piraí en 2006, [The participation of civil society in health and social policy councils in the city of Pirai, State of Rio de Janeiro in 2006] *Ciencia & saude coletiva*, 18(7):2059-68.
URL: www.scielo.br/pdf/csc/v18n7/21.pdf
Country: Brazil
Community: Community representatives
Health system area: Health planning and budgeting
Summary: In Brazil, social policy councils were created by the Brazilian Federal Constitution of 1988 to introduce participatory management at the municipal level within wider administrative and financial decentralisation. The Councils include representatives of civil society and the public and private sectors. They aim to discuss and monitor the management of public policies at every level of Government. The health sector was the pioneer of participatory management with wider health system reforms also introduced in 1988 as part of the Constitution, establishing incentives for decentralisation and municipal management mechanisms, including the health boards tied to municipal departments of health. Findings are reported from interviews with 19 councillors representing civil society organisations (CSO) who have participated in the health or other councils in Piraí city, and representatives from 5 departments (health, the environment, education, social assistance) in the city. The rapid rise in the number of councils without a proportional increase of in the number of organisations and people involved created challenges in the city, including finding people available to participate and ensuring representative functioning. Exhaustion among CSO directors has been observed and there is competition among different sectoral councils for finding CSO directors. While health improvements demand intersectoral action, the structure of separate sectoral councils means that CSO representatives may end up specialising in one sector rather than being able to advocate and contribute towards more comprehensive action across sectoral boundaries.
Keywords: Health council, civil society; intersectoral mechanisms; Brazil

Citation: Baatiema L, Skovdal M, Rifkin S, Campbell C (2013) 'Assessing participation in a community-based health planning and services programme in Ghana,' *BMC health services research* 13:233.
URL: www.ncbi.nlm.nih.gov/pmc/articles/PMC3733901/pdf/1472-6963-13-233.pdf
Country: Ghana
Community: Rural residents; committee members
Health system area: Health planning and budgeting;
Summary: The Community-based Health Planning and Services (CHPS) is a national initiative adopted in 1999 as an extension of a 1994 pilot. It seeks to increase rural access to health services while empowering local communities to take greater control over their health, and to promote community-driven health services, with support from the central Ghana Health Service. The strategy advocates the active participation of community leaders and members in planning and implementation of PHC facilities and activities, through mobilisation of community leadership, decision making and resources in within defined catchment areas. In the Wa Municipality of western Ghana access to specialist health care is difficult for most residents and skewed in favour of communities in the Wa municipal area. The Nachanta CHPS health care facility opened in 2008, one of fourteen in the municipality. In 2011 a study was implemented to assess the perspectives of adult service users, providers and committee members and community participation assessed in needs assessment, leadership, organisation, resource mobilisation and management. Participation in needs assessment scored lowest but was fair to excellent for the other areas. A range of factors impacted on this including: community mobilisation of local in kind and cash resources to support CHPS, integration with the pre-existing community structures of unit committees, and health volunteers, traditional birth attendants) and community representatives being able to work independently without external interference from health professionals. The findings suggest external design of the programme and limited community control of the CHPS. Participation was male dominated, with fewer opportunities for women to participate than men, especially in relation to resource mobilisation, leadership and management. Service users were not involved in selection of CHPS community leaders, only being asked to contribute to maintaining the facility.
Keywords: evaluation; health Planning; community involvement; CHPS; Ghana

Citation: Bhatia K (2014) 'Community health worker programmes in India: A rights-based review,' *Perspectives in Public Health 134*(5): 276-282. 10.1177/1757913914543446 [doi]
URL: www.ncbi.nlm.nih.gov/pubmed/25169614?dopt=abstract
Country: India
Community: Rural residents; CHWs
Health system area: Health planning and budgeting; Implementing and co-ordinating health action
Summary: The Indian government in the 1970s initiated two national CHW programmes. In 1975 the Integrated Child Development Services Scheme introduced one Anganwadi worker and helper per village to provide nutrition, pre-school education, and health services to children under 6 years. It continues to date. In 1977, the Swasthya Rakshak included about 400 000 male CHWs to provide basic health care at village level. Protests from the Sawsthya Rakshak CHWs led to funding for the programme being stopped, until it ceased. The Anganwadi CHWs also formed unions and achieved reforms including paid maternity leave, medical insurance and an increase in their fixed payments. In 2006, the Accredited Social Health Activist (ASHA) programme was introduced nationally in the context of the national Health Mission - a comprehensive and broad-based government health care plan. ASHAs are selected, trained, monitored and given fixed performance-based incentives per task by the government. They have improved coverage for mothers and neonates in participating areas, and facilitated access to basic health care. Three key features make the programme different from previous CHW initiatives: transparent administration; regular performance evaluation of ASHA by external academic institutions and experts; and the establishment of community monitoring systems at village level. A problem with the ASHA programme has been the performance-based payments: with report of inadequacy and irregularity of payments, a lengthy and complex process for claiming payment, pressures faced at home and work by the ASHAs, and the importance of training and adequate remuneration to motivate them. The authors raise concerns that CHW volunteer status and the flexibility of their tasks and timings impede their rights, limit setting any standard service conditions for them and reduce their power to negotiate for their rights.
Keywords: Health workforce pay; performance financing; CHWs; India

Citation: B-Lajoie MR, Hulme J and Johnson K (2014) 'Payday, ponchos, and promotions: A qualitative analysis of perspectives from non-governmental organization programme managers on community health worker motivation and incentives,' *Human Resources for Health 12*: 66-4491-12-66. 10.1186/1478-4491-12-66 [doi]
URL: www.ncbi.nlm.nih.gov/pubmed/25475643?dopt=abstract
Countries: LMICs
Community: CHWs
Health system area: Health planning and budgeting; Heath policy deliberation
Summary: This study examines the perspective of health programme managers from 16 international NGOs on approaches to designing CHW incentives. Programme managers strongly relied on national government to provide clear guidance on CHW incentives schemes. Some respondents indicated that a systems approach with multiple cadres of health workers chosen by the community with equity between equivalent-level workers and a career path could avoid vertical programmes competing for CHWs with vastly different incentive schemes. Perspectives on remuneration varied greatly, from fears that it is unsustainable, to the view that it is a basic human right, and a mechanism to achieve greater gender equity. There was also a concern that if you make CHWs a well-paid job, it will attract men for the salary, and push women out of work. Simultaneously, some respondents highlighted concerns with assumptions of women being expected to work for free or not paying (poorer) people. Programme managers were interested in exploring career paths and innovative financing schemes for CHWs, such as endowment funds or material sales, to heighten local ownership and sustainability of programmes. The findings suggest consensus that incentives should reflect the nature of the work asked of CHWs, and the potential for motivation through sustainable financial schemes other than regular salaries.
Keywords: Payment; incentives; CHWs; LMICs

Citation: Bispo Junior JP, Sampaio JJ (2008) ' Participação social em saúde em áreas rurais do Nordeste do Brasil' [Social participation in health in rural northeastern Brazil], *Revista panamericana de salud publica* 23(6):403-9.
URL: www.scielosp.org/scielo.php?script=sci_arttext&pid=S1020-49892008000600005&lng=en&nrm=iso

Country: Brazil
Community: Committee members
Health system area: Health planning and budgeting; Enablers and barriers in health action
Summary: Permanent health councils in Brazil exist at municipal, state and federal levels, to define public policies and monitor management and finances. Councils should have 50% representation from the community and 50% health professionals and service providers. This study analysed social participation in two Municipal Health Councils (CMS) in Adenike Coutinho (Bahia) and Guimarães (Ceará) during 2005. A range of challenges were identified by council members including: lack of confidence in the representativeness of the councils; lack of participation by users with higher levels of education; irregular practices regarding membership structure and nomination of members; continuous "reshuffling" of the council structure; and irregular poorly attended meetings. Financial management is a main weakness of the councils. Despite legal requirements for the CMS to regularly monitor and inspect financial performance, councillors were not able to monitor or intervene on the health budget. They were usually presented with accounts for approval at the deadline accompanied by the claim that the rejection would trigger the suspension of financial transfers to the municipality. These weaknesses can make participation mechanisms legitimise power and co-opt social movements.
Keywords: health budgets; citizen's councils; Brazil.

Citation: Condo J, Mugeni C, Naughton B, Hall K, Tuazon MA, Omwega A, et al. (2014) 'Rwanda's evolving community health worker system: A qualitative assessment of client and provider perspectives,' *Human Resources for Health 12*: 71-4491-12-71. 10.1186/1478-4491-12-71 [doi]
URL: www.ncbi.nlm.nih.gov/pubmed/25495237?dopt=abstract
Country: Rwanda
Community: General public; CHWs
Health system area: Health planning and budgeting; Implementing and co-ordinating health action;
Summary: The Rwanda Ministry of Health expanded its community health programme in 2007, aiming to place 4 trained CHWs in every village in the country by 2009. By 2011 there were approximately 60,000 CHWs, comprising 3 CHWs per village. CHWs are required to have a minimum of 6 years of education, and are elected by their communities. As part of a larger report assessing CHW capacity relating to community-based nutrition (CBN) in Rwanda, a cross-sectional descriptive study was conducted to collect qualitative information regarding educational background, knowledge and practices of CHWs, and the benefits of community-based care as perceived by CHWs and community members. CHWs were found to be closely involved in the community, and widely respected by the beneficiaries. Rwanda' s community performance-based financing (cPBF) was an important incentive, but many CHWs did not understand the system, and were also strongly motivated by community respect. Key challenges identified were: an overwhelming workload; too broad a range of work; irregular trainings, inadequate training on communication skills; and lack of sufficient supervision. For example, most of the CHWs did not receive any initial training yet were often left to deliver infants when women did not make it to the health centre before giving birth. Since 2012, each village has a pair of CHWs and one CHW who manages maternal and newborn health. The cPBF system was strengthened, and comprehensive training, focusing on capacity building, conducted for all CHWs. Workloads continue to be a significant challenge as the system is under-resourced.
Keywords: Training; payment; motivations; performance; CHWs; Rwanda

Citation: Eftekhari MB, Mirabzadeh A, Forouzan AS, Dejman M, Afzali HM, Djalalinia S, Peykari N, Roshanfekr P (2014) 'A Qualitative Study of Community-based Health Programmes in Iran: An Experience of Participation in IR Iran,' *International journal of preventive medicine* 5(6):679.
URL: www.ncbi.nlm.nih.gov/pmc/articles/PMC4085919/
Country: Islamic Republic of Iran
Community: Health service users
Health system area: Health planning and budgeting; Implementing and co-ordinating health action; assessing health needs and priorities
Summary: The study assessed Community-based health programmes (CBHP) in Iran advocating for more participation-friendly policies. Thirteen CBHPs active for the last 5 years were assessed drawing input from programme principals and managers, volunteers and service users. The programmes included a primary health care network, a polio eradication campaign, healthy

villages, healthy cities, a women health volunteers programme and an addiction control and prevention programme. The recruitment of volunteers/ community members by government organisations was centralised (selection criteria included having a minimum literacy level, a previous history of participation, being native and having "reliable status in the community"). Even where the community was responsible for selecting community representatives, respondents reported that the selection process was undertaken by the village's most empowered individuals. In NGO programmes the volunteers were usually chosen by the service users and volunteer participation was more appreciated and respected. Dialogue with community leaders and residents, financial and spiritual incentives, and tangible benefits such as learning skills were reported to be useful for engaging and maintaining volunteer participation, but a lack of financial resources was also reported. While all involved capacity building in the beginning, some programmes did not provide regular refresher training, sometimes due to financial constraints. Community participation ranged from support to advisory roles to being a main partner, such as in the health city programme, with fewer examples of the latter. For intersectoral collaboration, strong and dedicated partners and a supportive policy environment were reported as critical, Top-down approaches and inconsistent funding were observed to weaken participation and partnerships.
Keywords: primary health care; participation levels; CHWs; Iran

Citation: Greenspan JA, McMahon SA, Chebet JJ, Mpunga M, Urassa DP and Winch PJ (2013) 'Sources of community health worker motivation: A qualitative study in Morogoro region, Tanzania,' *Human Resources for Health 11*: 52-4491-11-52. 10.1186/1478-4491-11-52 [doi]
URL: www.ncbi.nlm.nih.gov/pubmed/24112292?dopt=abstract
Country: Tanzania
Community: General public; CHWs
Health system area: Health planning and budgeting; Health policy deliberation
Summary: This study explored sources of CHW motivation in the Morogoro Region of Tanzania. Twenty CHWs were interviewed, 35% of whom had been working for >15 years, and literature on CHW motivation from 1987-2012 reviewed. CHWs are volunteer workers and the policy has been for every village health committee to appoint two CHWs, although the policy was under revision at the time of the study. Self-reported CHW workload ranged from a commitment of 4 days per year for large health campaigns to 3 days per week for routine health services. They performed a variety of tasks, from running environmental sanitation campaigns, to conducting home visits with pregnant women and children, making referrals to health centres, responding to emergencies, and providing health education. Sources of CHW motivation were identified at different levels. At individual level, CHWs are predisposed to volunteer work and apply knowledge gained to their own problems and those of their families and communities. They described being encouraged by changes they see in their communities, especially where their work helped them address a gap in health service provision. Families and communities provided moral, financial, and material support, including service fees, supplies (e.g. buying notebooks), money for transportation, and help with farm work and CHW tasks. Resistance to CHW work exhibited by families and community members was limited. The organisational level provides motivation in the form of stipends, potential employment, materials, training, and supervision, but inadequate remuneration and supplies discourage CHWs. Supervision can also be dis-incentivising if perceived as a sign of poor performance. Tanzanian CHWs who work despite not receiving a salary have an intrinsic desire to volunteer but a lack of remuneration still imposes a burden on their families. Also, CHWs' intrinsic desire to volunteer does not preclude a desire for external rewards. Adequate and formal financial incentives and in-kind alternatives would allow already-motivated CHWs to increase their commitment to their work.
Keywords: Incentives; motivations; CHWs; Tanzania

Citation: Howe D, Batchelor S, Bochynska K (2011) 'Finding our way: Youth participation in the development and promotion of youth mental health services on the NSW central coast,' *Advances in Mental Health 10*(1): 20-28.
URL: http://www.tandfonline.com/doi/abs/10.5172/jamh.2011.10.1.20
Country: Australia
Community: Youth health service users
Health system area: Health planning and budgeting; Meso-level supporting mechanisms
Summary: In 2006 the NSW Youth Mental Health Service Model Central Coast Pilot (NSW YMHSM – CC Pilot) in Australia funded and developed a model for youth participation in mental

health, which was implemented and evaluated between 2007 and 2009. A Youth Alliance was established of 15 young people from across the Central Coast, aged between 15-25 years old, supported by a full-time paid coordinator, with training and development opportunities to prepare them for their role. The Youth Alliance was actively involved in the development of youth mental health services and participated in training, consultations, working parties and community awareness activities. An evaluation found that the Alliance recruitment process was highly acceptable to young people, and successfully engaged young people currently or previously using mental health services. It engaged young people from diverse backgrounds as 'consultants' including indigenous young people, those from different cultures and languages and from low socioeconomic groups. The Alliance conducted 63 consultations with numerous services across the Central Coast which provided opportunities to influence the design and development of youth mental health services, and reached over 4000 young people. The 'consultants' indicated that they had gained numerous skills including teamwork, communication, presentation and consultancy skills, and skills in public speaking and time management. They reported that they were valued and empowered by their participation in the project. Challenges included the reliability and availability of the Alliance consultants, getting a balance between support and allowing autonomy and control, and the availability of funding which was project based. Those from more disadvantaged backgrounds were more difficult to contact and often required greater support to complete allocated tasks. Once funding for the coordinator ceased, the level of youth participation declined, raising the need to adequately resource such processes.
Keywords: Mental health services; health planning; co-design; youth; Australia

Citation: Kamuzora P, Maluka S, Ndawi B, Byskov J, Hurtig AK (2013) 'Promoting community participation in priority setting in district health systems: experiences from Mbarali district, Tanzania,' *Global health action* 6:22669.
URL: http://www.globalhealthaction.net/index.php/gha/article/view/22669
Country: Tanzania
Community: Rural residents
Health system area: Health planning and budgeting; needs assessment and priority setting; Meso-level supporting mechanisms
Summary: In Tanzania, within decentralisation, civil society and citizens are being asked to play a greater role in decision-making on services through health committees and boards. In 2006, a 5-year project was initiated to test the application and effects of an 'Accountability for Reasonableness (AFR)' approach to priority setting in resource-constrained settings. AFR involves different stakeholders in priority-setting to include a wide range of values, enhance legitimacy, and facilitate the implementation of decisions. It assesses if the evidence and principles used in priority-setting are: relevant; publicly accessible; and able to be challenged and revised in response to new evidence. AFR was implemented in Mbarali district through participatory action research involving the Council Health Management Team (CHMT) an action research team and academic researchers. The CHMT comprises district level health and social welfare officials. Districts produce an annual council health plan, approved by the community Health Services Board comprising elected community members, officers from other departments and the private sector. A baseline study before the intervention found limited participation in and impact of district-level committees and boards on district health plans. After applying the AFR approach CHMT members, community representatives - women, youth, elderly, disabled, people living with HIV, and other stakeholders - participated in the preparation of the district annual budget and health plans. The authors report better identification of community needs and priorities, increased knowledge of the community representatives about priority setting, increased transparency and accountability, trust among health systems and communities, and perceived improved quality and accessibility of health services. However, lack of funds to support their work, limited time for deliberations, short notice for the meetings, and lack of feedback on the approved priorities constrained the performance of the community representatives. They note that external facilitation and support is required to enable health professionals and community representatives for such processes.
Keywords: health planning; committees; priority setting; Tanzania

Citation: Kessy FL, Ramsey D (2014) 'Improving health services through community participation in health governance structures in Tanzania,' *Journal of Rural and Community Development* 9(2):14-31.
URL: http://journals.brandonu.ca/jrcd/article/view/826/179

Country: Tanzania
Community: Rural residents
Health system area: Health planning and budgeting; Meso-level supporting mechanisms
Summary: Decentralisation policy in Tanzania has facilitated the formation of local health governance structures to ensure greater participation of communities in the management of health services. These include Council Health Services Boards (CHSBs) and Health Facility Governing Committees (HFGCs). Community Health Funds (CHFs) were introduced as a means to involve communities in the financing of health services. Funds generated by the CHFs and a matching grant from the Ministry of Health and Social Welfare are managed by the CHSBs and HFGCs, and with funds from user fees, are used to improve services. A study of 14 out of 133 councils in mainland Tanzania, covering 8 health zones, included both good and relatively poorly performing councils with respect to CHFs. The study found that service boards and facility governing committees provide accountability checks of health managers and providers, forging links between the technical-medical professionals and communities, and supporting communities' participation in service provision. However, there are weaknesses in the recruitment process, attendance of members at meetings, in regular community consultations and information and dissemination and in the representation of community views in higher structures such as the full council, the highest legal organ at local council level. Health facility staff and managers such as District Medical Officers were found to be unresponsive to the role of community members, questioning the legitimacy of lay people with a low educational level to 'control' medical professionals. Despite achievements such as reprimanding irresponsible health workers, addressing medicine stock outs, and mismanagement of patients, there are factors working against community participation in these governance structures. The author calls for capacity strengthening on the roles and functions, of community members planning and budgeting skills, and improved understanding of the division of roles and responsibilities among governance structures.
Keywords: health boards; councils; representation; Tanzania

Citation: Lockett-Kay JE (2005) 'Community participation in the establishment of a primary health organisation in the Horowhenua: a longitudinal case study: a thesis presented in partial fulfilment of the requirements for the degree of Doctor of Philosophy in Management at Massey University, Turitea, Palmerston North, New Zealand.'
URL: http://mro.massey.ac.nz/bitstream/handle/10179/661/02whole.pdf?sequence=1&isAllowed=y
Country: New Zealand
Community: Rural residents
Health system area: Health planning and budgeting; Meso-level supporting mechanisms
Summary: In February 2001 the Minister of Health New Zealand announced the Primary Health Care Strategy and identified Primary Health Organisations (PHOs) as the vehicles for planning, funding and coordinating primary health care services. Community involvement in planning and development was seen as integral to implementation of the strategy. This study examines the establishment of the Horowhenua PHO. A Steering Committee was established comprising community representatives, iwi (tribe) and local health professionals working in the District Health Board Funding Division and the District Health Board (DHB) Primary Health Care Reference Group. A consultancy group recommended establishment of a 17-member working party with representatives from the Horowhenua, Otaki and Kere Kere communities to prepare for the formation of one PHO for the 3 communities. However, the Otaki and Kere Kere communities decided to create their own PHO establishment plan, as they did not consider a single PHO to be in their community's best interests. The study identified that community participation in the planning enabled integration of community knowledge and its unique "ways of doing". It found dynamic interdependencies within the Horowhenua community and with external stakeholders, changing power relationships, in managing material resourcing and access to essential information. By the PHO formation date in July 2004 the Steering Committee had become a strong, cohesive team which had pride in and ownership of its establishment of the PHO. The research points to how interdependencies between stakeholders and achieving inclusiveness in decision-making calls for ways of addressing power imbalances between "expert" stakeholders and community, where each bring to the partnership a set of attributes and knowledge which collectively informs the entire planning process.
Keywords: Health planning; primary health care; indigenous knowledge; New Zealand

Citation: Luis IP, Martinez S, Alvarez A (2012) 'Community engagement, personal responsibility and self help in Cuba's health system reform,' *MEDICC Review* 14(4);44-47
URL: http://www.scielosp.org/pdf/medicc/v14n4/v14n4a10.pdf
Country: Cuba
Community: General public
Health system area: Health planning and budgeting; health policy deliberation
Summary: Cuba's Constitution upholds the right of all Cubans to health care and protection and public health legislation establishes community involvement as one of its basic principles. The significant improvements in health over several decades have been attributed in part to various forms of community engagement in health promotion and disease prevention activities combined with accessible care and intersectoral action for population health. The systems for this were adapted to Cuba's health system and supported by political systems, law and policy. There is some report that involvement has been more highly developed in collaborative or joint management forms without extending to 'self-management or negotiated participation'. While the system is argued to enable participation, the collaboration is argued to be through representatives at various jurisdictional levels of governmental structures: electoral districts and their corresponding popular councils; municipal and provincial assemblies; and the national parliament, rather than in people as families directly improving or solving their health problems and needs. A strategy paper, Public Health Projections for 2015 in Cuba, emphasises the need to strengthen mechanisms for community engagement for population health promotion and disease prevention. This is argued to be important to address noncommunicable diseases and to complement other efforts at service reorganisation and decentralisation.
Key words: committees; health promotion; community representatives; Cuba

Citation: Murray ZK (2010) 'The nature of community participation in municipal public health planning in Queensland.' Thesis for PhD, Griffith School of Environment Science, Environment, Engineering, and Technology, Griffith University: Queensland.
URL: www120.secure.griffith.edu.au/rch/file/776fe413-531f-da60-6484-339f9a308f27/1/Murray_2011_02Thesis.pdf
Country: Australia
Community: General public
Health system area: Health planning and budgeting; assessing health needs and priorities; Health policy deliberation
Summary: The WHO Healthy City approach advocates community participation in local level public and environmental health planning and practices. In Queensland, the Healthy Cities approach has been used to develop a model of municipal public health planning (MPHP). The MPHP initiative provided a case study of community participation in practice to local level public and environmental health planning and management. Key informants from local representatives, local government staff, health staff, community members/NGOs and state or federal government staff from three MPHP projects in Southeast and Central Queensland identified that community participation in MPHP is important to both enhance decision-making and to foster support, enthusiasm and commitment to implement and sustain project activities beyond planning stages. They saw the main purpose as to engage stakeholders and mobilise a community voice in developing shared goals and joint actions, having the right to "have a say" in decision-making, not to control it. They identified enabling factors as: active consultation and advice from community members, service providers and other professionals that work in the local area; sustained leadership; mechanisms for two-way communication and cooperative arrangements for stakeholders at all stages of development including discussion forums, stakeholder working groups and collaborative steering committees. Potential threats were identified as loss of key political and organisational champions, and the lack of funding and commitment to move from planning to implementation.
Keywords: healthy cities; municipal health planning; participation; Queensland

Citation: Naimoli JF, Perry HB, Townsend JW, Frymus DE and McCaffery JA (2015) 'Strategic partnering to improve community health worker programming and performance: Features of a community-health system integrated approach,' *Human Resources for Health 13*: 46-015-0041-3. 10.1186/s12960-015-0041-3 [doi]
URL: www.ncbi.nlm.nih.gov/pubmed/26323276?dopt=abstract
Countries: Low- and middle-income countries (LMICs)

Community: General public; CHWs
Health system area: Health planning and budgeting; Implementing and co-ordinating health action; Oversight, monitoring and evaluation
Summary: This paper presents evidence on CHW performance, synthesis records, author consultations, documentation on large-scale CHW programmes published after the synthesis and other relevant literature. A minimum package was identified of four strategies that provide opportunities for increased cooperation between communities and health systems and address traditional weaknesses in large-scale CHW programmes. The strategies are: joint ownership and design of CHW programmes; collaborative supervision and constructive feedback; a balanced package of incentives; and, a practical monitoring system incorporating data from communities and the health system. Benefits from the simultaneous implementation of all four strategies could outweigh those produce by each independently. Measures for joint ownership and design include development of a broad framework through national level dialogue, adapted at community level; co-creation through early discussions with community leaders in CHW selection, role development and support; community needs analysis; and establishing community committees, oversight, management and or advisory groups. Promising approaches to collaborative supervision and constructive feedback included shared goal setting between CHWs and supervisors, having stronger peer assessment, on-the-job training and mentoring, community assessment of CHW and other health worker performance, and using supervisory checklists with recommended actions, with a balanced package of incentives (financial and non-financial). Examples cited include: Rwanda's government-sponsored Community Performance-Based Financing scheme (see Condo et al, 2014); the ASHA scheme in India (see Bhatia 2014); and Nepal's mixed-model of both paid and part-time voluntary CHWs. A practical monitoring system that monitors and assesses both individual CHW performance and system issues is proposed. The involvement of community leaders and groups is recommended with Uganda and India cited as examples of where this has worked. Finally, three concrete actions for advancing the learning agenda on CHW performance are proposed: comparative analysis by the global health community; and retrospective and prospective analysis by countries.
Keywords: Health planning; CHWs, strategies; LMICs

Other publications including information about social participation in *health planning and budgeting* listed elsewhere in this document include:
1. Otieno et al (2012); Siriliang (2013); and Vega-Romero et al (2008) in *Section 3.2*;
2. Chilundo et al (2015 in *Section 3.4*;
3. Costa Sde et al (2013); de Freitas et al (2015); Lewis (2014); Strachan et al (2015); Yeboah-Antwi et al (2014) in *Section 3.5*; and
4. Little et al (2013); Mitsunaga et al (2014); and Schuttner et al (2014) in *Section 3.6*.

3.4   Participation in health policy deliberation

Citation: Atanasova-Pieterse D, Kerekovska A, Popova S (2013) 'Citizen participation in healthcare in Bulgaria: the gap between citizens, health experts, and local officials,' *Scripta Scientifica Medica* 45(3):82-5.
URL: http://press.mu-varna.bg/ojs/index.php/ssm/article/download/311/311
Country: Bulgaria
Community: Urban residents
Health system area: Health policy deliberation
Summary: An opinion poll was conducted in 2009 in three diverse Bulgarian municipalities (one large, one medium size and one small in different settings) to investigate the views of the different stakeholders about citizen involvement in local healthcare decision-making. Representatives (351) from three groups (citizens, municipality officials and health experts) took part in personal interviews. There was a significant difference in the opinion among the three groups about: the citizen role in the healthcare decision-making in the municipalities; the availability of information and opportunities for citizen participation; and the consideration of the citizen's views by municipal decision-makers. The experts and the municipal officials would like citizens to play a more prominent role in healthcare decision-making, while citizens prefer consultation or roles that don't involve participation. More than 60% of the municipal officials thought that the citizens are informed, have possibilities for participation and views considered by

the municipal decision-makers while the majority of the health experts and citizens had the opposite opinion. The authors observe that bridging the gaps requires proper information and possibilities for participation, and citizens motivated by mutual respect, openness and understanding of the benefits of their involvement in public health.
Keywords: policy deliberation; opinion polls; Bulgaria

Citation: Avard D, Bucci LM, Burgess MM, Kaye J, Heeney C, Farmer Y, Cambon-Thomsen A (2009) 'Public health genomics (PHG) and public participation: points to consider,' *Journal of public deliberation* 5(1):7.
URL: www.publicdeliberation.net/cgi/viewcontent.cgi?article=1068&context=jpd
Countries: United Kingdom; Canada
Community: General public
Health system area: Health policy deliberation; Oversight, monitoring and evaluation
Summary: Public health genomics combines genetics, medicine, lifestyle, behaviour, and other environmental factors to better understand what makes people healthy. Large-scale population biobanks, which collect biological tissues, personal health information, and genomic data, are being introduced worldwide to increase knowledge on chronic diseases such as diabetes and heart disease, to support health promotion and preventive public health. Experts recognise the need for public participation to address the many social, legal and ethical complexities raised by the introduction of biobanks for public health research. This paper presents the definition and goals of public participation; the timing and tools of participation; and the evaluation of public impact. These principles were applied to three large scale genetic biobank projects – 1 in Canada and 2 in the United Kingdom (England and Scotland). A separate biobank deliberation project (the British Columbia Biobank deliberation project) had conceptualised public participation as a way for the public to discuss their hopes and concerns about biobanks, and provided a frame of reference for the study. The three case studies indicate that participation is necessary in assessing a variety of goals including but not limited to: improving relationships with the public, and increasing public confidence in biobanking projects. Participants included people from urban and rural areas, members from organised groups, users of services, and marginalised populations. Participation focused on informing or educating the public, and on gathering information to help shape the development of the biobank. Different designs and tools were used to facilitate public participation including newsletters and websites to inform the public, questionnaires and opinion polls to take the pulse of the public, and workshops or focus groups to give the public the opportunity to inform the experts. Public participation was conducted in the early stages when the biobank projects were still being defined; but there was limited knowledge on the effects of this or on how public input would be incorporated into the long range plans for biobanks. This needs further evaluation studies.
Keywords: participatory policy deliberation; biobanks; public health research; UK; Canada

Citation: Blakey H (2005) 'Participation - why bother? The views of Black and Minority Ethnic mental health service users on participation in the NHS in Bradford,' report of a community research process undertaken by the International Centre for Participation Studies, University of Bradford and Sharing Voices (Bradford).
URL: https://bradscholars.brad.ac.uk/bitstream/handle/10454/3798/PWB_report_Aug_05_full.pdf?sequence=1&isAllowed=y
Country: United Kingdom
Community: Service users
Health system area: Health policy deliberation
Summary: The NHS and other service providers have made progress in developing mechanisms for user participation but do not always reach all sections of the community. The *Participation – Why Bother?* project (2005) aimed to identify how the process of involving people in decision-making in the NHS could be improved for voices from black and minority ethnic (BME) communities to be heard, and for BME communities to be involved in decision-making on health services, particularly in mental health services. Five community workshops with 63 people were held, followed by a workshop for key health service providers from Bradford District, to facilitate a dialogue between community participants and service providers; to help community members reflect on the value of participation for them; and to help service providers identify organisational barriers to greater participation. Following this a joint meeting of both community participants and service providers was held. The community workshops revealed a wealth of skills, knowledge and

experience, which service providers could be using to improve services. The biggest barrier was the belief that the health service will not listen, and that change won't follow. Participants did not feel valued as a source of solutions, lacked information, were disempowered and so did not feel encouraged to invest time and energy in engaging. The workshops, however, provided an opportunity for people to reflect on participation in the health service, and on internal barriers to this and to address key attitude constraints. The final session allowed all to discuss achievable developments within the participation structures, service providers to demonstrate to members of the BME communities the value placed on their participation, and for community participants and health service staff to make plans to implement community recommendations.
Keywords: health policy; marginalised communities; mental health; United Kingdom

Citation: Chilaka MA (2015) 'Drawing from the well of community participation: an evaluation of the utility of local knowledge in the health impact assessment process,' *Community Development* 46(2):100-10.c
URL: www.tandfonline.com/doi/abs/10.1080/15575330.2015.1014060
Country: United Kingdom
Community: General public
Health system area: Health policy deliberation
Summary: Engagement with local residents is increasingly being used as a source of evidence for making health impact assessment (HIA) predictions. HIA aims to improve the quality of policy decision-making through recommendations to enhance predicted positive health impacts and minimise negative ones, but has been criticised for weak community engagement. A study to investigate the constraints of engagement and to gauge the usefulness of local knowledge in HIA evidence was implemented with 52 HIA practitioners in the UK. The study found that 81% had undertaken engagement with local residents, through focus groups, workshops, questionnaire surveys, interviews and other less common approaches. More than one-third of the practitioners found engagement difficult despite rating local knowledge to be a useful source of evidence. Reported constraints in engagement included time constraints; poor attendance by residents; lack of resources (funds, personnel, venue, logistics); and conflict among residents. While focus groups and workshops were the most commonly used methods of engagement, the findings demonstrated the necessity of using several methods to engage with local residents in enriching the HIA evidence base, given the heterogeneity of communities. Local knowledge usefully complemented scientific knowledge with local context and perspective. Participants stressed the link between the quality of the engagement process and the quality of local knowledge gained. The authors suggest that community engagement processes should be further developed and refined and capacities built to strengthen the utility of local knowledge in HIA evidence.
Keywords: policy deliberation; health impact assessment; United Kingdom

Citation: Chilundo BG, Cliff JL, Mariano AR, Rodriguez DC and George A (2015) 'Relaunch of the official community health worker programme in Mozambique: Is there a sustainable basis for iCCM policy?' *Health Policy and Planning 30 Suppl 2*: ii54-ii64. 10.1093/heapol/czv036 [doi]
URL: www.ncbi.nlm.nih.gov/pubmed/26516151?dopt=abstract
Country: Mozambique
Community: General public; CHWs
Health system area: Health policy deliberation; health planning and budgeting; Implementing and co-ordinating health action
Summary: In Mozambique, integrated community case management (iCCM) of diarrhoea, malaria and pneumonia is embedded in the national CHW programme, mainstreaming it into government policy and service delivery. Since 1978, the CHW programme (Agentes Polivalentes Elementares (APEs) has functioned unevenly, was suspended in 1989, but relaunched in 2010. Despite the suspension, many APEs continued working, often supported by NGOs. The MOH also continued to supply APEs with medicines through a kit system adopted in the 1980s. Sporadic attempts were made by the government to revive the APE programme, in 1992 and 1993. The 2010 CHW programme aims to extend community access to health care by 20% and deploy 6343 APEs by 2015/16. Document review and key informant interviews with respondents from the Ministry of Health (MOH), multilateral and bilateral agencies and NGOs in Maputo was implemented in 2012. Factors supporting sustainability included: consultative development across MOH departments and partners; review of national policies and guidelines, such as on non-payment of APEs; changes to regulations to allow APEs to prescribe certain medicines;

operational guidelines and tools; standardising training; giving APEs the necessary equipment and supplies to carry out their tasks; upgrading the old APEs and including them in the revitalised programme; slow and careful implementation to enable learning, problem solving and adaptation; approval of standardised registers and reporting documents and commitment to demonstration of impact. Barriers identified included: Ministry of Finance exclusion from consultations; poor coordination with MOH departments and district level health services; short-term APE contracts, with low pay and no career path; low educational level blocking integration into public service; weak supply chain with frequent medicine stock-outs; weak supportive supervision systems; reliance on external funding for salaries, drugs, supplies and supervision; and a weak and decreasing contribution of the state budget to the health sector.
Keywords: policy development; determinants; CHWs; Mozambique

Citation: Freile-Gutiérrez B (2014) 'Participación ciudadana en el contexto de la evaluación de tecnologías sanitarias,' [Citizen participation in the context of health technology assessment] *Revista medica de Chile* 142:S27-32.
URL: www.scielo.cl/scielo.php?script=sci_arttext&pid=S0034-98872014001300005&lng=en&nrm=iso&tlng=en
Countries: Chile, International
Community: General public; service users
Health system area: Health policy deliberation; Enablers and barriers in health action; Meso-level supporting mechanisms
Summary: This paper provides an overview of public participation in health technology assessments (HTA) including a focus on Chile. It presents findings of a 2006 survey of consumer participation in HTA in countries belonging to the International Network of Agencies for HTA. The 2006 survey found that while there is 'consumer' participation in some aspects of the HTA process: it is not systematic; half of the HTA summaries of reports are not in a suitable form for citizens; and a third involve consumers in the dissemination of HTA materials. Most HTA agencies (83%) are however, interested in involving the public. Countries identified to better adhere to principles of community participation include UK, Germany, Sweden and Canada, and the Agency for Healthcare Research and Quality (AHRQ) and Centers for Medicare and Medicaid Services (CMS) in the United States are also noted to involve some level of participation. A 2011 review of successful practices identified that public involvement is brought in at two levels – consultation and participation in policy and research. Both deliberative and non-deliberative methods are used for citizen participation in HTA, where "deliberation" is defined as "analysis and weighting of the factors involved in the issue, to reduce uncertainty. Non-deliberative methods include citizen panels, focus groups, consensus building exercise, surveys, public hearings, open, citizen advisory committees, community planning, vision, notification, distribution and request for comment, referendum and structured referendum value. Examples of deliberative methods include citizens' juries, citizens' advice, planning groups, consensus conferences and deliberative voting. In the case of Chile, the National Health Strategy 2011-2020 makes a commitment to increase to 100% the proportion of health services and regional Ministries of Health who have implemented mechanisms for citizen participation and users, and the exercise of rights. This includes the process of setting the Explicit Health Guarantees (GES), where a range of activities have been taken including: *focus groups* in 2008 to determine the importance attached by the population to health problems included in the trial *(non deliberative* method, field *policymaking* level, *consultation);* three studies were conducted by government to establish social preferences in the GES such as the social prioritization of investments in health (1996) and a GES Advisory Council in 2006 that includes patient testimonials and a dialogue with civil society *(non-deliberative* method, at *policymaking* level, level *information).*
Keywords: health technology assessment; participatory review; international; Chile

Citation: Guizardi FL, Pinheiro R (2008) 'Novas práticas sociais na constituição do direito à saúde: a experiência de um movimento fitoterápico comunitário,' [New social practices constituting the right to health: the experience of a community phytotherapy movement,] *Interface - Comunic., Saúde, Educ* 12(24):109-22.
URL: www.scielo.br/scielo.php?script=sci_arttext&pid=S1414-32832008000100009
Country: Brazil
Community: Urban residents
Health system area: Health policy deliberation; Implementing and co-ordinating health action

Summary: The study reports experiences of phytotherapeutic (herbal) pharmacies in the municipalities of Vitória and Vila Velha in Brazil. The experience takes place in the context of a popular movement, where health service users chose a different type of care to meet their health needs. Local (church supported) community pharmacies provide an alternative to the biomedical approach to health. Over half of the residents (52%) reported choosing herbal medicine, only a minority linking it with ease of access (7%), or as an aid to western medicine (5%), and 18% referring directly its effectiveness, "natural" aspects, with less side effects. Respondents found the community pharmacies more caring, they were treated without discrimination and or regard to their capacity to pay, and they were also described as community gathering places, with people meeting and exchanging experiences. Ministry of health issued guidance on the use of alternative therapies was seen to be a response to community led demand. The authors suggest that these local community actions establish a counterbalance to the power devices and mechanisms in healthcare, thus opening up new possibilities for constructing citizenship rights.
Keywords: herbal medicine, health rights; community demand; Brazil

Citation: Haworth R, Melling B (2010) 'From rhetoric to reality: breaking down the barriers. To what extent are service users collaborating in decision making processes within the NHS?' paper presented at *Breaking down the barriers. Proceedings of the 13th International Research Conference*, Staffordshire University (10-11 September 2009)
URL: http://usir.salford.ac.uk/18956/5/Breaking_down_the_barriers_paper_2009.pdf
Country: United Kingdom
Community: General public
Health system area: Health policy deliberation
Summary: The white paper *The new NHS modern and dependable* (1997) and subsequent legislation (1999, 2000 and 2006) together with *The Local Government and Public Involvement in Health Act* (2007) set an agenda for greater public participation in local health services delivery in the UK. The NHS has historically used either a democratic or consumerist model for including patients and the public in health policy decision-making. The democratic approach is premised on the right of citizens and taxpayers to health services but also to participate collectively in managing such services, such as through the no longer operational Community Health Councils and Citizens' Juries. These approaches were criticised because of the lack of representation for different sections of society. The consumerist approach is modelled on the consumer/provider or supplier relationship with key examples being the 1992 Patients' Charter which set out a number of rights and standards that seemed mimic the expectations of commercial market relationships such as the right to choose a GP and rights to complaints procedures. The more recent policies (2007 Act) include elements of both democratic and consumerist approaches. Service users are democratic citizens with 'social rights' and individual consumers of local health care services. Decentralisation has also contributed to a shift in governance and led to the concept of participative governance. However, the way some forms of knowledge and expertise are valued over others mean that lay people who participate on governance bodies may end up being marginalised. Therefore, training of lay people is proposed to equip lay participants in management knowledge and attributes to participate so that their contribution is not to remain tokenistic. To move England beyond a weak track record in public participation in decision making in the NHS the authors recommend: (i) a clearer definition of participation in government documentation that can be easily identified and understood by those using and providing NHS services; (ii) better information for the public about their right to participate in decisions; (iii) managers to be better trained in sharing decision making; and (iv) inclusion of the most marginalised groups in decision making processes.
Keywords: Health policy; democratic model; consumerist model; United Kingdom

Citation: Jakubowski E, Lister G, Skavron R (2006) 'Ninth Futures Forum on health systems governance and public participation: Amsterdam, The Netherlands, 10-11 October 2005.' WHO Regional Office for Europe: Copenhagen.
URL: http://apps.who.int/iris/bitstream/10665/107357/1/E89766.pdf
Countries: Belgium, Finland, France, Germany, the Netherlands, Portugal; European region
Community: General public
Health system area: Health policy deliberation; Meso-level supporting mechanisms
Summary: This Futures Forum was organised to review the progress European countries are making in public participation in health policy and to learn from country experiences. A national

level public consultation in France (1998) involved the public in the decision making process and integrated public opinion in generating policy options for excluding certain medicines from the package of benefits under solidarity funding. The 2006 health reforms in the Netherlands focused on introducing greater competition and choice in statutory health insurance coverage. The 2004 reforms in Germany invited patients' representatives (NGOs, consumer agencies and self-help groups) to participate in the Federal Joint Committee of Sickness Funds, Physicians and Hospitals, deciding on coverage. Public involvement in priority setting in regional level planning processes is outlined in Sweden through general elections of county councillors and public health committee meetings. The federal Patients' Rights Commission in Belgium and, public participation in strategic health planning in Portugal are also included. Three factors were identified as preconditions for participation in policy making: (1) the quality of health education and information; (2) transparency; and (3) health system design including locating voice, representation and choice within the current culture of each health system, and the policy under consideration. For example, representation may be more appropriate than surveys when dealing with system-wide changes at the national or local level. Irrespective all mechanisms require: political commitment and training at all levels for behaviour change; a legal basis for patients' rights; a network organisation to support local initiatives and technical resources such as training; measures of patient perception and expertise to engage communities across ethnic and social divides as part of a broadly based approach to active citizenship.

Keywords: Health policy; voice; representation; Europe

Citation: Lehmann U and Matwa P (2008) 'Exploring the concept of power in the implementation of South Africa's new community health worker policies: A case study from a rural sub-district,' EQUINET Discussion Paper Series 63. EQUINET, CHP: Harare.
URL: https://equinetafrica.org/bibl/docs/DIS64POLlehmann.pdf
Country: South Africa
Community: Rural residents; CHWs
Health system area: Health policy deliberation
Summary: This study explored how policies are shaped and transformed in the implementation of two CHW policies in a rural sub-district in South Africa. Key informant interviews and focus group discussions were undertaken with CHWs, members of 3 community health committees and the provincial health promotion directorate. Results show that tensions between role players, as well as selective communication and lack of information, led to a 'thinning down' of a complex and comprehensive policy to focus solely on the payment of stipends to CHWs. As frontline implementers at the district and community levels did not have information to understand the content and scope of the policy, their actions were shaped by what they were informed about: the need to pay stipends to selected CHWs and to have them work in specialised fields. While they did not have the power to change the rules that were set and implemented by the provincial actors, they used their knowledge of local conditions, control over local knowledge and distance from the provincial capital to shape implementation at the service level. Information, communication and knowledge turned out to be the most crucial elements impacting on how the policies were translated into practice. Access to information allowed the provincial actors and facility managers to select which aspects of the policies they wanted to see implemented, choosing the narrowest possible interpretation of the policies. Both were concerned primarily with 'conformance' rather than 'performance'. The exercise of authoritative power by the province and NGOs rendered CHWs powerless, except for their ability to withdraw their input – which many of them did at the expense of coverage and access. All but one role player used power, whether authoritative or discretionary, to narrow and thin the scope of the policy from its initial intent. This one role player, used her discretionary power, against resistance from authority, to strengthen the underlying values and the mission of the policy. While this person did not 'conform' to policy processes, as set out by authority, she enhanced the 'performance' of the policy through her actions. General recommendations were made: to regard implementation "as an integral and continuing part of the political policy process rather than an administrative follow-on"; to ensure that policy formulation accompanies implementation; to begin any policy development by assessing the status quo; and to develop less fixed and more flexible policy documents suited to negotiation and to being reshaped during implementation.
Keywords: Health policy; CHWs; South Africa

Citation: Lehmann U, Gilson L (2013) 'Actor interfaces and practices of power in a community health worker programme: a South African study of unintended policy outcomes,' *Health policy and planning* 28(4):358-66.
URL: http://heapol.oxfordjournals.org/content/28/4/358.full.pdf+html
Country: South Africa
Community: Rural residents
Health system area: Health policy deliberation
Summary: This paper reports on micro-practices of power by those at the frontline of service delivery in the implementation of a national community health worker (CHW) policy in a rural South African sub-district. Power was categorised as 'power over, power with, power to and power within'. The sub-district is both implementation tier and plays a mediating role between provincial and national policy makers and frontline service providers in facilities and communities. In the early 2000s new, government-led CHW initiatives were advanced through a policy framework aimed at harmonising and institutionalising existing CHW projects; and a national government large-scale job-creation programme across health and other sectors to reduce unemployment through basic skills training. The two policies were implemented as one programme in the health sector, drawing on pooled funding (from the health and public works departments) creating work opportunities through skills development, with a stipend paid by government. Prior CHW programmes were led by non-profit organisations, received no government payment, with voluntary mature female CHWs who had limited formal education, often serving for many years. The new programme gave preference to younger, more educated CHWs who would receive stipends. This led to a tension in implementation of the policy at district and sub-district level undermining implementation of the skills development; leading CHWs to withdraw services; and lack of acceptance of younger paid CHWs by communities. The findings suggest a need to frame policy implementation strategies in a manner responsive to complex, multi-layered power practices, with space for implementers in negotiation with others to translate and re-formulate policies in ways that support innovation, local learning and local adaptation.
Keywords: policy implementation; community health workers; South Africa

Citation: Matos AR (2011) ' A importância da participação cidadã nas políticas de saúde: o caso da reestruturação dos serviços de saúde materno-infantil em Portugal,' [Citizen Participation relevance in health policies: the case of the maternal and child health services restructuring in Portugal] *Saúde e Sociedade* 20(3):604-16.
URL: www.scielo.br/pdf/sausoc/v20n3/07.pdf
Country: Portugal
Community: General public
Health system area: Health policy deliberation
Summary: This study describes and analyses the maternity wards closure in Portugal, as part of the restructuring of maternal and child health services (May 2006 and December 2007), and the consequent protest actions by those affected by the measure. A decision to close maternity wards with less than 1500 deliveries per year - based on a report by a Committee of obstetricians, paediatricians, nurses and midwives - sparked extensive debate on the criteria used to determine the concentration of births in maternity wards, on infant mortality and on equal access to quality services. When 9 out of 23 maternity wards which failed to meet the 1500 births/year threshold were closed, the population of these villages protested, in various ways, for about two years against the closure. The 2006 protests focused on the potential cost cutting nature of the move, on the failure to supply the required human and technical resources to ensure quality or improved services; and to detail arrangements for ensuring that women who lived distances greater than 20km or 30 minutes from the maternity wards were accompanied by a nurse specialist. The protests included road blocks, slow marches, vigils, imposing symbols for mourning in buildings and public spaces and legal action, including filing of interim measures and billboards placed at strategic points in Portugal and with party logos. Protestors were largely the residents of localities with closed maternity wards and local government opposition parties. Some of the firefighters' unions participated because they were responsible for the transport of urgent patients. While the protest actions were not regarded by government as legitimate spaces for citizen participation, they indirectly created other spaces for dialogue. In certain areas (Amarante, Lamego and Oliveira de Azeméis) protests led to the immediate visit of the Minister of health who compromised with the population to improve local health services.
Keywords: health services; citizen protests; policy making; Portugal

Citation: Oh J, Ko Y, Alley AB, Kwon S (2015) 'Participation of the Lay Public in Decision-making for Benefit Coverage of National Health Insurance in South Korea,' *Health Systems & Reform* 1(1):62-71.
URL: www.tandfonline.com/doi/pdf/10.4161/23288604.2014.991218
Country: South Korea
Community: General public
Health system area: Health policy deliberation; Enablers and barriers in health action
Summary: Public pressure to increase the National Health Insurance (NHI) benefit in South Korea since the early 1980s led the NHI Services in 2012 to establish a lay citizen's council, named the Citizen Committee for Participation (CCP), to help incorporate social value judgments in prioritising benefits. The CCP procedures were tested and refined through three experimental councils held in 2008, 2010 and 2012. The Accountability-for-Reasonableness was used as a guiding framework. It defines practical conditions to seek reasonableness when a society needs to make a decision in a limited resource setting. The first CCP was held in September 2012 and included 30 people who were randomly selected out of a group of 2,650 applicants, excluding those who did not meet the definition of "lay public" (such as those with neither expertise nor strong financial interest in the policy area). At the first CCP conference, the number of Committee members supporting an increase in the premium for better benefit coverage rose, and the number of medical service items the Committee agreed to be covered fell slightly, after information and deliberation were provided. The official body accepted nine service items that were at the top of the priority list of 23 items supported by the lay public committee for coverage expansion in 2013. There was no political criticism or policy debate, following allocation of budget to cover these new items in 2013. The CCP was institutionalised as an annual conference by the NHI service. Areas identified for improvement include making the findings of the Committee publicly available and allowing enough time for information provision and deliberation, beyond the two-days in the past. The Korean experience indicates that the general public does not necessarily demand ever-increasing benefits when they are as involved in the process.
Keywords: Health policy; Citizen Participation; benefit packages; insurance; South Korea

Citation: Ottmann GF, Laragy C (2010) 'Developing consumer-directed care for people with a disability: 10 lessons for user participation in health and community care policy and programme development,' *Australian health review* 34(4):390-4.
URL: www.publish.csiro.au/?act=view_file&file_id=AH09759.pdf
Country: Australia
Community: Children with disabilities
Health system area: Health policy deliberation; Implementing and co-ordinating health action.
Summary: This paper outlines lessons derived from a longitudinal study conducted between 2003-2008 on the development of a 'consumer' directed care programme for families with disabled children in Melbourne. A Consumer-Directed Care (CDC) project for people with disabilities and their carers or families was hosted by a large Australian provider of aged and social care. The CDC gives individuals with disabilities skills to maximise control of their lives and their environment, for people assess their own needs, determine how and by whom these needs should be met, and to monitor the quality of services received. The project was constructed in three stages. Potential participants and knowledge and infrastructure were identified for the participatory approach. Participants received detailed briefings about a variety of CDC approaches and met with families in already established CDC projects. A project steering committee and two participant working groups were formed to drive the development of policies and procedures and to design innovative housing solutions for people with disabilities. In the development phase a project officer was employed, policies and procedures developed within the overall operational and administrative infrastructure of the provider, informal support groups created, consumer feedback and evaluation processes designed and safeguards developed to protect and support participants. In the subsequent development phase, the CDC programme was fine-tuned and evaluated. Ten lessons were identified: (1) engage users in the design process as early as possible; (2) use open, inclusive communication, understanding potential concerns and framing the policy issue to build trust and meaningful collaboration; (3) weave various strands of evidence together; (4) lever ongoing commitment and support from management and key stakeholders; (5) implement knowledge transfer and cultural change processes, with (6) capacity building; (7) mediation of power differentials; (8) community building; (9) participant reengagement strategies; and (10) solid project management skills.
Keywords: consumer-directed care, people with disabilities; participation; Australia

Citation: Park Y, Kim CY, You MS, Lee KS, Park E (2014) 'Public participation in the process of local public health policy, using policy network analysis,' *Journal of preventive medicine and public health* 47(6):298-308.
URL: www.ncbi.nlm.nih.gov/pmc/articles/PMC4263003/pdf/jpmph-47-6-298.pdf
Country: South Korea
Community: Urban residents
Health system area: Health policy deliberation
Summary: In Korea, public health citizen groups and private sector have made consistent efforts to establish a participatory forum for hearings and discussions on public sector policies, including in relation to health insurance. This paper reviews the local level policy process using a policy network analysis with participants of the policy network. The analysis showed that the public is not yet actively participating in the local health policy decision-making and implementation. In decision-making, most of the network actors were public sector actors, while others participated in only a limited number of issues after the major decisions were made. In the implementation process, the programme was led by the health centre, while other actors participated passively.
Keywords: policy deliberation; health insurance; Korea

Citation: Quantz D, Thurston WE (2006) 'Representation strategies in public participation in health policy: the Aboriginal Community Health Council,' *Health policy* 75(3):243-50.
URL:www.researchgate.net/publication/7372983_Representation_Strategies_in_Public_Participation_in_Health_Policy_The_Aboriginal_Community_Health_Council
Country: Canada
Community: Indigenous community
Health system area: Health policy deliberation; Enablers and barriers in health action; Meso-level supporting mechanisms
Summary: Since the 1980s, Canada has introduced university-based recruitment and training programmes for Aboriginal health care workers and a Community Health Representative programme providing a referral link for Aboriginal persons to existing health care services, with a focus on service delivery. More recently, several Aboriginal advisory committees have been established, working with government health planners at provincial and regional levels. Health care reform in Canada has focused on decentralisation/ regionalisation of health services. In Alberta, government legislation creating regional health authorities requires each authority to have a Community Health Council to provide input from the general public. In 1996 the Calgary Health Region created an Aboriginal Community Health Council (ACHC) to promote provision of culturally appropriate health services for Aboriginal people in metropolitan Calgary and several First Nation reserves. The Council was comprised of 18 individuals appointed through a nomination and review process intended to reflect the diversity of the Aboriginal population. This was partially achieved through Council by-laws and informal efforts to identify under-represented groups. Non-members could also attend the ACHC and make announcements or raise concerns with many observers later becoming formal Council members. The public was involved in partnerships with community organisations, networking, consultation activities and the identification of special needs groups. The Council provided adaptable process to support long-term relationships and opportunities for participation in health policy development; support the enabling structures; and good working relationships with various health region staff and health region board members.
Keywords: policy deliberation; Aboriginal Health Council; indigenous community; Canada

Citation: Rasanathan K, Posayananda T, Birmingham M, Tangcharoensathien V (2012) 'Innovation and participation for healthy public policy: the first National Health Assembly in Thailand,' *Health expectations: an international journal of public participation in health care and health policy* 15(1):87–96
URL: http://onlinelibrary.wiley.com/doi/10.1111/j.1369-7625.2010.00656.x/epdf
Country: Thailand
Community: General public
Health system area: Health policy deliberation; Meso-level supporting mechanisms
Summary: The new 1997 Thai constitution emphasised participatory democracy and decentralisation. National health assemblies (NHA) have been held annually since 2001, as a mechanism to promote active multi-sectoral involvement in the formulation of healthy public policy. The NHA seeks to improve intersectoral collaboration and public participation to develop healthy public policy. By 2008 the NHA brought together over 1500 people from government agencies, academia, civil society, health professionals and the private sector to discuss key health issues

and produce resolutions to guide policy making. The assemblies contributed to the enactment of a new National Health Act in 2007, the establishment of the National Health Commission (NHC) and Office overseeing the annual NHA, with the NHA organising committee (NHAOC) involving at least 60% of members from outside government agencies and aiming to reflecting all stakeholders' members. The NHA approach is adapted from the annual World Health Assembly of the World Health Organization. NHA resolutions are not binding on policy makers and service providers, aiming to support compliance by setting norms that derive legitimacy from the process and range of actors involved in their formulation. All constituencies can submit proposals for agenda items to the NHAOC that are selected using pre-determined criteria, viz: public health importance; public interest; and potential for policy development and implementation. The NHAOC then commissions a technical background paper and a draft resolution for each item, made available to all constituencies, and published on the NHA website. All constituencies at the NHA have equal speaking rights. New or revised resolutions can be proposed and only passed by consensus. Where consensus cannot be reached the chair of a subcommittee may establish a working group and the item deferred to the next NHA to allow time for consultation and consensus-building. The NHA – costing overall YS$1 million- is funded from the annual budget of the NHC Office. Three challenges are identified: does the representation of groups and networks who attend adequately reflect the real health needs of the country; how does the NHA ensure the implementation of its resolutions; and how to develop networks and build capacity in the health assembly process, especially in the process of developing recommendations, considering resolutions and advocating their implementation?

Keywords: policy deliberation; national health assembly; Thailand

Citation: Thurston WE, Vollman AR, Meadows LM, Rutherford E (2005) 'Public participation for women's health: strange bedfellows or partners in a cause?' *Health care for women international* 26(5):398-421.
URL: www.calgaryfamilymedicine.ca/Research/pubhidden/182-before-2010/649-682public-participation-for
Country: Canada
Community: Women; rural residents
Health system area: Health policy deliberation
Summary: One focus of health system reform in Canada in the 1990s was the regionalisation of health services administration, including a commitment to public participation in planning by some health authorities. Women were reported to perceive their participation as minimal and their needs as not addressed, despite this commitment. This case study explores the partnership between a regional health authority and a faith community, and how this collaboration impacted on women's participation in health policy development. Surrounding the formal partnership of the government health services and Salvation Army was a less formal or informal network of connections that supported both the faith community and the health services. This included an active network of women's health NGOs such as the Women's Health Collective; a network of reproductive services; a network of shelters for abused women; the Calgary Action Committee Against Violence; the Calgary Immigrant Women's Association; and the Calgary Communities Against Sexual Assault a partnership of state services providing medical services to the victims of sexual assault through the Calgary Sexual Assault Response Team. Through these organisations, the collective voices of individual women are captured and delivered to policy and decision makers. The development of a formal partnership was a success in this case. The greatest success for women was maintenance of a political space in which women's health as a priority could be discussed, allowing women's organisations to challenge the status quo in health service delivery and to advocate for equity. It introduced the opportunity for gendered analysis and feminist philosophy and highlighted the role of informal communication in formal participation mechanisms. The partnership is a creative example of how a governmental body can work with a faith community and nongovernmental organisations to meet common goals in women's health.
Keywords: policy implementation; women's health; partnership; Canada

Other publications including information about social participation in *health policy deliberation* listed elsewhere in this document include:
1. Jeffrey and Ervin (2011); and Mubyazi et al (2008) in *Section 3.2*;
2. Greenspan et al (2013); and Murray (2010) in *Section 3.3*;
3. Cornwall and Leach (2010) in *Section 3.7*; and
4. Bispo Junior and Martins (2012); and Cross et al (2008) in *Section 3.8*.

3.5   Participation in designing, implementing and co-ordinating health action

Country: Malawi
Community: Urban residents
Health system area: Implementing and co-ordinating health action
Summary: This paper reports on the Tingathe approach in 2007-2011 in Lilongwe District Health Office Malawi working with CHWs, to improve uptake and utilization of prevention of mother-to-child transmission (PMTCT) of HIV, early infant diagnosis and care and treatment of HIV-exposed infants (HEI) and HIV-infected children (HIC). Recruitment and training of CHWs in community sensitisation and education, health-centre and community-based HIV testing and counselling (HTC) and active case finding of patients was undertaken. CHWs had to be literate in English, to have completed primary school, live in the catchment area, be able to ride a bicycle and be HIV-infected or affected. Selection was through group interviews, followed by individual interviews. Training involved a 10-week programme and quarterly half-day refresher training. CHWs were paid between $50-100 per month, given a bicycle, mobile phone airtime, and bags for supplies and materials. Each CHW has a patient load of 50-100 clients at one time, is supervised weekly by the Site Supervisor and monthly by the programme coordinator, with biannual performance evaluations. CHWs enrolled HIC in clinical care and provided adherence support, and were assigned to HIV-positive pregnant women during antenatal care as part of the PMTCT component. CHWs followed the women at home and the health centres, from initial diagnosis up until cessation of breastfeeding and final testing of infants, with either discharge or successful enrolment of HIC into care. This resulted in a greater than seven-fold increase in average rate of monthly HEI enrolment, and earlier median age of enrolment for the infants. The results demonstrated the importance of a comprehensive strategy for identification of HIC due to possible lack of awareness about availability of HIV services for children. These findings demonstrate that a multipronged approach utilising CHWs can improve identification and enrolment into care of HEI and HIC.
Keywords: HIV/AIDS; PMTCT, early infant diagnosis; CHWs, Malawi.

Country: Pakistan
Community: Rural residents
Health system area: Implementing and co-ordinating health action.
Summary: This study explored the comprehensiveness of the primary health care approach applied in Pakistan's National Maternal, Newborn and Child Health (MNCH) Programme launched in 2005, and its level of community participation. A key strategy was the introduction of community midwives (CMWs). Community participation was limited to awareness raising. There was not much knowledge among communities about their role in health programmes or about the MNCH programme in their area. CMWs complained about the community's perceptions of them. CMWs are usually volunteers selected by the community, and accountable to the community. However, the government pays the CMWs, creating a potential accountability issue. Service providers reported that politicians influenced the selection of MNCH Programme Managers and CMWs at the district level, negatively affecting communities' acceptance of CMWs and their accountability to the community. Competing interests developed between CMWs, and other community health workers such as lady health workers (LHWs), despite the fact that they were meant to coordinate and cooperate with each other. In theory, LHWs introduce CMWs to the community and refer cases to them; the two cadres collaboratively develop referral and transport networks; and collaboratively hold planning workshops to mobilise the community for establishing referral and transport linkages. However, the study found that the LHWs expressed ignorance of the presence of CMWs, and CMWs reported lack of cooperation from LHWs. The main recommendation was that the primary health care programme needs to be revised to incorporate current thinking on community participation, intersectoral action and evidence-based decision-making.
Keywords: community midwives; CHWs; Pakistan.

Citation: Banerjea N (2011) 'Voluntary participation and self-governance: A study of community health volunteering in Kolkata, India,' *Cultural Dynamics* 23(3):197-218.
URL: http://cdy.sagepub.com/content/23/3/197.short
Country: India
Community: Urban residents
Health system area: Implementing and co-ordinating health action
Summary: Participatory discourse rarely focuses on how female volunteers understand their participatory role in community programmes. It is therefore important to look at why and where urban poor women continue to partner with the state (or not) in delivering essential health services to their peers. This study draws on personal and collective assessments of a group of 18 women volunteers in an urban slum in east Kolkata, India in 2001-3. The women were volunteers in a reproductive and child health (RCH) programme seeking to support access to these services through community involvement, for an allowance of $4. The volunteers: were marginally educated; involved in a range of regular and irregular wage work; had an average income of US$13 per month and an average joint family income of about US$71 per month. They received ongoing training to maintain the health records of approximately 100 households in her neighbourhood; provide health education; offer primary health care, contraceptives, vitamin supplements and other simple remedies; and sustain provision of basic health advice. Volunteers were supervised by paid NGO employees and tested on their knowledge during training. The volunteers demanded a wage increase when frustrated by the increasing workload i.e. from 50 to 100 households. The demand was accompanied by acts of resistance e.g. leaving a meeting early, and the threat that they would collectively stop working. While they did not carry out their threats, they showed that they were not merely passive and consenting actors but 'irritable participants'. The findings indicate that the women developed an ambivalent relationship with their volunteering roles and demanded a 'salary' equivalent to their 'work'.
Keywords: community health workers; reproductive health; payments; India

Citation: Bang C (2015) 'Promoting Mental Health and Community Participation: A study on participatory arts practice, creativity and play in the city of Buenos Aires, Argentina,' *Health, Culture and Society* 8(1):61-71.
URL: http://hcs.pitt.edu/ojs/index.php/hcs/article/view/183/242
Country: Argentina
Community: Urban residents
Health system area: Implementing and co-ordinating health action
Summary: In Argentina, the National Law for Mental Health 2010 provides for a transformation from the asylum-based approach to a comprehensive approach model but enforcement has been variable. Outside this official discourse, isolated initiatives have emerged through healthcare and mental health professional teams working jointly with community organisations. Many use art and play and create spaces for community participation. This paper describes one such initiative in Buenos Aires in a setting of a number of migrants precariously working and settled in tenements, family hotels and squatted houses, who were widely deprived of their basic rights. In 2006, a few institutions from the neighbourhood created a territory-based institution network to work for a better quality of life drawing on growing community participation, mental health promotion. Ten-fifteen state and civil society organisations work with two participating health institutions (a Community Action Health Centre at the first level of care in a General Hospital, and an Outpatient Mental Health Centre). The joint actions involve organising collective events in public spaces and streets with art, creativity and play. Participatory processes were used to organise the event(s); in the collective artistic creation; and in the progressive participation of health professionals in network activities. The authors conclude that such experiences have transformative potential, creating community conditions suitable for joint decision-making within health care.
Keywords: Mental health; social networks; marginalised groups; creative arts; Argentina

Citation: Bhengu BR (2010) 'An investigation into the level of empowerment of rural women in the Zululand district of KwaZulu-Natal province of South Africa,' *Curationis* 33(2):4-12.
URL: www.ncbi.nlm.nih.gov/pubmed/21469511
Country: South Africa
Community: Rural residents; women
Health system area: Implementing and co-ordinating health action
Summary: An empowerment project to improve the participation of rural women in primary health

care (PHC) was launched in Zululand district, South Africa in 1999. It sought to enable women in the locality of the clinics to play a more active and informed role in their health and that of their families through local nurses. It included three modules: (1) economic, justice and political enlightenment; (2) health and health promotion; and (3) education, gender issues, power and change, including communication. Nurses from Primary Health Clinics in the project received 2-days training to run empowerment groups for women, supported by a teaching guide on content, methods and visual aids. The training focused on: human rights; domestic violence and how to deal with it; how to access social assistance; the promotion of good education for children; the promotion of health of self and family; caring for a family member who is ill; and income generation. Groups of women formed in collaboration by the clinics could apply for funding administered by the University of KwaZulu-Natal for income generation projects coordinated by the clinic staff. The women were taught how to conduct business including writing of business plans and banking. An evaluation of the project covered 2 funded clinics; 2 not funded; and 2 clinics that had not progressed. Eight themes emerged: i. women's groups engendered a climate of sharing and support; ii. women were enabled to act as resource people, educating and advising women in the community; iii. communication improved among women and within the wider community; iv. the survival economy improved with a range of income generating projects; v. self-reliance was fostered by the project, with women making plans without consulting their husbands or waiting for government support; vi. charity was fostered e.g. sharing of fresh produce with needy communities; vi. women reported their husbands becoming more accommodating about them attending meetings; and viii. attendance at clinic meetings was seen as evidence of women realising their rights. A partnership developed between the groups and the PHC nurses, with sharing of resources such as the empty clinic rooms for group activities, and women's groups assisting with clinic activities. The study revealed some improvement in the women's realisation of their rights, and in communication, self-confidence and reliance. The authors recommend education for empowerment to be transformative, and for people to network for financial and technical support.
Keywords: community education; empowerment; South Africa

Community: General public; CHWs
Health system area: Implementing and co-ordinating health action
Summary: The Family Health Strategy (FHS) in Montes Claros, State of Minas Gerais is a model of comprehensive health care with social relations between family, community and professionals. The FHS teams are multi-professional with differing competencies and skills. The Community Health Agent (ACS) is a key figure in the FH team (health family) and maintains the flow of information between families and the other professionals in the team. ACSs make family registrations and home visits, identify familial ties with health risks and inform the family health team. A median of 40 home visits were made weekly, with ACSs spending a median of 120 hours monthly. ACSs instruct families about available health services, arrange referrals and schedule consultations/ exams, perform health education and teamwork reflections. They work with groups of different sizes for health education – from 20 up to 50 people. Some also assist in the clinical environment. Most ACSs spend time on health promotion and prevention of diseases including community mobilisation for collective sanitation and environmental improvement. Health surveillance activity was mostly performed by female ACS. The majority of ACSs who provide health education and those who are responsible for referrals feel they are professionally qualified for such tasks. ACS are noted to be a core element of the system but should not be seen as a panacea for weak health systems. Their performance requires investment in professional training to maintain the quality of their work, with surveillance activities and teamwork assisting them to be jointly responsible for primary care with the rest of the team in the territory. The study found that teamwork in family health should be re-evaluated, and more time allowed for meetings and inclusion of ACS in planning of team activities. The ACS acts as a social mediator translating community needs to health staff and ensuring links and cultural identity for the population in the public health system.
Keywords: family health; CHWs; health teams; Brazil

Citation: Coyne P (2011) 'Ecocultural health and resilience in regional Australian communities: Mitigating the psychological distress of environmental crisis through community arts participation,' Thesis, Murdoch University: Western Australia.
URL: http://core.ac.uk/download/files/343/11237643.pdf
Country: Australia
Community: Rural residents
Health system area: Implementing and co-ordinating health action
Summary: Psychoterratic (psyche- mind, terra- earth) distress is identified in the concept of 'solastalgia': the loss of solace experienced in relation to negatively perceived environmental change in one's home environment, and is evidenced in mental health of regional Australians suffering the impacts of human induced (artificial) and natural, negatively perceived environmental change. This document proposes that community arts is a suitable vehicle to link issues of environmental health and community mental health, using an ecocultural health lens. Ecocultural health is a framework which incorporates human health as a subset of ecological health from the scale of global health to the health of small communities. Community arts can, it is argued, effectively seek to remediate local ecological health conditions and mental health issues within the community. Examples of community arts projects include: theatre making, film making, photography and music workshops for young people; community street performances using ecological issues to promote community dialogue; and a project for recording spoken and visual history of recent droughts affecting farming communities. Community arts can alleviate the burden on poorly or inadequately resourced regional mental health services and regional public health promotion efforts. Community arts has positive effects on pride and sense of place, with positive effects in turn on social cohesion and policy development.
Keywords: Health promotion, mental health; ecology social; community arts; Australia

Citation: Delgado-Gallego ME, Vazquez-Navarrete L (2006) 'Barreras y oportunidades para la participación social en salud en Colombia: percepciones de los actores principales,' [Barriers and opportunities for social participation in health: the main social actors' perceptions] *Revista de salud publica* 8(2):128-40.
URL: www.scielosp.org/pdf/rsap/v8n2/v8n2a01.pdf
Country: Colombia
Community: Urban residents; service users
Health system area: Implementing and co-ordinating health action
Summary: An exploratory qualitative study in 2000/1 assessed the views of community members, health personnel and policy-makers in two towns involved in implementing the Colombian policy for social participation in the towns to identify barriers and opportunities for community involvement. Health system and social reforms introduced in Colombia in the 1980s were underpinned by the principle of participation, and defined the different types of participation (citizen or individual and collective; community or institutional) and institutional mechanisms for this. Opportunities for participation were described in terms of suitable conditions such as mechanisms linked to companies or health services and or specific health personnel to handle complaints. Health personnel identified users' knowledge and attitudes as barriers for participation, together with their own inability or weak authority to change or control user participation. Identified barriers for personnel and users alike were their lack of knowledge, apathy and fear of revenge. Community groups/members also identified a lack of social cohesion and a lack of time, particularly among working age adults, as barriers. Registering a complaint was seen as a nuisance because people expected to be 'entangled' and sent from place to place with no result. Lack of institutional transparency, limited receptiveness and responsiveness regarding participation were seen as system barriers. Medical and administrative staff were seen to downplay user issues. In contrast policy-makers were confident in the law and saw obstacles to participation mainly in health institutions. Users perceived an ability to achieve change through their direct participation and both users and leaders saw the need for training of institutions, and users and leaders' appeared to be critical of their reality and saw themselves as key interlocutors with institutions and the state. The authors note that similar institutional actors would also need to see this community role to build and sustain a participatory culture.
Keywords: Health services; participatory practice; community; health workers; Colombia

Country: Afghanistan
Community: General public; CHWs
Health system area: Implementing and co-ordinating health action
Summary: Reconstruction efforts in Afghanistan integrated capacity investments for community based service delivery, including the deployment of over 28,000 CHWs to ensure access to basic preventive and curative services. The Basic Package of Health Services prioritised maternal and child health, birth spacing and disease control. One male and one female CHW were selected and trained for each village health post, serving up to 150 households. Their role included treatment of childhood diseases, provision of contraceptives, health promotion and demand-creation for preventive and maternal health services at the supporting health facility. The Community Based Health Care Department (established 2005) oversaw the deployment of a facility-based cadre of Community Health Supervisors and also introduced various incentive systems and mechanisms to maintain CHW motivation. Recently it implemented women's Family Health Action Groups, based on the Care Group Model. Female CHWs engage 10-15 respected female volunteers to conduct health promotion activities for around 10 neighbouring households, resulting in improved health behaviours, utilization of services, and improved child survival. Since 2005, the 28,459 CHWs were trained and deployed. However, over 50% of women are still not accessing antenatal care due to distance or transport and the increasing number of security incidents since 2009 have led to temporary or permanent facility closures. A capacity assessment of the CHW system indicated that more than 70% of the NGO's provide comprehensive training for CHWs, 95% CHWs reported regular supervision, and more than 60% of the health posts had adequate infrastructure and essential commodities. Barriers reported included unrealistic and expanding task expectations, unsatisfactory compensation mechanisms, inadequate transport and lack of commodities. The CHWs were reported to be highly valued and providing equitable, accessible and affordable 24-h care, and were appreciated by communities.
Keywords: health care; CHWs; maternal health; Afghanistan

Country: Norway
Community: Urban service users
Health system area: Implementing and co-ordinating health action; Enablers and barriers in health action
Summary: This study focuses on user participation in community mental health services in Norway based on the experiences of users and professionals within the same service. Data were collected from three community mental health centres which are part of the municipal services in a Norwegian city of approximately 150,000 citizens. The centres are defined as 'meeting places' or 'low threshold services' which can be used as steps towards rehabilitation for some and mainly a venue for social contact for others. No medical records are kept at the centres with users choosing how and when to access the centres. All informants valued user participation in the service and highlighted the importance of the environment. However, users and professionals gave different perspectives. Service users considered it important to have user-participation but also felt that mental health problems may lead people to feel too anxious to take part in activities or discussions. Keeping the centres safe and free from conflict was emphasised by all users in the study. Some also noted the importance of having competent leaders – users or professionals – who take responsibility and ensure that the centre functions. Professionals saw user participation as an important mechanism for building user confidence. They framed user participation as a right achieved through collaboration between users and professionals. Health professionals emphasised the need to clarify what user participation means in practice. The need for support and availability of professional help was emphasised by all users, so that participation not be seen as a way of reducing support and services.
Keywords: Mental health centres; influence; user participation; Norway

Citation: Elstad TA (2014) 'Participation in a 'low threshold' community mental health service: an ethnographic study of social interaction, activities and meaning.' Thesis for the degree of Doctor of Philosophy, Norwegian University of Science and Technology: Trondheim.
URL: http://brage.bibsys.no/xmlui/handle/11250/196936
Country: Norway
Community: Urban service users
Health system area: Implementing and co-ordinating health action
Summary: 'Low threshold' community mental health services have been encouraged as part of a 'recovery oriented' approach, and in Norway are seen as a strategy for mental health promotion. Three centres in municipal community health service in a Norwegian city are described. People choose how to attend the service, and there are no intake procedures or medical records kept about service users. Participation in activities and decision-making is encouraged, but not a prerequisite for using the centres (see also Elstad and Eide, 2009). This paper suggests that a mix of professional and peer-support provides opportunities for receiving social support, as well as for active participation and mutual relationships among service users in daily life. Participation and mutual support were reported to enhance self-confidence and experiences of recognition. Attending the service based on their own felt needs helped many to also participate in the wider community. Professionals described knowledge and experience as important for a flexible, low threshold approach in mental health work. This service organisation permitted more egalitarian relationships with users, than work in institutions.
Keywords: community mental health; health promotion; user perceptions; Norway

Citation: de Freitas C, Martin G (2015) 'Inclusive public participation in health: Policy, practice and theoretical contributions to promote the involvement of marginalised groups in healthcare,' *Social Science & Medicine* 135:31-9.
URL: http://europepmc.org/abstract/med/25939074
Country: The Netherlands
Community: Migrant community
Health system area: Implementing and co-ordinating health action; Health planning and budgeting
Summary: The Netherlands has a longstanding history of public participation, albeit largely dominated by middle-class citizens. The delegation of responsibility from government to market agents for the development of diversity-sensitive healthcare services in 2004 raised the question of how to ensure participation from marginalised groups, including migrants. Simmons and Birchall's (2005) Participation Chain Model (PCM) provides a framework to assess demand-side and supply-side factors and the institutional dynamics of participation. The framework was used in a case study of user participation in a Dutch mental health advocacy project involving Cape Verdean migrants – Project Apoio. Cape Verdean immigrants started settling in the Netherlands in the 1950s. In the early 2000s they were largely unknown to mental healthcare providers and had no voice in healthcare decision-making. The stigmatisation of mental illness, communication problems and difficulties in navigating the healthcare system undermined their use of and involvement in mental healthcare. Project Apoio sought to tackle these problems using participatory initiatives, This included a *comissão de apoio* - a user committee set to disseminate information about the project, enable dialogue between users, providers and health authorities and foster Cape Verdeans' access to psychosocial care. A *grupo de conversa* was also set up - a peer-support group promoting exchange of information and psycho-social support for people affected by psychosocial distress. Employing an approach sensitive to both top-down and bottom-up incentives for participation, Project Apoio's initiatives became an example of spaces sponsored by public authorities which maintain a direct connection with the local user movement. The project ended in 2009, however, when its host organisation filed for insolvency. The authors suggest that both health authorities and civil society organisations have a role in creating 'hybrid' spaces that promote the inclusion of marginalised groups in healthcare decision-making.
Keywords: Mental health; migrants; user committee; peer support; the Netherlands

Citation: Galaa S (2008) 'Community participation in health delivery and management in Ghana: Lessons from selected districts in Northern Ghana,' *Ghana Journal of Development Studies* 5(1):39-57.
URL: www.ajol.info/index.php/gjds/article/view/35066/31567
Country: Ghana
Community: Rural residents
Health system area: Implementing and co-ordinating health action; assessing health needs and priorities

Summary: This paper provides an overview of the modes by which communities have participated in health care delivery and management in three districts over 25 years in Ghana. Case studies of four community participation programmes (surveillance, disease control/prevention, primary health workers and community health management) were undertaken in three districts (Yendi, Builsa and Lawra) in northern Ghana in 2000-2002. The three districts were involved in community-based health programmes since 1985. Communities participated in a broad range of activities from health literacy and education and social mobilisation to needs assessment and programme planning. Community involvement in needs assessment and problem definition faced a challenge of community data collection via surveillance and growth monitoring programmes rarely being used. The case studies also show that participation by community auxiliary staff in curative health services is the most contentious form of participation, with public health professionals divided on this aspect. A range of representative mechanisms for group and team participation were identified including community health committees. While participation initially focused on minimising costs through use of community workers, there has been a shift to use participation to not only increase availability but also acceptance and utilisation. The author proposes a Coalition for Participation and Partnerships in Health (CPPIH) as a framework for broadening participatory planning and decision-making nationally, replicating the Village Level Action Planning (VAP) that engages community representatives and technical line agencies in the planning processes.
Keywords: Primary health care; community-based programmes; CHWs; representation; Ghana.

Citation: James AM (2007) 'Principles of youth participation in mental health services,' The Medical Journal of Australia 187(7 Suppl): S57-60. jam10307_fm [pii]
URL: www.ncbi.nlm.nih.gov/pubmed/17908029?dopt=abstract
Country: Australia
Community: Young people
Health system area: Implementing and co-ordinating health action; Enablers and barriers in health action; Meso-level mechanisms
Summary: *Headspace*, the National Youth Mental Health Foundation established in Australia in July 2006, highlights the mental health care sector's commitment to young people. The resources of the Foundation include a Youth Services Development Fund to help support the development of more accessible, effective and integrated approaches to service delivery in local communities. Examples of what can be achieved at national and local levels via existing youth participation programmes, are briefly presented including: *Ybblue*, the youth programme of beyondblue; Reach Out!, a web-based service; Headroom, providing health promotion and a website; and Platform Team (ORYGEN Youth Health), comprising current and past clients who advise the service and provide peer support (described in Monson and Thurley, 2011). Links are provided to key sites about these different initiatives. Future challenges or principles for expanding youth participation in mental health services are identified including: avoid tokenism; set realistic expectations; acknowledge the diversity of young people; and avoid entrenching young people as "professional advocates" as mental health care aims for recovery. They also raise that participation requires both commitment and flexibility to accommodate demands of study and the effects of illness; and that youth participation needs to be is adequately resourced;
Keywords: Mental health services; youth; peer support; Australia

Citation: Jaskiewicz W and Tulenko K (2012) 'Increasing community health worker productivity and effectiveness: A review of the influence of the work environment, '*Human Resources for Health 10*: 38-4491-10-38. 10.1186/1478-4491-10-38 [doi]
URL: www.ncbi.nlm.nih.gov/pubmed/23017131?dopt=abstract
Countries: Low and middle income countries (LMICs)
Community: General public; CHWs,
Health system area: Implementing and co-ordinating health action;
Summary: This article explores approaches to improve the environment for CHW productivity and effectiveness, drawing on a desk review of selective published and unpublished articles and reports on CHW programmes in developing countries. The model proposes three broad-based and interrelated inputs: capacity (knowledge, skills and attitudes); motivation; and organisational support or the "opportunity to do the job well" (resources, physical and social environment, working conditions). This article focuses on organisational support. The work environment encompasses four elements that affect CHW productivity - workload, supportive supervision, supplies and equipment, and respect from the community and the health system. When CHWs have a manageable workload

(a realistic number of tasks and clients), an organised manner of carrying out these tasks, a reasonable geographic distance to cover, the needed supplies and equipment, a supportive supervisor, and respect and acceptance from the community and health system, they can function more productively and contribute to an effective community-based strategy. The paper provides details of BRAC's *Shasthya Shebikas* CHW programme in Bangladesh, as an example where CHWs have a broad set of job responsibilities to accomplish and yet are considered highly productive and effective in their work. These CHWs cover 250-300 households within a small neighbourhood in their villages, are well respected by the government sector, receive strong supervision from higher level CHWs e.g. attendance at household visits, have monthly refresher trainings to update knowledge and problem-solve and regular opportunities to restock (see also USAID and MCHIP, 2013). It is not clear which of these elements make the most important difference to the *Shasthya Shebika* programme and or how they relate to create the positive productivity outcome.
Keywords: CHWs; enabling environments; LMICs, Bangladesh

Citation: Javanparast S, Baum F, Labonte R, Sanders D, Heidari G and Rezaie S (2011) 'A policy review of the community health worker programme in Iran,' *Journal of Public Health Policy 32*(2): 263-276. 10.1057/jphp.2011.7 [doi]
URL: www.ncbi.nlm.nih.gov/pubmed/21368846?dopt=abstract
Country: Iran
Community: Rural residents; CHWs
Health system area: Implementing and co-ordinating health action; health planning and budgeting
Summary: After 1978, Iran established a PHC network and a new CHW programme. It built on and refined the pre-existing schemes (e.g. the Behdar training project, 1942) that used local health workers to serve the rural poor. Integrated preventive and curative services delivered at the new village health houses and by trained CHWs (*behvarz*) were a priority strategy to narrow the urban-rural health gap. Each health house covers a target population of about 1500, is the place from which the *behvarz* works and is the most peripheral health delivery facility in rural areas. Health indicators in rural areas have improved significantly, due to both improved community care, and improvements in wider determinants such as increased economic growth, improved literacy and environmental conditions. The CHWs programme scope and workload has changed from basic health care to now include elders' health, youth health, noncommunicable diseases (NCDs) and community engagement in health promotion activities (see also Nikniaz et al, 2007). CHWs are recruited from local communities with strong evidence of the engagement of local people, religious leaders, and rural families. Behvarz recruitment committees were established to identify and lead a recruitment drive in rural areas in response to identified shortages engaging local communities, religious leaders and media. Behvarz must complete a written examination and interview. Since 2004 they must have completed secondary education. Behvarzes receive an initial (2-years) and ongoing training. Trainees must remain in and serve at their villages for 4 years after completion of the initial training. The topics for training have been reviewed and updated over the years. In-service training of a behvarz is recognised at regular intervals and there is a regular behvarz journal. The behvarz is a full-time employee of the Iranian government health system, providing sustainability and making employment attractive. To promote quality and retention, the programme offers a training allowance and personal loans, gives an 'excellent behvarz award', and celebrates 'National Behvarz Day'. In 2006, an elected 'behvarz council' is established at local health centres, the district, provincial, and national levels to engage behvarzes in problem identification and solving, knowledge transfer, and policy-making. The study concluded that: recruitment of the Iranian CHWs from the communities they serve facilitated the programme effectiveness and acceptability; provision of a comprehensive training programme enabled the CHWs to provide comprehensive care and health promotion; and CHWs had significant role in addressing social determinants of health through community development and intersectoral collaboration.
Keywords: Primary health care; CHWs; Iran

Citation: Kambou SD, Magar V, Hora G, Mukherjee A (2007) 'Power, pleasure, pain, and shame: assimilating gender and sexuality into community-centred reproductive health and HIV prevention programmes in India,' *Global public health* 2(2):155-68.
URL: www.tandfonline.com/doi/abs/10.1080/17441690601066375?journalCode=rgph20
Country: India
Community: Rural residents
Health system area: Implementing and co-ordinating health action;

Summary: CARE and ICRW partnered with the Inner Spaces, Outer Faces Initiative (ISOFI) to undertake a 2-year action research project to more effectively integrate gender and sexuality into CARE's sexual and reproductive health (SRH) programmes in India and Vietnam. CARE India situated ISOFI in two sites of a USAID-funded project, which was providing reproductive health, child health and nutrition, and HIV/AIDS prevention services to 6.6 million women and children living in marginalised urban and rural communities across 10 Indian states - the Lucknow District, Uttar Pradesh and the Bhilwara District, Rajasthan in 2005. The model creates space for practitioners to explore and understand their own attitudes and experiences of gender and sexuality and enhances staff learning and personal development. Five intervention models were used sequentially with members from all parts of the community in the first 6-9 months. Participants obtained skills to construct logical, practical inquiry around gender and sexuality, and to use Participatory Learning and Action, using social and vulnerability mapping, mobility mapping, cartooning, body-mapping focusing on points of power, pleasure, pain, and shame, and bi-directional time lines. The interventions led to more effective promotion of condom use at key access points; engaged police in meetings (who had been a threat to sex workers) and built relationships between community members and health care staff. It shifted personal values towards greater equity and acceptance, and broadened the scope of programming to include points of action to improve the health and well-being of the most vulnerable.
Keywords: gender, community development, women; participatory action research; India

Citation: Karwalajtys T, Kaczorowski J, Chambers LW, Hall H, McDonough B, Dolovich L, Sebaldt R, Lohfeld L, Hutchison B (2013) 'Community mobilization, participation, and blood pressure status in a Cardiovascular Health Awareness Program in Ontario,' *American journal of health promotion: AJHP* 27(4):252-61.
URL: http://ajhpcontents.org/doi/pdf/10.4278/ajhp.101221-QUAL-408
Country: Canada
Community: Residents, CHWs
Health system area: Implementing and co-ordinating health action; health literacy/ promotion/ information; Enablers and barriers in health action.
Summary: A demonstration project of the Cardiovascular Health Awareness Program (CHAP) in two Ontario communities tested the scalability and subsequent reach of the programme for community health promotion. CHAP is a community-based health promotion programme targeting cardiovascular risk factors, including detection and management of high blood pressure (BP), treatment and management of which remain suboptimal in Canada. CHAP cardiovascular risk assessment and education sessions are held in community pharmacies, and volunteer peer health educators assist participants to measure their BP. The information is then sent to their family physician and/or usual pharmacist. Volunteers also distribute education materials and resources to act on modifiable risk factors using a protocol based on the participants' BP. The demonstration project set up an environmental scan to identify potential stakeholders and champions within each community. Community cardiovascular profiles were developed using existing data to provide a snapshot of local demographics, language, education and employment, and listed local family physicians, pharmacies and resources. The Kidney Foundation hired a co-ordinator and a community health nurse for each site. A communication plan was developed and volunteers recruited and trained as peer health educators from people aged 55 years or older to maximise peer interaction. A 10-week schedule of morning sessions for each community was developed accompanied by community-wide advertising and direct invitation. Physicians could invite their older patients using "prescriptions" for a specified number of CHAP sessions or mailed letters. Nearly all local family physicians participated in CHAP. Over 90 older adult volunteers were recruited and 84% completed the training. A community-level evaluation found it was linked with 3 fewer annual hospital admissions for CVD per 1000 people aged 65+ years. CHAP was found to depend on identifying natural partners; engaging communities and building local capacity to promote local ownership of the programme; with standards to offer CHAP in diverse communities and with varying resources while ensuring an evidence based approach.
Keywords: Hypertension, community-based care; volunteer health workers; Canada.

Citation: Kema KM, Komwihangiro J and Kimaro S (2012) 'Integrated community based child survival, reproductive health and water and sanitation programme in Mkuranga district, Tanzania: A replicable model of good practices in community based health care,' *The Pan African Medical Journal 13 Suppl 1*: 11.

Country: Tanzania
Community: Rural residents
Health system area: Implementing and co-ordinating health action; health literacy/ promotion/ information
Summary: This paper presents the outcomes of a community-based approach to improving health in 24 rural villages in Mkuranga District Tanzania, involving a 5-year water, hygiene and sanitation project (2001); and 2-year child survival and reproductive health projects (2002). The initiative was informed by AMREF's Community Based Health Care model, with joint planning, implementation and monitoring and evaluation in all three projects. Community mobilisation included community forums, inter-village competitions, community theatre groups, village health days and house-to-house visits. A training curriculum and different training packages were developed and used to train (largely government) committees, to strengthen health management systems for community and district leadership on prevention and control of communicable diseases. Community Own Resource Person (CORPs) are community volunteers, and the primary implementers of programme activities in their villages. They were selected by community members following an agreed set of criteria with the community including: literacy, living in the respective village, willingness to work as a volunteer and acceptability of an individual by the community. CORPs received training with health addressed as a broad community development issue, and constant supportive supervision to support performance and build confidence. As incentives CORPS received certificates of appreciation and participation, t-shirts, bags, document folders and bicycles to facilitate transport during their work. Information and communication materials were designed through participatory workshops with community members and programme staff. To sustain interventions: multisectoral steering committees were formed at district level; private public community partnerships were set up, particularly for water well management; and local resources and technology used. Key outcomes identified include: functioning village health and water committees and water and sanitation services; increased utilisation of services including antenatal care and improved child nutrition. There was 96% retention of CORPs over 5 years.
Keywords: Community health; intersectoral action; CHWs, community development; Tanzania.

Country: Australia
Community: Women; rural residents
Health system area: Implementing and co-ordinating health action; Enablers and barriers in health action; Meso-level supporting mechanisms
Summary: Women's Health Services (WHS) in Perth, Western Australia, work with women from over 60 different nationalities, including newly arrived migrants and refugees. WHS provide multidisciplinary PHC including clinical services, counselling, information, community workshops, referral and outreach to women. An alcohol and other drug (AOD) service was established (1989) to provide gender-specific counselling, information and education services to women experiencing problems as a result of their own or someone else's alcohol or drug use. However, few ethnic women attended the AOD services. Staff attributed this to service delivery not matching women's needs and a consumer reference group (CRG) was established to look at barriers to accessing AOD services and to explore the types of services women wanted. Preliminary work over 3+ months looked at considerations such as representativeness, funding for interpreters, and potential stigma by association for women participating in an AOD reference group to assist WHS to plan programmes, improve service access, and improve AOD information for women and their families. Women were invited to participate based upon their capability and interest (as 'consumers') rather than as representatives of a social group. Participants experienced few out-of-pocket costs, due to flexible meeting times, child care provision, healthy snacks at meetings for women coming straight from English classes or work and offering transport if a meeting was held away from WHS. Two staff members acted as liaison and were 'available,' to listen to personal problems and participant barriers. An evaluation after one year found a number of positive features including: group diversity; a safe environment for sharing; opportunities for meeting similar women and building social networks; and increased knowledge about AOD issues and the different services available.

The main barrier was poor English. Members indicated that they wanted to do more practical, action-orientated work, such as sharing information with the community and talking to people about AOD. Some members undertook further volunteer work with WHS, gained employment in AOD-related areas, or returned to tertiary studies, often citing their experiences in the work as contributing to their self-confidence to undertake these activities.
Keywords: alcohol and drug services; integration; women; consumer reference group; Australia

Citation: Lemos PN, Hirooka LB, Nunes SA, Arantes R, Mestriner SF, Mestriner Junior W (2010) 'O modelo de atenção a saúde bucal no Médio e Baixo Xingu: parcerias, processos e perspectivas,' [The oral health care model in Middle and Low Xingu: partnerships, processes, and perspectives] *Ciencia & saude coletiva* 15 Suppl 1:1449-56.
URL: www.scielo.br/scielo.php?script=sci_arttext&pid=S1413-81232010000700056
Country: Brazil
Community: Indigenous community
Health system area: Implementing and co-ordinating health action
Summary: The Xingu Indigenous Park (PIX) was created in 1961 to provide indigenous peoples with medical, social and educational support for physical and cultural wellbeing. The Special Indigenous Sanitary District (DSEI-Xingu) was established in August 1999, through an agreement supported by xinguanas leaders, signed by the National Health Foundation (FUNASA), manager of the subsystem of indigenous health, and the UNIFESP, which became executor of the basic health system. Several partners collaborate with the Ministry of Health (MoH) in the implementation of Special Indigenous Health Districts to organise health care services for indigenous peoples, with institutional partnerships and participation of indigenous peoples in health management in their territory. The PIX is divided into three areas of coverage, each with a multidisciplinary health team comprising doctors, nurses, dentists, indigenous nursing assistants (IEA) and indigenous health agents (AIS). In the field of oral health, a multi-professional team involving graduates of the University of São Paulo (indigenous and non-indigenous) trained in prevention and health promotion. Services are designed and delivered in a culturally appropriate way, taking demographic and epidemiological profiles into account, as well as the historical and cultural context, local leader roles and other relevant features. Educational programmes for the population, employing preventive indigenous health agents and the distribution of brushes, toothpaste and floss to communities has reduced the prevalence of oral diseases and increased the percentage of children from 5-14 years with good oral health. The community interaction with oral health teams was promoted through meetings, lectures, assessment workshops of health services, individualised attention, distribution of toothbrushes and toothpaste, brushing practices and training of indigenous health agents (AIS) and indigenous agents of oral health (AISB). The care model not only introduced new technologies for the treatment of caries and periodontal disease, but a new approach, with: decentralised health promotion actions, shared with indigenous health agents, teachers, shamans, parents and others, under the responsibility and guidance of the health team. Indigenous community oral health agents mediate the connection between practitioners and the indigenous community.
Keywords: Oral health services; indigenous health workers; Brazil

Citation: Lewis L (2014) 'User involvement in mental health services: A case of power over discourse,' *Sociological Research Online* 19(1): 6.
URL: www.socresonline.org.uk/19/1/6.html
Country: Scotland
Community: Health service users
Health system area: Implementing and co-ordinating health action; Health planning and budgeting
Summary: This paper presents findings from a localised ethnographic study of user involvement in mental health services in Scotland in two service user/community groups: a statutory sector service user group attached to a local psychiatric hospital; and a voluntary sector community group including service practitioners, providers and service users. The first group provided information about available mental health services and activities and acted as a channel for service users' views. The second had a stronger lobbying function with regard to mental health policy and services. A research process involved feeding back and discussing interpretation of findings through oral presentations, newsletter articles and a briefing paper. Service users identified a number of practical suggestions for progressing user involvement such as having an equal representation of services users and providers at a meeting. Some also indicated that while breaking the rules of the game (e.g.

expressing their views with anger) did not change anything, they felt the need to do it. However, fear often prevented people from expressing their concerns, and the dominant discourse of mental illness was maintained by its use, such as to delegitimise service user inputs on the basis of illness. A lack of attention to the social causes of mental distress/illness and the implications of these for services was observed. It was found that user involvement can constrain and contain service users' voices and influence and work to defend the interests of powerful groups and to resist organisational change. This can nullify its potentially transformative influence and further marginalise service users, especially women and other groups. User involvement in service commissioning was found to be supported by public resourcing of self-organising user groups and for these groups to have their own ways of engagement and accountability.
Keywords: Mental health services; user involvement; Scotland

Citation: Mendez CA, Lopez JJ (2010) 'La participación social en salud: el desafío de Chile,' [Community participation in health: the challenge in Chile] *Revista panamericana de salud publica* 27(2):144-8.
URL: www.scielosp.org/pdf/rpsp/v27n2/a09v27n2.pdf
Country: Chile
Community: Citizens
Health system area: Implementing & co-ordinating health action; Enablers & barriers in health action
Summary: In 2002, social participation in health was identified as one of the guiding principles of the health system reforms in Chile, understood as a mechanism for improvement of the health sector, for auditing the quality, effectiveness and opportunity of services, as well as the efficient use of resources. A 2012 law concerned the duties and rights of people and consultative councils were established with representatives of different social organisations and groups, including from the community. The councils advise the facility director and primary care teams on management to improve the health and quality of life of the population. The law also established rights of citizens including to decent treatment, access to information, informed consent, regulation of clinical research, consultations and complaints and user participation. Despite, the official discourse and creation of spaces for social participation, the authors observe the citizen participation is absent in the reforms. Health teams tend to perceive social participation from a utilitarian and not empowering perspective. The authors observe that social participation in the reforms call for: spaces for decision-making; improved coordination between the different bodies involved in the participation; public information on participation; mechanisms and funding; together with evidence that demonstrates the impact of different strategies for social participation; and the inclusion of the most vulnerable populations.
Keywords: Health reforms; social participation; councils; Chile

Citation: Mercader HF, Kyomuhangi T, Buchner DL, Kabakyenga J and Brenner JL (2014) 'Drugs for some but not all: Inequity within community health worker teams during introduction of integrated community case management,' *BMC Health Services Research 14 Suppl 1*: S1-6963-14-S1-S1. Epub 2014 May 12. 10.1186/1472-6963-14-S1-S1 [doi]
URL: www.ncbi.nlm.nih.gov/pubmed/25078968?dopt=abstract
Country: Uganda
Community: Health service users; CHWs
Health system area: Implementing and co-ordinating health action
Summary: In 2010 the Ugandan Ministry of Health formalised a policy to use a lay CHW programme for health promotion and to provide integrated community case management (iCCM) to assess and treat ill children under five years old. Only CHWs with iCCM training can distribute selected medicines. In 2012, iCCM was implemented in Kyabugimbi sub-county of Bushenyi District in Uganda. 'Basic CHWs' were trained in standard health promotion and 'iCCM CHWs' also trained in iCCM intervention. Both sets of CHWs received a training certificate, canvas bag, and t-shirt plus other materials. The iCCM CHWs also received a respiratory timer, a sick child job-aid, a wooden medicine box, referral forms and a started supply of medicines. Further some iCCM CHWs were given mobile phones. Following seven months of iCCM intervention, focus group discussions and key informant interviews were conducted with community leaders, caregivers of young children, and the CHWs ('basic' and 'iCCM'). 'Basic CHWs' reported feeling hurt and overshadowed by 'iCCM CHWs' and reported reduced self-esteem and motivation. iCCM training and tools were perceived to be a significant advantage, which fuelled feelings of segregation. CHW cooperation and team dynamics varied from area to area, although there was

an overall discord amongst CHWs regarding inequity in iCCM participation. Despite this discord, reasonable personal and working relationships within teams were retained. The study found that training and supporting only some CHWs within village teams unexpectedly and negatively impacted CHW motivation for 'basic CHWs', but not necessarily team functioning. CHW programmers should consider minimising segregation when introducing new programme opportunities through providing equal opportunities to participate and receive incentives, while seeking means to improve communication, CHW solidarity, and motivation.
Keywords: CHWs; integrated community case management; incentives; Uganda

Citation: Micikas M, Foster J, Weis A, Lopez-Salm A, Lungelow D, Mendez P and Micikas A (2015) 'A community health worker intervention for diabetes self-management among the Tz'utujil Maya of Guatemala,' *Health Promotion Practice 16*(4): 601-608. 10.1177/1524839914557033 [doi]
URL: www.ncbi.nlm.nih.gov/pubmed/26113496?dopt=abstract
Country: Guatemala
Community: Indigenous community; CHWs
Health system area: Implementing and co-ordinating health action; Health literacy/ promotion/ information; Oversight, monitoring and evaluation; Enablers and barriers in health action
Summary: A needs assessment by the Organization for the Development of Indigenous Maya (ODIM) in 2009-2010 showed diabetes to be a high concern, with a demand for health services in the local language (Tz'utujil). A culturally relevant education intervention for diabetic patients receiving treatment at ODIM's rural primary care clinic in two rural communities was developed by clinic personnel, CHWs and university students and implemented over 4 months in 2012. Over 150 ODIM-clinic patients received at least one consultation for diabetes. The self-management curriculum and intervention was informed by focus groups with diabetic patients, community key informants, and CHWs. Twenty-one CHWs participated in a 1-week course of "train-the-trainer" sessions focusing on the diabetes disease process and principles of management. Eight of the trained CHWs were then selected to work as paid diabetes health promoters through an application and interview process including: a written test on training content, observation of the candidates' instructional style, and feedback from the Diabetes Programme Coordinator. Selected CHWs received additional training on the principles of health education, motivational interviewing and health behaviour theory, and were engaged in discussion and analysis of themes from the focus group discussions. Each CHW was allocated a caseload of 15-20 patients with whom they hold a weekly diabetes club meeting consisting of: a focused lesson about a specific aspect of type 2 diabetes self-management; and group exercises such as chair exercises, group walking, and relay races. The CHWs also conducted weekly home visits and preconsults in the clinic to monitor each patient's progress and discuss specific challenges, create goals and tailor exercise and nutrition plans. CHWs took over the development of the curriculum modules for the club meetings after the 7-months. A one-group, pre- and post-test design was implemented by the CHWs to evaluate the effectiveness of the educational intervention comparing measures of health, knowledge, and behaviour in patients pre- and post-intervention. This found a significant decrease in mean blood glucose levels from baseline and follow-up but not in the health beliefs and practices, in part because the survey that did not translate well to the cultural context of this community.
Keywords: Diabetes; prevention and management; CHWs; Guatemala

Citation: Monson K, Thurley M (2011) 'Consumer participation in a youth mental health service,' *Early intervention in psychiatry* 5(4):381-8.
URL: http://onlinelibrary.wiley.com/doi/10.1111/j.1751-7893.2011.00309.x/pdf
Country: Australia
Community: Urban youth, service users
Health system area: Implementing and co-ordinating health action; Oversight, monitoring and evaluation
Summary: The 'youth' consumer participation programme is part of the Orygen Youth Health (OYH) intervention in Melbourne. The model aims to support increased consumer centredness of service delivery, and the recovery of those involved in participation activities. OYH incorporates a clinical programme (OYH-CP), a research centre and a training and communications programme. The service is composed of a range of specialist outpatient clinics, an inpatient unit, psychosocial recovery programmes, an access team and a family support programme. The 'consumer' participation aims to: improve service delivery to clients; improve mental health literacy; promote help seeking among young people; and reduce stigma regarding mental illness. Youth participation

is overseen by a psychosocial recovery programme, with a dedicated coordinator and a youth participation steering committee comprising representatives from all OYH programmes and young people. The Platform team is composed of past and present clients of OYH-CP working together to inform and improve services, meeting fortnightly to discuss research projects, service changes, education materials and other initiatives, such as staff selection and public speaking. A Peer Support programme aims to instil hope in young people experiencing mental illness; support clients to actively engage with the recovery process; reduce the trauma, disorientation, and boredom associated with hospital admission; and provide peer-delivered psycho-education. Peer Support Workers are recruited from interested ex-clients of OYH-CP, comprehensively trained and volunteer their time via a roster system to support inpatient and outpatient services. All young people who participate in the activities are compensated for their time, travel and potential lost income and recognition of their skills. An evaluation is yet to be done.
Keywords: peer support; youth; mental health; Australia

Citation: Morrison C, Dearden A (2013) 'Beyond tokenistic participation: using representational artefacts to enable meaningful public participation in health service design,' *Health policy* 112(3):179-86.
URL: http://dx.doi.org/10.1016/j.healthpol.2013.05.008
Country: United Kingdom
Community: Health service users
Health system area: Implementing and co-ordinating health action
Summary: UK policy seeks to involve patients and the public in the design of health services, but in practice it is argued to be frequently tokenistic. The Better Outpatient Services for Older People (BOSOP) was a one-year service improvement project to identify areas in a hospital setting that could be improved, and to explore possible solutions. Participatory design methods were used to enable older patients and staff representatives to work together for improvements. BOSOP collected people's stories through visiting older people in their homes and recording their experience of their last visit to hospital and any other stories. These were transcribed and shared with the design team to start creating emotional maps - visual representations that highlight aspects of patient experience. Two groups, one of patients and carers (public participants) and one of health professionals, worked separately to create their own maps. The emotional maps provided an initial collection of the patients' and health professionals' experiences and concerns to be shared with the alternate group. Both groups jointly prioritised issues for future design sessions. Two teams (public participants and health professionals) worked to design solutions: one group focused on 'getting to' the hospital; and the other with 'arriving at' the hospital. The latter brought together a patient, a health professional, a road engineer, and a designer, to explore options for safer drop-off of patients at hospital using a large map of the road layout of the hospital and sketching different solutions, bringing technical expertise and the stories into the conversation as they proposed and negotiated possibilities. Stories and emotional maps established patients' and health professionals' personal experience as a valid and relevant form of evidence. The use of the large map and tracing paper as representational artefacts enabled the development of a new language game that allowed the group to work with road engineers and designers to solve the problem together. Using appropriate representational artefacts provides a mechanism that enables both parties to collaborate each drawing on their own familiar ways of expressing themselves and can support more meaningful public participation in health service design and improvement.
Keywords: Health services; participatory mapping; co-design; UK

Citation: Nandi S and Schneider H (2014) 'Addressing the social determinants of health: A case study from the Mitanin (community health worker) Programme in India,' *Health Policy and Planning 29 Suppl 2*: ii71-81. 10.1093/heapol/czu074 [doi]
URL: www.ncbi.nlm.nih.gov/pubmed/25274643?dopt=abstract
Country: India
Community: Rural residents; CHWs
Health system area: Implementing and co-ordinating health action; Enablers and barriers in health action
Summary: The Mitanin Programme, a government CHW programme in Chhattisgarh State. India in 2002 acts on local priorities, including the social determinants of health (SD). The Mitanins, all female volunteers, undertake family level outreach services, community-organisation and social mobilisation on health and its determinants along with advocacy for improvement in the health

system. Lessons from this programme led to the formulation of the national Accredited Social Health Activist (ASHA) Programme (see Bhatia 2014) and all the Mitanins were subsequently recognised as ASHAs. The training the Mitanins received was not only content based but also about the ways to work on the issue. They used training modules and resource materials as a source of information to get service providers and village councils to perform their duties. The Mitanins drew on their support structure and external agencies/people such as supportive government staff, and local governance structures to pressure them to intervene in issues. Training and on-the-job support as well as the provision of health services (e.g. immunization) greatly facilitated the Mitanin's work. Lack of payment (apart from certain small incentives with the inception of a national CHW programme) made the Mitanin post unattractive for village elites and enabled Mitanins to retain their autonomy. Furthermore, the health department only has a supportive not monitoring or supervisory role and in 2012 accountability was placed with the village councils who make all payments to them. Through these processes the Mitanins developed identities as agents of change and advocates for the community, with respect to local cultural and gender norms and in ensuring accountability of service providers.
Keywords: social determinants of health; CHWs, autonomy; India

Citation: Ndou T, van Zyl G, Hlahane S and Goudge J (2013) 'A rapid assessment of a community health worker pilot programme to improve the management of hypertension and diabetes in Emfuleni sub-district of Gauteng Province, South Africa,' *Global Health Action 6*: 19228. 10.3402/gha.v6i0.19228 [doi]
URL: www.ncbi.nlm.nih.gov/pubmed/23364086?dopt=abstract
Country: South Africa
Community: Rural residents; CHWs
Health system area: Implementing and co-ordinating health action
Summary: The involvement of CHWs in TB and HIV care in South Africa, suggests that they could make an important contribution in the management of NCDs. This study examines the outcomes of the Kgatelopele CHW programme (2008) at one clinic in the Gauteng province in improving the management of hypertension and diabetes by home delivery of medication and assessment of basic clinical indicators. The CHWs provide social support and counselling to improve patient literacy and adherence, and to encourage appropriate visits to the clinic. Patients enrolled on the programme were visited once a month by one member of a team of six CHWs who had a month's supply of medication for delivery to named patients. Patients had to visit the clinic every 6 months for review by a doctor and a renewed prescription. CHWs attend a 14-week training course focusing on home-based care, skills in adherence counselling and health promotion, and chronic illnesses, including hypertension and diabetes. The study compares treatment outcomes (clinic compared to CHW) and describes operational challenges. The findings suggest that hypertension control was improved by CHW home visits compared to usual clinic care, although diabetes was better controlled among clinic patients. The authors note that not having to travel to the clinic and having care provided in the home setting improved control of hypertension. The programme was seen as especially helping older people who faced mobility and cost barriers in travelling to the clinic. It also reduced the patient load at the clinic, although health service weaknesses (insufficient visits by the rotating doctor; a shortage of glucose strips; inadequate funding and limited follow up from clinics) hindered monitoring and self-management.
Keywords: Non-communicable diseases; hypertension; CHWs; South Africa

Citation: Nikniaz A, Alizadeh M (2007) 'Community participation in environmental health: Eastern Azerbaijan Healthy Villages project,' *Eastern Mediterranean health journal* 13(1):186-92.
URL: https://extranet.who.int/iris/restricted/handle/10665/117242
Country: Islamic Republic of Iran
Community: Rural residents
Health system area: Implementing and co-ordinating health action
Summary: The Healthy Villages project in East Azerbaijan was designed by the provincial health centre. It aimed to establish a village committee comprising village residents to oversee activities and mobilise the community and facilitate their participation and contribution; increase community and health workers' awareness and conduct health and hygiene training; improve the water supply and sanitation systems, solid refuse collection and disposal, and food safety; enable the village residents to become partners for improvement of the rural environment; and improve coordination among different public organisations to improve the rural environment. The project focused on the

activities of health houses which cover 1 large village and 1+ satellite villages. Four aspects of the project were monitored: staff training, community training, establishment of the women's and men's health committees and community and intersectoral participation. Health staff training began at senior management levels followed by other managers and environmental health workers. Community education included face-to-face training of village residents, dissemination of information by mobile and mosque speakerphones, creative writing exercises about health-related issues in schools and advertisements and films. Each health committee includes: 4–8 members elected by local people; health workers, whose task was to direct the project at the village level including the local PHC worker in the health house; and other members such as the village head, older men and women, teachers, religious leaders and ordinary community members. Coordination with other public organisations and sectors was through district health committees. From 1992-2000, the 10 phases of the project covered 1680 villages, with 3605 training courses for health staff and village residents on environmental health conducted. Each phase included 10 steps, 4-5 of which involved communities, including priority setting and planning with the health committees. Men's and women's health committees in villages were established in 92% and 62% of villages respectively. Public collection of animal waste and improved the disposal collection process was associated with a decrease in the prevalence of parasitic disease in the area.
Keywords: Environmental health; village committees, information, intersectoral action; Iran

Citation: Nxumalo N, Goudge J, Thomas L (2013) 'Outreach services to improve access to health care in South Africa: lessons from three community health worker programmes,' *Global Health Action* 6: 19283
URL: http://dx.doi.org/10.3402/gha.v6i0.19283
Country: South Africa
Community: Urban residents
Health system area: Implementing & co-ordinating health action; Enablers & barriers in health action
Summary: This article examines three CHW programmes in the Eastern Cape and Gauteng South Africa: a small local NGO (Khanya), a local satellite of a national NGO, (Eden) and a government-initiated service (Zola). All programmes were delivered in predominantly poor urban households usually lacking identity documents needed to obtain social benefits. The Khanya CHW programme aimed to improve general health outcomes through home-based care. These CHWs were: paid a monthly stipend; residents of the community they served; and trained in a Department of Health 69-day training workshop. The Zola CHW programme was part of a national government employment generation scheme. Zola CHWs were recruited from the local community, attending a 5-day training course on HIV/AIDS, TB and cancer, and paid a monthly stipend but no internal career progression opportunities. These CHWs disseminated HIV information, including on how to access government sector services. The Eden programme sought to improve child health outcomes in households affected by HIV/AIDS. After a community recruitment process the Eden CHWs were required to complete 14 training modules and ongoing assessments over 2 years. They were paid a stipend and received ongoing supervision and mentorship, and internal career progression was encouraged. Their role included linking neglected or abused children with health and legal services, and providing daily care to child-headed households. Eden CHWs also received training to work with other service providers including police and social development to address social determinants of ill-health. The CHWs were given travel and cell-phone allowances to accompany clients to access services. Relationships with participatory structures at community level stimulated coordinated responses from service providers. In contrast, not having these elements limited CHWs in the Khanya and Zola programmes in providing outreach services.
Keywords: social determinants of health; CHWs; South Africa

Citation: Sirilak S, Okanurak K, Wattanagoon Y, Chatchaiyalerk S, Tornee S, Siri S (2013) 'Community participation of cross-border migrants for primary health care in Thailand,' *Health policy and planning* 28(6):658-64.
URL: http://heapol.oxfordjournals.org/content/28/6/658.full.pdf+html
Country: Thailand
Community: Migrant workers
Health system area: Implementing and co-ordinating health action
Summary: The Ministry of Public Health of Thailand (MOPH) recognises that access to healthcare services is a human right for migrants; however, the government was unable to provide adequate basic health services for all migrants. Community involvement and co-

operation was seen as one way to solve the problem of inadequate health workers and poor communication between public-health personnel and migrants. In 2003, the MOPH and the International Organization for Migration developed a migrant health-volunteer programme in six districts of the northern Thailand. The programme recruited long-term migrants (registered or unregistered) willing to serve their communities voluntarily. They served as communicators between health authorities and migrant communities, and as community educators, to increase community knowledge of basic hygiene, disease prevention, and how to get treatment, if needed. One volunteer per 50 households is selected by socio-metric technique and approved by the community, or 5–10 volunteers per factory. Initial training of two days is provided, followed by refresher courses/training twice per year. The training covers basic health issues, such as personal hygiene, maternal and child health and community sanitation. Migrant health volunteers receive no payment but a T-shirt that gives them visibility. With the co-operation and support of various agencies, the migrant-volunteer programme was scaled up to cover 27 districts in seven provinces of Thailand. A cross-sectional study in 2008 found that <5% of volunteers were selected by the community; that almost all had attended a training course; and most were assigned to be health communicators. Volunteers' attitudes were very positive. Most migrants reported that the volunteers' work was useful, citing examples such as reduced abortions after the migrant volunteers distributed contraceptive pills and condoms. Areas for improvement include: clarifying the supervision and strengthening the training of volunteers, including through use of group exercises, role play and demonstration to include illiterate volunteers.
Keywords: community health workers; migrants; volunteers; Thailand.

Citation: Small R, Taft AJ, Brown SJ (2011) 'The power of social connection and support in improving health: lessons from social support interventions with childbearing women,' *BMC public health* 11 Suppl 5:S4.
URL: www.ncbi.nlm.nih.gov/pmc/articles/PMC3247027/pdf/1471-2458-11-S5-S4.pdf
Country: Australia
Community: Women
Health system area: Implementing and co-ordinating health action
Summary: This paper looks at the relationship between social connectedness and good health, examining social support interventions with mothers of young children, particularly those seen as disadvantaged, or 'at risk'. Health education and/or information is provided, with a focus on parenting skills to improve child health outcomes, and on non-professional 'supporters'. Two trials were implemented to improve the wellbeing of mothers (emotional and physical). One involved a universal approach, befriending all mothers in the first year after birth. The other used a targeted approach, offering support from a lay 'mentor mother' to childbearing women experiencing intimate partner violence. These mothers were referred to the study by their family doctor or maternal and child health nurses. In the former, befriending strategies were developed and tried in consultation with local mothers, through steering committees and meetings with mothers. In the latter trial, local women provided support, matched with women in primary care contacts identified as vulnerable to partner violence. They were trained in empathy and social support. The trials demonstrated that non-professional support interventions raise challenges of adequate reach, identification of those in need of support; balancing the level of training and support to the voluntary and lay nature of the role; managing the length of time support is offered, how 'closure' is managed and whether interventions impact on social connectedness into the future. In both trials the interventions were reported by the women involved as useful in overcoming loneliness, in being understood, not being judged, and feeling an increased sense of their own worth.
Keywords: maternal health; community health workers; volunteers; Australia

Citation: South J, Kinsella K, Meah A (2012) 'Lay perspectives on lay health worker roles, boundaries and participation within three UK Community-based health promotion projects,' *Health education research* 27(4):656-70.
URL: http://her.oxfordjournals.org/content/27/4/656.full.pdf+html
Country: United Kingdom
Community: Urban residents
Health system area: Implementing and co-ordinating health action
Summary: This paper examines lay interpretations of lay health worker roles within three UK community-based health promotion projects: a breastfeeding peer support service aimed at increasing uptake and duration of breastfeeding through one-to-one and group support; a

walking for health scheme aimed at increasing participation in physical activity through establishing local walking groups; and a neighbourhood health project, with broad aims around health improvement, which ran a range of community-based activities. Across the three projects, participants reported lay health workers having both a bonding role in bringing people together in social groups and a bridging role in connecting people to services. Overall, the quality of the relationship between lay worker and participants, not the organisational function, was perceived as significant. Participants understood peer roles, distinguishing those roles from professional activity and viewing them as complementary to formal service provision, for example arranging an organised walk around school opening times. The findings across the three case studies suggest that there was a spectrum of participation, although the depth of participation and the roles adopted differed between projects and between individuals. Choosing to take an active stance appeared to be a result of many factors, including social circumstances such as level of literacy needed for training and the desired level of responsibility. This study provides further evidence, based on lay perspectives, that the bridging role of lay workers is central to achieving health benefits, particularly where health inequalities exist. A critical point is that for lay health worker programmes, the intensity of participation should be defined not by 'power over, but by 'responsibility for,' with the quality of relationships between community members who receive the intervention and community members who take on a caring role emerging as a key feature.
Keywords: breastfeeding; physical activity; community health workers; United Kingdom

Citation: Strachan DL, Kallander K, Nakirunda M, Ndima S, Muiambo A, Hill Z and inSCALE study group (2015) 'Using theory and formative research to design interventions to improve community health worker motivation, retention and performance in Mozambique and Uganda,' *Human Resources for Health 13*: 25-015-0020-8. 10.1186/s12960-015-0020-8 [doi]
URL: www.ncbi.nlm.nih.gov/pubmed/25925007?dopt=abstract
Countries: Mozambique; Uganda
Community: General public, CHWs
Health system area: Implementing and co-ordinating health action
Summary: This paper describes two interventions designed by the Innovations at Scale for Community Access and Lasting Effects (inSCALE) project to address worker motivation, retention and performance for CHWs in Uganda and Mozambique drawing on behavioural theory. In both countries the Ministries of Health use CHWs to deliver health promotion and ICCM of childhood disease. Funding is from external funders in both Uganda and Mozambique but with the NGO role moving from implementation to technical support and quality assurance. National and district/provincial governments are responsible for ensuring management and supply for all commodities as well as coordination of implementation. A theoretical review suggested that CHWs be promoted as members of a collective by highlighting a sense of shared experience, focusing on alignment between worker and programme goals, and emphasising actions that lead to good performance. CHWs were reported to value feedback and feeling connected to the health system and their community, are motivated by status and community standing, and want to be provided with the necessary tools to perform. Two interventions were developed: a participatory, local community approach which is the establishment of village health clubs in Uganda, to promote community access to technical and local health knowledge through CHW and community member exchange; and an information communication technology (ICT) approach whereby CHWs are provided with mobile phones and solar chargers as both are key tools for CHW work and signifiers of role that are likely to confer status. The ICT approach supports links to peers and supervisors, as well as being able to provide data and be a job aid to support patient consultation in Mozambique. The interventions are currently being evaluated.
Keywords: CHWs; incentives; Mozambique, Uganda

Citation: Swartz A (2013) 'Legacy, legitimacy, and possibility: An exploration of community health worker experience across the generations in Khayelitsha, South Africa, '*Medical Anthropology Quarterly 27*(2): 139-154. 10.1111/maq.12020 [doi]
URL: www.ncbi.nlm.nih.gov/pubmed/23804283?dopt=abstract
Country: South Africa
Community: Urban residents; CHWs,
Health system area: Implementing and co-ordinating health action
Summary: In South Africa, CHWs have a varying array of titles from CHWs to health volunteers to community advocates. Twenty CHWs in the peri-urban area of Khayelitsha were interviewed

on their experience of providing community health under difficult conditions. Many older CHWs say that *ubuntu*, a notion of shared African humanity, is being "killed off" by the younger generation, whereas younger CHWs often described older women as being "jealous" of the opportunities that this younger generation has for education, training, and employment. The paper highlights how younger CHWs are potentially more employable because they have had the opportunity to complete secondary education. There is still however a scarcity of paid jobs and competition for funding. All CHWs, irrespective of their age and experiences, are still caught in the same structural position where they are not fully recognised by the South African Department of Health and not all are afforded remuneration. Positioned as serving their own community, CHWs are subjected to the same scarcities faced by the populations they serve— including scarcity of resources, employment, and optimal health care. There are different claims made to legitimacy (primarily, legitimacy based on a caring tradition versus legitimacy based on the acquisition of technical knowledge and skills through training). The author calls for closer attention to the experiences of CHWs when designing public health policies for the delivery of health care services in impoverished communities in South Africa.

Keywords: Health policy; CHWs, motivations; South Africa

Citation: Tallo VL, Carabin H, Alday PP, Balolong E, Jr., Olveda RM, McGarvey ST (2008) 'Is mass treatment the appropriate schistosomiasis elimination strategy?,' *Bulletin of the World Health Organization* 86(10):765-71.
URL: www.ncbi.nlm.nih.gov/pmc/articles/PMC2649512/pdf/07-047563.pdf
Country: Philippines
Community: Rural residents
Health system area: Implementing and co-ordinating health action; Health literacy/ promotion/ information;
Summary: In 2004, the Philippines' Department of Health adopted mass chemotherapy to eliminate schistosomiasis, and mass treatment was offered to an eligible population of 30 187 residents of 50 villages in Western Samar as part of an ongoing epidemiological study (STEP). Advocacy, information dissemination and social mobilisation activities were conducted before mass-treatment. Focus group discussions with farmers, women and teachers in six villages obtained perceptions and beliefs about schistosomiasis causes and treatment. An orientation workshop held in each village two weeks before mass treatment was attended by village midwives, leaders, village health workers (VHWs), school teachers and other residents mobilised by the village leaders. Community representatives decided on the treatment sites, and the individuals mobilised to assist in activities during the mass treatment. Posters were placed in strategic places and flyers announcing the date of the mass treatment and advantages of participation were distributed to households. The village heads were provided a list of the community residents who had tested positive for the bacteria to encourage them to participate. In 46 villages, activities included: (i) a village assembly, public address system or bell-ringing on the day of treatment; (ii) a house-to-house information drive; or (iii) both approaches. Out-of-school youth and VHWs were mobilised for house -to-house visits in 21 villages and no additional dissemination was done in four. Community involvement was measured using a participation index. Mass-treatment in the 50 villages following the mobilisation strategy, resulted in far lower participation than expected, with higher among males, preschool and school-age children, non-STEP participants and those who had been tested. At the village-level, higher involvement in mass treatment was associated with increased participation but with variation across communities in their abilities to mobilise village leaders and volunteers. The authors suggest that future mass-treatment campaigns convince local authorities and villagers to contribute more time and effort to the activities and to better address misconceptions about vulnerability to the disease, reactions to the medicine, and information on the disease impact.
Keywords: Health care, mass-treatment; literacy; community mobilisation; Philippines

Citation: Torri MC (2012) 'Multicultural social policy and community participation in health: new opportunities and challenges for indigenous people,' *The International journal of health planning and management* 27(1):e18-40.
URL: http://onlinelibrary.wiley.com/doi/10.1002/hpm.1094/abstract
Country: Chile
Community: Indigenous community
Health system area: Implementing and co-ordinating health action; oversight, monitoring and evaluation.

Summary: This article analyses the case study of Makewe Hospital, one of the pioneering experiences of an intercultural health initiative in Chile that has succeeded in involving local communities in multicultural health policy in a poor region of the country. The Hospital is managed by the Mapuche since 1999 and supported by strong community participation and minimal intervention from the state. The hospital provides a range of Western health services under the direction of a Western-trained Mapuche medical director, includes an intercultural health worker, and patients are seen by a Mapuche staff member and a Western physician. This means that if patients have health needs that can only be met by traditional medicine, they are referred appropriately to traditional Mapuche health specialists such as machis. The administration is under the Indigenous Health Association of Makewe-Pelale, with 35 member communities, community leaders and machis (Mapuche shamans) in the area. Another component of the intercultural initiative is a traditional clinic and pharmacy managed by the Makewe Hospital Association. The Indigenous Association has developed various mechanisms to encourage participation from communities including the Committee of the Wise that meets whenever an important issue emerges. The official intercultural programmes have focused heavily on education, awareness raising and changing the attitudes of health workers toward Mapuche patients and Mapuche culture. Community participation in the intercultural health programme in Makewe has facilitated the creation of an autonomous relationship between the state and the Indigenous Association. It has improved the flexibility and the creativity of the administration, enabling cultural and social rights to be addressed within the healthcare system. Concerns about sustainability have been addressed through persistent negotiations with the state based on massive participation and support from communities.
Keywords: Health services; Indigenous communities; committees; intercultural; Chile

Citation: USAID and MCHIP (2013). 'Developing and Strengthening Community Health Worker Programmes at Scale: A Reference Guide and Case Studies for Programme Managers and Policy Makers.' Jhpiego Corporation, USA
URL: www.mchip.net/sites/default/files/mchipfiles/CHW_ReferenceGuide_sm.pdf
Countries: Bangladesh, Brazil, Ethiopia, India, Iran, Nepal and Pakistan
Community: General public
Health system area: Implementing and co-ordinating health action
Summary: This manual guides policymakers and programme managers wishing to develop or strengthen a CHW programme, drawing lessons from other countries that have implemented CHW programmes at-scale. It includes case studies of large-scale CHW programmes from Bangladesh, Brazil, Ethiopia, India, Iran, Nepal and Pakistan, It includes information on the type of programme being implemented (and the formal recognition, location of CHWs in primary care facilities or communities); the community's role; selection, training and retention of CHWs; supervision; financing; and demonstrated impact and continual challenges. The guide distinguishes between full-time, paid CHWs, with formal pre-service training, and volunteer, part-time workers. The most effective planning mechanism is reported to be a feedback loop, where community-level information is fed through the multiple sub-levels (district, regional) to the national level, where policy, funding, and evaluation can be continually revised. Other key or critical factors identified include: ensuring effective governance arrangements; undertaking proper costing of the direct and indirect costs of a CHW programme and ensuring ongoing and sustainable funding to meet these costs; and developing appropriate recruitment policies and processes that provide for appropriate training, supervision and monitoring and evaluation of outcomes.
Keywords: community health workers; Bangladesh, Brazil, Ethiopia, India, Iran, Nepal; Pakistan

Citation: Yeboah-Antwi K, Hamer DH, Semrau K, Waltensperger KZ, Snetro-Plewman G, Kambikambi C, et al. (2014) 'Can a community health worker and a trained traditional birth attendant work as a team to deliver child health interventions in rural Zambia?' *BMC Health Services Research 14*: 516-014-0516-2. 10.1186/s12913-014-0516-2 [doi]
URL: www.ncbi.nlm.nih.gov/pubmed/25344701?dopt=abstract
Country: Zambia
Community: Rural residents; children; CHWs
Health system area: Implementing and co-ordinating health action; Health planning and budgeting;
Summary: This paper assessed whether CHWs and trained TBAs can work as teams to ensure a continuum of care for all children under-five in Zambia. TBAs are supported by Neighbourhood Health Committees (NHCs), linking them with the community and the formal health system.

NHCs are community-based health management structures involving community members and health workers. LINCHPIN is an integrated, community-based newborn care and community case management package delivered through an enhanced district-wide community health programme linked to health facilities and NHCs. CHWs and trained TBAs, supported by NHCs, were teamed to provide a continuum of newborn and curative care for children 0– 59 months in Lufwanyama rural district. CHW-TBA teams were trained in teaming concepts and their level of team work assessed every six months for two years. They were scored on teamwork and task work. The task work score was the sum of the scores for meeting with NHCs to discuss work and performance; conducting behaviour change communications sessions targeting women on newborn and child care; problem solving; participating in outreach services; supporting referral of a pregnant woman or sick child; conducting intra-team referral; and conducting postnatal care visits to a mother with a newborn 6– 8 weeks. The personal, community and service factors likely to influence the level of teaming were assessed. The training emphasised performing the joint tasks and the need to document tasks performed. After two years, twenty-one teams scored "high", twelve scored "low," and fourteen were inactive. Teamwork was rated as high for mutual trust, team cohesion, comprehension of team goals and objectives, and communication, but not for decision making/planning. Task work was rated highly for joint behaviour change communication and outreach services with local health workers, but not for intra-team referral.
Keywords: child health; community health workers, traditional birth attendants, Zambia

Other publications including information about social participation in *designing, implementing and co-ordinating health actions* listed elsewhere in this document include:
  i. Amerson (2013); Batten (2008); Bhengu (2010); Findley et al (2013); Kieler (2008); Lemos et al (2010); Molale (2012); Perestelo-Perez et al (2013); Ribeiro et al (2015); and Tallo et al (2008) in *Section 3.1*;
  ii. Vega-Romero et al (2008) in *Section 3.2*;
  iii. Bhatia (2014); Condo et al (2014); Eftekhari et al (2014); Naimoli et al (2015); and Chilundo et al (2015) in *Section 3.3*;
  iv. Guizardi and Pinheiro (2008); and Ottmann and Laragy (2010) in *Section 3.4*;
  v. Aston et al (2009); Goodwin and Happell (2006); Nathan et al (2014); and Zulu et al (2014) in *Section 3.7*; and
  vi. Brooks (2008); and, Maluka and Bukagile (2015) in *Section 3.8*.

3.6 Participation in oversight, monitoring, evaluation and review of health services/actions

Citation: Adindu A, Ndep AO, Peter A (2012) 'Advancing Participation in Primary Health Care through Community Health Management Information Systems in Rural Africa,' *International Journal of Development Studies* 5(4):132-44.
URL:www.researchgate.net/profile/Anthonia_Adindu2/publication/258515094_Advancing_Participation_in_Primary_Health_Care_through_Community_Health_*Management_Information_Systems_in_Rural_Africa/links/0046352879f76e832e000000.pdf
Countries: Nigeria; Africa
Community: Rural residents
Health system area: Oversight, monitoring and evaluation
Summary: This paper makes the case for advancing participation through improved Community Health Management Information Systems (CHMIS) with a focus on Nigeria as an example. Most African countries have weak health information systems at the community level. In Primary Health Care (PHC) in Nigeria, every local government, ward, village, and health facility contributes to the health information system; using standardised monthly forms for community health workers, health facilities, local governments and the state. In practice, lack of reporting forms, increasing data demand, and workload on health facility staff have weakened the health information system. Primary health information systems at the community/rural level are even weaker. Numerous incongruities (at district and primary health facility levels) in the structure of PHC management information system have been reported, affecting both the process and outcome. The health information system is inconsistent with local information needs; there is no objective for a local information system; tools and data collection are only developed for national requirements; the federal timetable for data collection does not consider local constraints. Health

workers collecting data do not receive training in the health information system and there is minimal supervision and community involvement. The authors suggest that Community-based participatory research can be used to enhance the effectiveness of PHC, and a CHMIS could form the nucleus for bringing people together for research, skill building, education, planning and sustainable development. A CHMIS would increase the community's understanding of data collection and use; increase community skills in data collection, maintenance and reporting; create community-based data banks; have coordinated data collection informing policy making at local, state and federal levels; more congruent with the development needs of the country.
Keywords: health information system, community information systems; Nigeria, Africa

Citation: Draper AK, Hewitt G, Rifkin S (2010) 'Chasing the dragon: Developing indicators for the assessment of community participation in health programmes,' *Social science & medicine* 71(6):1102-9.
URL: www.ncbi.nlm.nih.gov/pubmed/20621405
Country: Djibouti
Community: Rural residents
Health system area: Oversight, monitoring and evaluation; Assessing health needs and priorities
Summary: An evaluation framework for assessing the role of community participation in health improvement was tested with literature on community-based programmes for child micronutrient deficiencies in low income countries. The framework converts and adapts the five dimensions of the participation continuum by Rifkin et al (1988) into a spidergram. The spidergram used five areas of success: community and professional leadership in introducing the intervention; planning and forging partnerships between community and professionals: women's involvement; external support for finance and programme design; and monitoring and evaluation of beneficiary involvement in programme activities. Process indicators for these areas were developed and operationalised, and used in a range of community participation experiences. The paper specifically explores their use the Basic development needs programme (BDNP) in Djibouti, launched by WHO in 1987. The BDNP aims to build community capacity to find local solutions to local problems. In each community involved, a village development committee (VDC) was established, and community and VDC members were trained in a range of skills, including financial management. The VDCs conducted a needs assessment, developed action plans for projects and, with support from local public sector departments, implemented and managed the projects. Interest free loans were provided for income generation activities and VDCs provided resources for literacy classes. Two community health workers and one midwife in each village were trained by the Ministry of Health and health promotion, immunisation, anaemia screening, malaria control, refuse collection and sanitation, school health and the construction of health centres were integrated in the programme. Comparison of health indicators with the national average shows positive outcomes, although only 14 out of 34 elements of the programme were directed towards health. Apart from monitoring and evaluation, a retrospective analysis using the framework scored the BDNP highest for leadership, planning and management, external support, and women's involvement. Positive scores were attributed to the strong role of the VDCs in the leadership, planning and management of local projects. Women were deliberately and actively involved, with some projects headed by women. Monitoring and evaluation components were scored low because they were conducted by external professionals and did not involve community members.
Keywords: evaluation framework; participation; integrated approaches; Djibouti

Citation: Duarte EB, Machado MdFAS (2012) 'O exercício do controle social no âmbito do Conselho Municipal de Saúde de Canindé, CEm' [The exercise of community participation in the sphere of Canindé's Municipal Council of Health] *Saúde e Sociedade* 21:126-37.
URL: www.scielo.br/pdf/sausoc/v21s1/11.pdf
Country: Brazil
Community: Urban residents
Health system area: Oversight, monitoring and evaluation; Meso-level supporting mechanisms
Summary: This study investigated community participation at the Municipal Council of Health of Canindé-EC Brazil in 2007. The Board and health council was established by Municipal law and has its own bylaws approved in 2004. The Board has two standing committees: one on basic care and a Budget and Finance Committee. A survey of 20 councillors indicated that they meet regularly to discuss issues raised by the constituencies. Directors did not receive training prior to becoming councillors, and different sectors of the community are not well represented. While users represent half of the members, many of them (from rural communities) live further away

from the municipality, are more likely to have lower educational level compared to other members and, do not have specialised training in health. Despite this, community service users have positive views regarding the effectiveness of the Board, and did not report obstacles to their active participation. The study recommends that in order to build on the progress to date, a policy of continuing education for councillors should be established and run regularly, given the high turnover of councillors. The findings also indicated a low demand for public participation due to low community awareness among the population about the Council. Greater dissemination and communication about the Council in the community is therefore recommended.
Keywords: monitoring; municipal health; Health councils; Brazil.

Citation: Give CS, Sidat M, Ormel H, Ndima S, McCollum R and Taegtmeyer M (2015) 'Exploring competing experiences and expectations of the revitalized community health worker programme in Mozambique: An equity analysis,' *Human Resources for Health 13*: 54-015-0044-0. 10.1186/s12960-015-0044-0 [doi]
URL: www.ncbi.nlm.nih.gov/pubmed/26323393?dopt=abstract
Country: Mozambique
Community: General public; CHWs
Health system area: Oversight, monitoring and evaluation;
Summary: Mozambique launched its revitalised community health programme in 2010 in response to inequitable coverage and quality of health services (see also Chilundo et al, 2010). The programme is focused on health promotion and disease prevention, with the intention that 20% of CHWs' (APEs) time is spent on curative services and 80% on promoting health and preventing illness. The 4-month training package limits training on curative care to testing and treating malaria, diagnosing and treating diarrhoea (oral rehydration only) and providing antibiotic treatment for acute respiratory infections in children, providing first aid and being able to detect health danger signs in children, adults and pregnant women. APEs are volunteers who are expected to serve 500 to 2000 inhabitants (depending on population density and geographical coverage), between 8-25 km from the health facility of their reference. This study reports on a health system and equity analysis on the APEs in the Moamba and Manhiça districts. The study found APEs in both districts were highly valued within their communities for the availability and quality of services they provided. However, demand and supply factors affected whether services were seen as responsive and appropriate, with differences between community expectations for curative services in a context of under-supply (and APEs' willingness to perform them) and official policy focusing APE efforts on preventive services and health promotion. Communities did, however, appreciate APEs' persistence in promoting community health through basic knowledge and good hygiene practices and saw them as more approachable than health facility staff. APEs' were found to be uniquely placed to understand the cultural and attitudinal aspects of healthy practices and health-seeking behaviour and to act as cultural brokers in this and in generating demand for services.
Keywords: primary health care; prevention; health promotion; CHWs; Mozambique

Citation: Jara CEM, Andrade MCT (2015) 'Participación En Salud Y Desarrollo Territorial: Experiencia Sanitaria En Una Comuna Del Sur De Chile,' [Health participation and territorial development: health experiences in a commune in Southern Chile] *Cienc enferm* 4PY - 2015;115–25.
URL: www.scielo.cl/pdf/cienf/v21n1/art_11.pdf
Country: Chile
Community: General public
Health system area: Oversight, monitoring and evaluation
Summary: The health reforms of 2005 in Chile include a guarantee by law of access to care with quality and respect for a person's dignity. This study investigated the association between the Offices for Information, complaints, suggestions and feedback (OIRS) and the activities of citizen participation in a commune in southern Chile. The results indicate that the idea of participation is associated with institutionalised participation, linked to the guidelines and requirements of health facilities and less so on the factors that influence the populations health and health needs. Nearly all respondents agreed that participation was focused on health promotion and prevention, such as to raise community awareness about their eating habits and healthy lifestyles. Less well agreed was that individuals be involved in diagnosis and care. While it is one of the main rights of the health system in Chile, this participation is viewed as an individual medical action. Health professionals also disagreed that citizens be involved in budgeting, but fewer disagreed with citizen engagement in facility management and development. The authors indicate that more

work is needed to understand the role health teams play, such as in moving from feedback and complaints forms to sharing community diagnosis.
Keywords: Primary health care, feedback and complaints; assessment; Chile.

Country: Kenya
Community: Rural orphans and separated children
Health system area: Oversight, monitoring and evaluation
Summary: The Orphaned and Separated Children's Assessments Related to their Health and Well-Being (OSCAR) project is a 5-year longitudinal cohort study (2010) to evaluate the effects of different care environments on the physical and mental health outcomes of orphaned and separated children (OSC) in western Kenya. A community-based Participatory Research (CBPR) was used for problem identification, planning and feasibility; implementation; and evaluation and dissemination. It aimed to engage the community so that the research aligned with the social, cultural and political contexts, and to achieve sustainable and culturally appropriate solutions. Community approval for the CBRT was obtained through district administrative processes and meetings with chiefs, village elders and community residents to explain the project; the recruitment of community Health Workers (CHWs); integrating community feedback into the protocol; and establishing a community Advisory Board (CAB) to review community feedback, and approve the protocol. During implementation, CHWs from each project location were integrated into the research team, and the research team became a member of the Children's Services Forum in the area. Monthly meetings were held with the Forum to ensure ongoing community feedback and input. The CAB reviewed findings of the work at its quarterly meetings and members were invited to develop dissemination materials. The project demonstrated the value of community involvement and participation in the research and successful implementation of the project, involving vulnerable people within complex community structures. There were challenges: communities identified other issues of concern, such as children with disabilities, single mothers and older people. This influenced their identification of households, with households without OSC included because they were perceived as being as needy as those with orphaned children. The authors indicate that CBPR requires careful consideration by researchers to address community opinions, needs, and participation in the research process.
Keywords: community based research; orphaned children; Kenya

Country: Ethiopia
Community: General public
Health system area: Oversight, monitoring and evaluation; Health planning and budgeting
Summary: The Ethiopian Federal Ministry of Health (FMoH) has identified the need to develop a scalable and comprehensive mobile health (mHealth) platform and strategy that could meet long-term needs and strengthen the PHC system including: referrals, data exchange, supply chain management, training, education and consultation. Health Extension Workers (HEWs) are the frontline workers for delivery of health education, basic curative care and preventive components of PHC in Ethiopia. HEWs have a variety of information and communication needs to provide effective care to their communities. An 18-month study was implemented on the use of mHealth by twenty HEWs and twelve midwives in two districts. A set of appropriate smartphone health applications using open source components, including a local language adapted data collection tool, and user-friendly dashboard analytics and maternal-newborn protocols were developed and evaluated. Health workers were engaged in: unrestricted use of and ownership of the phones; adaption of the system to allow health workers to make use of the information to track the progress of pregnant mothers and performance information; redesign of protocol forms based on health worker input; and involvement in the pre-testing phase. The customised application and protocols were pre-tested with health workers during the 3-month training. Most health workers

rapidly learned how to use and became comfortable with the touch screen devices so only limited technical support was needed. Ownership of the phones was a strong motivator for workers, with a low level of breakage/loss. Usage of protocol forms in postnatal care took a long time. Often the same patient ID was used for multiple patients, due to several reasons including multiple registration systems within a health facility. Supervisors provided little information about what data they needed to improve their role. Although it is too soon to show a direct link between mobile technologies and health outcomes, mobile technologies allow health managers to more quickly and reliably have access to data on service delivery.
Keywords: mHealth; information technology; CHWs; Ethiopia

Citation: Marston C, Renedo A, McGowan CR, Portela A (2013) 'Effects of Community participation on improving uptake of skilled care for maternal and newborn health: a systematic review,' *PloS one* 8(2):e55012.
URL: www.ncbi.nlm.nih.gov/pmc/articles/PMC3563661/pdf/pone.0055012.pdf
Countries: Bangladesh, Malawi, Nepal, India, Kenya
Community: Rural and urban residents
Health system area: Oversight, monitoring and evaluation.
Summary: This systematic review of published and 'grey' literature from 1990 on the effectiveness of community participation interventions in maternal and newborn health explored whether participation improved outcomes and how this was assessed, and the outcome measures used. Seven studies were included, only one of which was primarily qualitative, largely as qualitative studies did not measure the outcomes of interest. Several interventions were based on the innovative Warmi project in Bolivia, which aimed to improve maternal and child health using facilitated women's groups. The groups used ''autodiagnosis'' (similar to participatory action research) to identify and prioritise local problems, develop action plans accordingly, implement those plans, and then evaluate their own efforts. All groups identified the need to increase knowledge of reproduction, contraceptive use, and danger signs in pregnancy; improve immediate newborn care; and increase the proportion of women receiving skilled childbirth care. Actions taken included participatory development of education materials, savings schemes, and literacy programmes. Community participation had largely positive impacts on maternal/ newborn health as part of a package of interventions, although not necessarily on uptake of skilled care. Positive maternal and neonatal outcomes were found from raising community awareness of and dialogue on maternal and newborn health problems. Communities were often involved in designing and sometimes implementing solutions for problems identified, such as in setting community-generated funds for maternal and infant care, or improving or providing transport for obstetric emergency cases, often using local resources. In Kenya, dialogue between community members and health service providers was core, including in identifying shared priorities for action. In India, community generation of data in maternal death audits drew attention to clusters of deaths in certain areas, and prompted community and health provider responses. Two interventions with no impact on maternal and newborn health outcomes were externally initiated, but raised awareness, encouraged dialogue, and involved communities in designing solutions. The review suggests that qualitative investigation is needed alongside quantitative studies to understand complex interventions in context, describe predicted and unforeseen impacts, assess potential for generalisability, and capture the less easily measurable social/political effects of encouraging participation.
Keywords: participation; review; maternal health; Bangladesh, Malawi, Nepal, India, Kenya

Citation: McHunu GG (2009) 'The levels of community: involvement in health (CIH): a case of rural and urban communities in Kwazulu-Natal,' *Curationis* 32(1):4-13.
URL: www.curationis.org.za/index.php/curationis/article/viewFile/853/790
Country: South Africa
Community: Urban and rural residents.
Health system area: Oversight, monitoring and evaluation
Summary: The study aimed to describe the practice and levels of community involvement in health (CIH) in urban and rural communities in Kwa Zulu Natal (KZN). Community involvement and/or participation was defined as people becoming active participants in their own health care, by generating their own ideas, assessing their needs, being involved in decision-making, planning, implementing, and evaluating care. The study worked with health centre (clinics) in the chosen health sub-districts with all the community members using the clinic, health programmes and community health workers within the Ethekwini health district. A total of 31 participants were

interviewed from the urban and rural community. The rural community members felt they were in charge where they worked on projects without health professionals (sewing, poultry farming and candle making), demonstrating high levels of participation. The health professionals felt that community members were involved during implementation of such health programmes as breastfeeding and immunisations. In the rural group the two groups of CHWs (those working in the clinic and the community volunteers) functioned independently from each other, and there was no integration in their service provision. The CHWs linked to the clinic felt that there was community involvement in health from planning to evaluation whereas the volunteer CHWs not linked to the clinic felt there was not community involvement in the health programmes. In the urban community, community members helped each other as neighbours in times of need without the involvement of health workers. There were no community projects in the urban area and urban community members did not seek to involve themselves in clinic health programmes.
Keywords: community involvement; participation levels; health care; South Africa

Citation: Mitsunaga T, Hedt-Gauthier B, Ngizwenayo E, Farmer DB, Karamaga A, Drobac P, et al. (2013) 'Utilizing community health worker data for programme management and evaluation: Systems for data quality assessments and baseline results from Rwanda,' *Social Science & Medicine (1982) 85*: 87-92. 10.1016/j.socscimed.2013.02.033 [doi]
URL: www.ncbi.nlm.nih.gov/pubmed/23540371?dopt=abstract
Country: Rwanda
Community: General public; CHWs
Health system area: Oversight, monitoring and evaluation; Health planning and budgeting
Summary: The data routinely generated through CHW programmes are increasingly relied upon for providing information for programme management, evaluation and quality assurance. However, there are few published results on the quality of CHW-generated data, and what information exists suggests quality is low. An ongoing challenge is the lack of routine systems for CHW data quality assessments (DQAs). This paper describes a system developed for CHW DQAs and results of the first formal assessment in southern Kayonza, in May-June 2011. The Rwanda community health programme has 45,011 CHWs to deliver a broad range of preventive and curative services. In each village, a maternal health CHW monitors pregnant women and their new-borns and at least two multi-disciplinary CHWs carry out: integrated community case management (iCCM); malnutrition screening; and other preventive and behaviour change activities. The MoH standardised community health information system makes CHW data available at the subnational and national levels. During each sick child visit, CHWs complete an encounter form using an algorithm to guide them. Key data from each form are transferred to the iCCM consultation register and the CHWs use the registers to generate the monthly, village-level report. The village reports are then aggregated first at the cell level (a cluster of villages); then at the sector level (corresponding to the health centre) after which they are sent to the district level, where the data are entered electronically and transmitted to the central level. A DQA system was designed and field tested at the eight health centres in one of three rural districts. The results indicate challenges to achieving high quality CHW reports, including CHWs running out of forms, inconsistent reporting periods, design of forms and registers introducing problems with legibility and transcribing data, unclear indicator definitions, and inadequate training and supervision. There were also CHW issues, including limited literacy and numeracy, experience using iCCM tools, and patient volume. Some CHWs lack the required primary school education, limiting their ability to understand, record or tally information even with additional training or supervision.
Keywords: Community health information; CHWs; Rwanda

Citation: Mosquera J, Gutiérrez A, Serra M (2009) 'La experiencia de participacion ciudadana en el control social a la gestion en salud en Cali, Colombia,' [Citizen participation in accountability to health management in Cali, Colombia] *Colombia Médica* 40(1):95-102.
URL: www.scielo.org.co/pdf/cm/v40n1/v40n1a8.pdf
Country: Colombia
Community: Urban residents
Health system area: Oversight, monitoring and evaluation; Meso-level supporting mechanisms
Summary: In Colombia the secretariats of Municipal public health authorities have a duty to promote citizen participation, but it remains weak. A pilot process of social control in management of health services involved service users in Cali, with a focus on accountability. In total 745 people and 54 community leaders of five user associations linked directly, with the public networks in Cali

promoting their role in accountability. A self-assessment exercise by community members, leaders and public servants found that there was no clarity about the concepts of social control and accountability. Communities and the administration thought that the only responsibility of the administration was to *inform* users about actions with the communities being passive recipients. Further exercises have focused on using an instrument to prioritise issues for social control, with progress resulting in the understanding and practice of accountability; and on improving the mechanisms for communication between communities and the municipal health authority. This has provided the basis for development of a proposal to support improved design, development and evaluation of experiences of accountability. While the benefits of participation emerged from the pilot, despite the existence of legal provisions for citizen participation, there is a mismatch between these legal provisions and participation in practice. Challenges include: the technical limitations of communities in analysing information from the health sector; health sector obstacles in making information available; the view of public servants that their management should not be subject to scrutiny by the communities; a lack of qualified community leaders, and a reluctance among community leaders to be involved due fear of political backlash.
Keywords: accountability; health services; Colombia

Citation: Neupane S, Odendaal W, Friedman I, Jassat W, Schneider H and Doherty T (2014) 'Comparing a paper based monitoring and evaluation system to a m-health system to support the national community health worker programme, South Africa: An evaluation,' *BMC Medical Informatics and Decision Making 14*: 69-6947-14-69. 10.1186/1472-6947-14-69 [doi]
URL: www.ncbi.nlm.nih.gov/pubmed/25106499?dopt=abstract
Country: South Africa
Community: General public
Health system area: Oversight, monitoring and evaluation; Health planning and budgeting
Summary: Traditionally, CHWs use paper-based reporting forms that are regularly submitted to their supervisors. This study explored the use of a cell phone-based and paper-based monitoring M&E system to support the work of 10 CHWs during 2012-2013. CHWs were trained in both the paper-based M&E system and a Mobile communication (m-health) system, with continuous support and guidance. Under the paper system CHWs had a form for individual household visits plus a form for making a weekly and a monthly summary of all household visits. Team leaders aggregated CHWs monthly data into a team monthly summary form. The CHWs were given mobile phones to record exactly the same information as in the paper forms. CHW referrals under the paper-system were done using a form. They were done via text message to the facility under the m-health system. If the client attended, the facility manager completed either the rear side of the form or texted the CHW back. Clinical referrals, data accuracy and supervised visits were compared and analysed for both systems. Compared to the m-health system where data accuracy was assured, 40% of the CHWs showed a consistently high level (>90% correspondence) of data transfer accuracy on paper. Overall, there was an improvement over time. The most common error that occurred was summing. Few supervised home visits were recorded in either system. The focus group discussion with the CHWs found that carrying piles of paper was cumbersome as CHWs have to walk to their clients and that clients were concerned about the confidentiality of paper forms and so reluctant to raise their health questions. The m-health system enabled a longitudinal follow up of referrals with back and subsequent referrals linked to the same client. The m-health system automated calculation features addressed the data transfer and or calculations problems of the paper-system. Real-time data availability offered by the m-health system plays an important role in closing the gap between clients and health service providers and enables accurate tracking of referrals. Both systems need regular supervision and ongoing assessments of data quality.
Keywords: Monitoring; health information system; referrals, m-health; South Africa

Citation: Pelletier JF, D'Auteuil S, Ducasse C, Rodriguez Del Barrio L (2014) 'Participation publique et participation citoyenne des personnes utilisatrices de services en lien avec le Plan d'action en santé mentale 2005-2010 : leur rôle de porte-parole,' [Public participation and civic participation of service users in relation to the Mental Health Action Plan 2005-2010: their spokesperson function] *Sante mentale au Quebec* 39(1):175-93.
URL: www.revue-smq.ca/participation-publique-et-participation-citoyenne-des-personnes-utilisatrices-de-services-en-lien-avec-le-pan-daction-en-sante-mentale-2005-2010-leur-role-de-porte-parole/
Country: Canada

Community: Mental health service users

Health system area: Oversight, monitoring and evaluation.

Summary: The Quebec Mental Health Action Plan 2005-2010 (MHAP) recognises that people who use mental health services ('consumers') can be active agents of their own individual and collective recovery. It calls for greater consumer participation in local, regional and national decision-making in health and social services in Quebec. An Actor Network Theory conceptual framework was used to reflect on various forms and complexities of consumers' participation in the MHAP since its enactment, from the early 1960s. In some regions of Quebec, participation was coordinated by community organisations that designated their representatives. In others, local authorities included consumers on a more individual basis to give their opinion. In either case, their function as spokespersons proved to be a bi-directional function. In one direction, the spokesperson informed the governmental and institutional stakeholders about the expectations of consumers and about their daily life realities. In the other direction, they could explain and make more intelligible the health system using a lay language, helping people to be more informed partners. Their peers were able to get a clearer understanding of the progress made in effectively promoting active and effective participation. The MHAP did not provide clear indicators of how to assess progress in consumer participation, and the lack of clear expectations and means to support participation led to discrepancies from one region to another, making it difficult to assess overall progress. As the function of spokesperson got more professionalised with increased opportunities to participate in policy and decision-making, spokespersons spoke from an "us" rather than an "I" standpoint. Public participation evolved to one of civic participation, with the possibility to transcend the "us" and "them" dichotomy, to see the collective of members of a community. The authors argue that the terms and conditions of participation could be better defined and be made more predictable for equity in access to different levels of policy and decision-making.

Keywords: mental health; evaluation; participation; Canada

Country: Zambia

Community: Rural and urban residents;

Health system area: Oversight, monitoring and evaluation; Health planning and budgeting

Summary: As part of a primary care improvement project (BHOMA) in the Lusaka Province, Zambia, a CHW programme used a mobile phone-based application to strengthen connections between the clinic and the community through patient follow-up and referral, and to emphasise early treatment and referral of ill individuals via routine household visits. In 2010/ 2011 it was implemented at six primary care sites in rural and peri-urban health clinic sites and their catchment areas, working with CHWs. Computers were installed at clinics for data entry, and data were transmitted to central servers. Using a mobile phone to send data and receive follow-up requests, CHWs conducted household health surveillance visits (quarterly), referred individuals to clinic (as required), and followed up clinic patients where the system generated a request if the patient met certain criteria. CHW data fees were prepaid monthly by the project, solar power was supplied and CHWs had a bike for transport. CHW reporting generated a list of follow-up requests from the central server to the CHW's mobile phone. Programme monitoring occurred both at the sites and centrally. A team leader elected by the CHWs at each site was responsible for conducting bimonthly progress meetings with other CHWs. A trained clinic nurse held an additional monthly meeting at the clinic with all the CHWs. Individual performance reports were created for these meetings based on data submitted at both the facility and community, describing aspects such as patient attendance at clinic after CHW referral or number of follow-up requests completed. A specific strength of the programme was the scale of community outreach through CHW routine household visits, and reliable health surveillance networks for early detection and referral. Another strength was the comprehensiveness of the data system, with complementary and standardised collection tools allowing tracking of cases between community and clinic. Of all clinic cases sent for a follow-up request, CHWs performed one or more follow-ups on 74% of active requests and obtained outcomes on 63%. CHWs completed all planned aspects of surveillance and outreach, demonstrating feasibility.

Keywords: mhealth; referral; information systems; CHWs; Zambia

Citation: Vázquez ML, Flores A. Gonzalez ESC, Diniz CdS, Campbell AP, van Heerden ICM, Ahmadi IKG (2005) 'Nível de informação da população e utilização dos mecanismos institucionais de participação social em saúde em dois municipios do Nordeste do Brasil,' [Level of community information and use of mechanisms for social participation in health in two municipalities of Northeast Brazil] *Ciência & Saúde Coletiva* 10:141-55.
URL: www.scielo.br/pdf/csc/v10s0/a17v10s0.pdf
Country: Brazil
Community: Service users
Health system area: Oversight, monitoring and evaluation; Meso-level mechanisms
Summary: A series of institutional mechanisms for social participation in the health services were designed in Brazil, in the municipal health councils, dial health (disque saude) a 24-hour hotline, health conferences, and the health ombudsman as well as an indirect mechanism (PROCON). *The health boards* are collegiate bodies, permanent and deliberative in character, at all three levels of government, with joint participation of users. They formulate strategies to implement sectoral policies and control the implementation of health policies and actions, including economic and financial aspects. Started in 1941, and reinvigorated from 1986, the *health conferences* are forums of representation of various social segments, to assess the health situation and propose guidelines for the formulation of health policy in the relevant government levels. They are meant to be convened every four years and always with the joint participation of the user in relation to all the other threads. The dial-health constitutes a phone line to provide information and receive complaints relating to health. The *Health Ombudsman* is intended to receive complaints from any citizen, allegations of any individual or collective rights violations relating to health, as well as any act of administrative misconduct by public servants, ascertain the truthfulness of the facts and provide the appropriate measures. PROCON represents consumer protection which together with mass media might act as indirect mechanisms of participation. A study in two municipalities of Pernambuco (one rural and one urban) in 2000 found that about half of the interviewed population were aware of the existence of Disque Saude, suggestion boxes and the municipal health councils, with other direct mechanisms less well known. The functions of all mechanisms except for PROCON were inaccurately and vaguely defined. Only a small proportion of the population use the institutional mechanisms, and at the level of information rather than the expected social control. The authors recommend strategies to ensure the population know of the social control mechanisms and how they work in order to more actively participate.
Keywords: Oversight, monitoring; committees; involvement; Brazil.

Citation: Wakefield PA, Randall GE, Richards DA (2011) 'Identifying barriers to mental health system improvements: an examination of community participation in assertive community treatment programmes,' *International Journal of Mental Health Systems* 5:27.
URL: http://ijmhs.biomedcentral.com/articles/10.1186/1752-4458-5-27
Country: Canada
Community: Services users
Health system area: Oversight, monitoring and evaluation
Summary: The Assertive Community Treatment (ACT) seeks to ensure that members of the local community are involved in Community Advisory Bodies (CAB) and as "Peer Support Specialists" (PSS). This paper reports on the extent to which ACT programme standards related to community participation have been implemented based on a telephone survey of 66 ACT Programme Coordinators in Ontario, Canada. ACT programmes in Ontario must be sponsored by an organisation within the immediate community. The survey found that rural ACT teams are, doing significantly better than urban teams in having a CAB, but they are still not fully compliant. In having a PSS as part of the team, urban ACT programmes are doing slightly better than their rural counterparts, although on average neither group is fully compliant. Two important issues that contribute to lower levels of compliance are: internal resistance (within the ACT programmes themselves) to implementation; and, the lack of sponsoring agency support (or even active opposition by some sponsoring agencies to implementation). The reasons for low compliance are described as complex and linked to structural and human resources barriers, and the requirements of the standards themselves. Suggested approaches to improving implementation of community participation standards lies in improving the education of ACT programme administrators and team members about their use and enhancing clarity of the standards, to proactively monitor compliance.
Keywords: health services; standards; community oversight; monitoring; Canada

Other publications including information about *oversight, monitoring, evaluation and review of health services/actions* listed elsewhere in this document include:
  i.   Kieler (2008) in *Section 3.1*;
  ii.   Bhatia (2014); and Naimoli et al (2015) in *Section 3.3*;
  iii. Avard et al (2009) in *Section 3.4*;
  iv.   Micikas et al (2015); and, Monson and Thurley (2011) in *Section 3.5*;
  v.   Thurston et al (2005) in *Section 3.7*; and
  vi.   Berger and Otago (2010) in *Section 3.8*.

3.7   Impacts, enablers of and barriers to participation in health systems

Citation: Aston M, Meagher-Stewart D, Edwards N, Young LM (2009) 'Public health nurses' primary health care practice: strategies for fostering citizen participation,' *Journal of Community health nursing* 26(1):24-34.
URL: www.ncbi.nlm.nih.gov/pubmed/19177270
Country: Canada
Community: Public health nurses
Health system area: Enablers & barriers in health action; Implementing & co-ordinating health action
Summary: This article presents findings about public health nurses' perceptions about their role in fostering citizen participation and the facilitators and constraints to working with citizens as partners. The findings are based on a qualitative study of 147 public health nurses working in eastern Canada in family health, school health, and communicable disease control programmes or rural general care. Building capacity for partnership and citizen control emerged as a key theme in nurses' description of their practice with communities, including: working within a population health promotion perspective; building trust and rapport; engaging in respectful dialogue and actively listening to, believing in and emphasising clients' capabilities; building personal confidence and skills; and seeking input from poorer, more isolated mothers. They saw sharing information via print material and videos plus interactive approaches of asking questions more empowering than just delivering the information; and connecting to a broader social network. Many nurses developed partnerships with local organisations, community services and family resource centres. Reported constraints included: a lack of funding for health promotion and prevention programmes; misunderstanding of their roles by politicians, public and managers; lack of visibility; multiple demands; and a reduced presence at provincial planning tables.
Keywords: public health nurses, participation; partnership; Canada

Citation: Cornwall A, Leach M (2010) 'Putting the Politics Back into 'Public Engagement': Participation, Mobilization and Citizenship in the Shaping of Health Services.' Institute of Development Studies: Brighton.
URL: http://r4d.dfid.gov.uk/PDF/Outputs/CentreOnCitizenship/cornwall_etal.2010-putting.pdf
Countries: Bangladesh, Brazil, South Africa, United Kingdom
Community: General public
Health system area: Enablers and barriers in health action; Health policy deliberation
Summary: A ten-year long collaborative international research programme of the Citizenship Development Research Centre presents reflections on public participation in primary health care services, through case studies from Bangladesh, Brazil, South Africa and the UK. The cases raise the importance of recognising the multiple sites in which public and citizen engagement takes place, beyond the official spaces into which citizens are invited to participate, affected by the cultures, contexts and practices of engagement, and the tactics and styles. For example, claiming space in the streets, the shebeens (pubs or bars), the courts and the clinics gained visibility locally and globally for the Treatment Action Campaign in South Africa. In Brazil the health councils were used to advance agendas and hold space for participation. Various tactics were used including direct action and demonstrations, letter writing, petitioning, internet campaigns, strategic non-participation, pursuing claims in the courts, strikes, occupations, taking officials hostage to make demands and a variety of non-violent forms of protest and resistance. Much of what constitutes 'citizen participation' in these spaces actually amounts to being told about pre-existing health plans and programmes, and at best being involved in monitoring implementation of these plans and programmes. Paying closer attention to the synergies between mobilisation and invited

participation, provides greater insight into how people negotiate health citizenship and influence the institutions and decisions that affect their health.
Keywords: public engagement, power; determinants; Bangladesh, Brazil, South Africa.

Citation: Goodwin V, Happell B (2006) 'In our own words: consumers' views on the reality of consumer participation in mental health care,' *Contemporary nurse* 21(1):4-13.
URL: http://www.tandfonline.com/doi/abs/10.5172/conu.2006.21.1.4
Country: Australia
Community: Health service users
Health system area: Enablers & barriers in health action; Implementing & co-ordinating health action
Summary: A study in two rural areas in North East Victoria explored the views and opinions of users of mental health services about their participation in the planning and delivery of their care, and the role of nurses in facilitating this. There was a policy commitment to inclusion of consumers and carers at all levels of decision making in mental health arena in Australia after 1997. The services covered urban metropolitan and rural towns and farming communities. In remote parts access was hampered by distance, poor roads. The services cover culturally diverse Indigenous Australians, second-generation post-war migrants and more recent migrants. The study found limited consumer participation in care planning at either local or system levels. Concerns were raised about the attitudes of health care professionals and their importance for the establishment of a collaborative relationship. Despite positive experiences with nurses, participants described negative, even derogatory experiences as more common. Encouragement from nurses was seen as essential to support consumer collaboration in care planning and was also seen as having therapeutic value. Consumers and carers were also seen to need sufficient information to be effective in collaboration. The system barriers identified to effective participation related to high workloads and other pressures which limit the time nurses were able to spend with individual consumers, and the time available to encourage collaboration.
Keywords: mental health; consumer involvement; service delivery; decision-making; Australia

Citation: Nathan S, Braithwaite J, Stephenson N (2014) 'The scope and impact of community participation: The views of community representatives in an Australian health service,' *Journal of health organization and management* 28(3):405-21.
URL: www.ncbi.nlm.nih.gov/pubmed/25080652
Country: Australia
Community: Community representatives
Health system area: Enablers and barriers in health action; Implementing and co-ordinating health action; Meso-level supporting mechanisms
Summary: Community participation is explicitly included in Australian health accreditation standards. A cross-sectional survey was implemented of 49 Community representatives' (CReps) and of a sample of representatives and staff in a large health service in NSW as part of a process to strengthen local level participation. CReps are drawn from the local area facility or hospital. In 2010 there were six to twelve active members on each of eight community Networks in the region. CReps are often former or current patients, carers or people with an interest in the health system, chosen to reflect the local community as much as possible. Those from minority cultural backgrounds have been more difficult to recruit. Community Networks meet every two months and members can be appointed to other health service committees at the facility and regional level. Most CReps had positive attitudes about their value and potential influence. Having an external network or group supported their belief in their ability to add value to their health service. CReps felt they provided a link to, and represented, the wider community, although most thought staff did not understand their role or how to work with them. Some staff questioned their representativeness. Despite this, CReps appeared to successfully navigate bureaucracies to effect change without presenting a direct challenge to staff views or vocally asserting their legitimacy and representativeness on committees. The authors highlight the need for improved communication about CReps' roles and impacts to staff, and to encourage staff to pay more attention to the impact of CReps participation on service design and delivery, rather than their "representativeness". They propose that CReps be involved in staff training, to present their experiences of participation, how they have influenced policy and practice and the projects they have initiated for patients and carers. They also suggest that more focus be placed on documenting and communicating the outcomes from community participation in health services.
Keywords: Health services; community representatives; committees; networks; Australia

Citation: Nathan S, Braithwaite J, Stephenson N (2013) 'Facilitating the action of community representatives in a health service: the role of a community participation coordinator,' *BMC health services research* 13:154.
URL: www.ncbi.nlm.nih.gov/pmc/articles/PMC3646681/pdf/1472-6963-13-154.pdf
Country: Australia
Community: Community representatives
Health system area: Enablers and barriers in health action; Meso-level supporting mechanisms
Summary: The role of Community Participation Coordinators (CPCs) in a health service in South-Western Sydney, were examined in a triangulated multi-method, multi-site ethnographically informed three-year study of the Community Participation Programme. Two main mechanisms set in policy for community participation are local Community Networks and a CReps' Council at the district level. Each network is represented by two elected members. A CPC is employed at the local facility level reporting to the Hospital General Manager and is responsible for: working closely with staff and community to increase knowledge and skills in participation; promoting, recruiting and supporting CReps; advocating for and managing resources attached for participation at the facility level; and building capacity and providing on-going support for a culture of customer service. The CPC role appeared central to CReps becoming a more cohesive group and pursuing their own community focused agenda in the health services. Four key roles that CPCs undertake to support this were identified: building skills and confidence; engaging CReps in agendas for action: helping CReps navigate and understand the health system; and advocating to staff. This included focusing CReps as a group on small wins and discrete projects and bringing key health staff to network meetings. Coordinators were highly regarded by the CReps, but reported a lack of prestige and recognition about their role among some health staff, restricting their power and ability to work with CReps. Questions were noted on the role of the CPC as an advocate, and constraints to this in health services. The authors recommend that health services employ a facilitator to support, engage, navigate and advocate for CRep's role and influence in health services.
Keywords: Health services; community representatives; facilitators; Australia

Citation: Paiva FS, Stralen CJ, Costa PH (2014) 'Participação social e saúde no Brasil: revisão sistemática sobre o tema,' [Social participation and health in Brazil: a systematic review on the topic] *Ciencia & saude coletiva* 19(2):487-98.
URL: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1413-81232014000200487
Country: Brazil
Community: General public
Health system area: Enablers and barriers in health action;
Summary: This article presents the findings of a systematic review of the literature post 2000 on factors associated with the institutionalisation of health councils in Brazil. Key issues noted include: the oligarchisation and professionalisation of health advisers representing different social sectors; fragile relationships between representatives and the represented; a lack of clear rules regarding the how civil society organisations are selected; and formation of "policonselheiros" i.e. a specific group of social actors who occupy all the public advisory positions. Language privileging technical expertise and lack of time hindered dialogue between different members of the council, especially on financial matters. Users are trained as participants but there was limited information on training of professionals, service providers and executive representatives. Those holding scientific and technical knowledge were given greater legitimacy than the popular knowledge of service users. The population was traditionally understood to be beneficiaries of public policy and the state to have decision-making responsibility on when and how to offer benefits. While the councils were seen as having the potential to introduce a new culture of democracy and debate, the political culture of Brazil in policy deliberations has been characterised by cronyism, patronage, authoritarianism and paternalism. The biomedical and curative model has continued to dominate discussions and the health issues considered, focusing on curative services for specific diseases, without linkages to social or structural determinants of health such as housing, work, sanitation and or education. Investment in deliberative democracy of itself does not solve the lack of democracy. Identifying the barriers to achieving the original goals of the councils is argued to help to foster the construction of alternatives to strengthening these democratic mechanisms.
Keywords: Health policy deliberation; citizens' councils; review; determinants; Brazil

Citation: Ramirez NA, Ruiz JP, Romero RV, Labonte R (2011) 'Comprehensive primary health care in South America: contexts, achievements and policy implications,' *Cadernos de saude publica* 27(10):1875-90.
URL: www.scielo.br/scielo.php?script=sci_arttext&pid=S0102-311X2011001000002
Countries: Brazil, Colombia, Chile, Ecuador, Argentina, Bolivia, Peru, Venezuela, Paraguay, Uruguay
Community: General public
Health system area: Enablers and barriers in health action;
Summary: This 2007/8 review of South American (SA) experiences with primary health care since 1978 explored the role of citizen participation and the lessons learned from these experiences. It covered Brazil, Colombia, Chile, Ecuador, Argentina, Bolivia, Peru, Venezuela, Paraguay and Uruguay and regional analyses. Comprehensiveness and universality in health systems and PHC programme design were noted with increased involvement of social movements and community organisations in health services and programme decision-making. Bio-psychosocial and intercultural health models and empowerment ethos of most reforms implied a stronger role for the family, community, intersectoral service provision and policies and social participation in self-care, planning, administration, monitoring and evaluation of health system activities, creating greater political accountability and transparency. Rights-based approaches to health system reform were adopted alongside increased social and citizen mobilisation and participation, and led to increasing popular demands for government accountability. Brazil and Venezuela provided examples of bottom-up approaches with strong community participation and empowerment with an impact on the formulation, implementation and evaluation of health policies and programmes. In contrast top-down community participation, usually as part of externally mandated funding initiatives, were found to resulted in citizen contributions to decision-making that were less meaningful and responsive to health needs. Democratization of institutional processes and decision-making and the strengthening of citizen and community autonomy were found to be key and decentralisation to facilitate this, when accompanied by a transfer of power and resources to local communities. For example, in the health agents programme in Ceará, Brazil in the 1990s, decentralisation strengthened community capacity to voice local needs and interests and made PHC and health services more accessible, equitable and culturally appropriate as an integral part of the reorientation of the system, informing cultural changes in the health service.
Keywords: heath system reforms; citizen participation; review; Latin America

Citation: Ruano AL, Sebastian MS, Hurtig AK (2014) 'The process of social participation in primary health care: the case of Palencia, Guatemala,' *Health expectations: an international journal of public participation in health care and health policy* 17(1):93-103.
URL: www.researchgate.net/publication/51628588_The_process_of_social_participation_in_primary_health_care_The_case_of_Palencia_Guatemala
Country: Guatemala
Community: Urban and rural residents
Health system area: Enablers and barriers in health action; Health literacy/ promotion/ information; Meso-level supporting mechanisms
Summary: Social participation has been a key component of Guatemala's decentralisation process since the late 1990s. Formal participation is based on social development councils at community, municipal and national levels, although they are not specified in law. Each level of the council has specialised commissions. The health commission brings the health sector and council scheme together to provide space for social participation on health. The community-level health commission (CHC) linked to the community-level council keeps the community's environment healthy, provides information about disease outbreaks, establishes emergency plans to transport sick people, monitors health policies and provides feedback to the municipal-level health commission (MHC). The MHC is responsible for tailoring national policies to municipal needs and implementing programmes. It coordinates all health-related work in the municipality. In Palencia, with a largely rural population of subsistence farmers, there are 49 community-level councils and one MHC that has been meeting since late 2008. A lack of clear guidelines and regulations for social participation meant that the stakeholders own motivations, agendas and power resources play an important part in defining the roles of the participants. Institutional stakeholders (municipal government, NGOs, or health ministry participants) were found to have greater decision-making power and resources than community-level stakeholders, whose role was limited to identifying the needs of their communities and seeking help from the authorities. Satisfaction and the perceived benefits that the stakeholders obtain from the process play an important part in maintaining the

commission's dynamic. The authors argue that stakeholders need to perceive that the benefit they obtain does not outweigh the effort their role entails and that this needs stronger incentives and measures beyond the individual stakeholder's good will.
Keywords: participatory mechanisms; community involvement; committees; Guatemala

Citation: Serapioni M, Matos AR (2014) 'Citizen participation and discontent in three Southern European health systems,' *Social science & medicine* 123:226-33.
URL: www.sciencedirect.com/science/article/pii/S0277953614003657
Countries: Italy, Portugal, Spain
Community: General public
Health system area: Enablers and barriers in health action; Meso-level supporting mechanisms
Summary: The health systems of Italy, Portugal and Spain underwent reforms that brought citizen participation to the forefront through laws, plans and a range of activities involving the mobilisation of different actors. The 1978 reform of the Italian health system considered citizen participation a guiding principle and strategic issue and provided a law for quality assurance to be evaluated by users and their representatives. It did not, however, provide institutional mechanisms to effectively involve users in healthcare. Twenty years later, innovative participatory experiences are still rare in the Italian regional healthcare systems. Portuguese law in 1979 provided rights for users and professionals to participate in the planning and management of services, at central level (through the National Health Council) and at regional and local level (in regional health councils and municipal health commissions). However, the resources, organisational models and methods for such participation were not provided, little specific action was taken, and collective action has taken the form of protests and patient associations. More recently, innovative and institutionalised participatory practices have been implemented, including legally backed Community Councils within Primary Health Centre Groups. In Spain, citizen participation was specified in the General Health Law which created the Health Councils in Health Districts of the Autonomous Communities, involving representatives of local associations, health professionals' trade unions and Health District administrators. However, the mechanism was "more symbolic than real". More recently some Autonomous Communities have introduced new participatory mechanisms including a participatory health reform process, with a forum of patient association representatives and individual users; a participatory and administrative council comprising a health forum coordinator, executives and professionals from the health district; and, a virtual forum. The main challenges relate to training for participants and financial resources for the processes, as well as the disproportionate involvement of political decision-makers. The authors observe that the financial crisis has negatively affected citizen participation in the three countries, given reduced investments in healthcare. Collective mobilisations against austerity such as in citizen and health professional protests have emerged as participatory channels, challenging and attempting to influence closed decision-making.
Keywords: health reforms; participatory mechanisms; protest, civil society; Italy, Spain; Portugal

Citation: Tempfer CB, Nowak P (2011) 'Consumer participation and organizational development in health care: a systematic review,' *Wiener klinische Wochenschrift* 123(13-14):408-14.
URL: http://link.springer.com/article/10.1007%2Fs00508-011-0008-x
Country: International
Community: Service users
Health system area: Enablers and barriers in health action;
Summary: A systematic review of international published data on user participation in health care found the following factors associated with project success: adequate financing, partnerships with well institutionalised consumer organisations, advanced project logistics, small-scale projects, and adequate internal and external communication. Most consumer participation projects were performed in the research agenda setting, internal medicine/oncology, and health worker training. A geographical concentration on English-speaking countries (USA, UK, Canada, and Australia) was identified. Most studies were retrospective analyses without the use of a control group and without outcome assessment. This meant that generalisations on the efficiency of consumer participation projects in health care is not possible based on the available literature. Various methods were used for participation, but levels of consumer participation were found to be low. In terms of health worker training, it was reported that consumers tended to emphasise interpersonal skills as compared to technical abilities. Indirect evidence from the investigated studies suggests that the involvement of consumers into health care worker training improves empathy and communication skills of the trainees. However, based on the available evidence, an

evaluation of the efficacy of such projects was not possible, due to the lack of outcome assessment data. In terms of patient information and communication, five studies of consumer participation projects found that consumer participation increases the relevance and readability of information materials and telephone and on location interviews achieve a higher degree of consumer engagement regarding local community health goals as compared to questionnaires.
Keywords: Health information; consumer participation; determinants; review; International

Citation: Thurston WE, MacKean G, Vollman A, Casebeer A, Weber M, Maloff B, Bader J (2005) 'Public participation in regional health policy: a theoretical framework,' *Health policy* 73(3):237-52.
URL:www.researchgate.net/publication/7706874_Public_Participation_in_Regional_Health_Policy_A_Theoretical_Framework
Country: Canada
Community: Indigenous community; general public
Health system area: Enablers and barriers in health action; Oversight, monitoring and evaluation
Summary: Health sector reforms in Canada in the early 2000s that focused on acute care aimed to increase public input, albeit without evaluation of what methods work best and for what kinds of outcomes, and with a lack of differentiation between public participation as a means or end in itself. A framework was used to review participation in five case studies, to explain public participation initiatives as a process; policy making processes with a health region; social context as symbolic and political institutions; policy communities; and health of the population as the ultimate outcome of public participation. The five case studies were Grace Women's Health Services, the Aboriginal Health Council, the Family Liaison Council, the Health Advisory Council and the Diversity Initiative. The findings indicated a need to think of public participation as a process that unfolds over time, with techniques within this process. Evaluation of the effectiveness of public participation means being clear on interdependent features of what the initiative includes, its intended outcomes, the mechanisms and timings for achieving these and the processes to be monitored. Outcome evaluations should be based on an understanding of the complexity of the policy and decision-making processes, the many opportunities to influence actions, and both the short- and long-term outcomes of participation techniques and initiatives. The data on the case studies indicate that levels of government and organisations outside of the health sector have an important influence in understanding whether and how a public participation initiative achieved its intended outcomes when directed at the local health sector.
Keywords: evaluation of participation; councils, partnerships; determinants; Canada

Citation: Zulu JM, Kinsman J, Michelo C and Hurtig A (2014) 'Integrating national community-based health worker programmes into health systems: A systematic review identifying lessons learned from low-and middle-income countries,' *BMC Public Health 14*(1): 1.
URL: http://bmcpublichealth.biomedcentral.com/articles/10.1186/1471-2458-14-987
Countries: Brazil, Ethiopia, India; Pakistan
Community: General public
Health system area: Enablers & barriers in health action; Implementing & co-ordinating health action;
Summary: Despite the development of national community-based health worker (CBHW) programmes in several LMICs, their integration into health systems has not been optimal. This paper presents the findings of a systematic review of published research to understand factors that may influence the integration of national CHW programmes into health systems in LMICs. From the 36 papers which were selected and analysed four programmes from Brazil (Community Health Agents), Ethiopia (Health Extension Workers), India (Accredited Social Health Activists) and Pakistan (Lady Health Workers) met the inclusion criteria. Different aspects of each of these programmes were integrated in diverse ways into their respective health systems. Factors that facilitated the integration process included the magnitude of countries' human resources for health problems and the associated discourses about how to address these problems; the perceived relative advantage CHWs have in delivering health services over highly skilled health workers; and the participation of some politicians and community members in programmes. Factors that inhibited the integration process included a rapid scale-up process; resistance from other health workers; discrimination of CHWs based on social, gender and economic status; ineffective incentive structures; inadequate infrastructure and supplies; and hierarchical and parallel communication structures. Based on these findings the authors recommend adoption of a stepwise approach to the scale-up and integration process.
Keywords: CHWs, health systems; integration; Brazil, Ethiopia, India and Pakistan

Other publications including information about *impacts, enablers of and barriers to social* participation listed elsewhere in this document include:

1. Amerson (2013); Bryant et al (2008); and Silva et al (2013) in *Section 3.1*;
2. Robinson et al (2012) in *Section 3.2*;
3. Bispo and Sampaio (2008), Eftekhari et al (2014), and Kessy et al (2014) in *Section 3.3*;
4. Freile-Gutiérrez (2014); and Oh et al (2015) in *Section 3.4*; and
5. Elstad and Eide (2009); James (2007); Karwalajtys et al (2013); Lee et al (2009); Mendez and Lopez (2010); Micikas et al (2015); Nandi and Schneider (2014); Nxumalo et al (2013); Small et al (2011); and South et al (2012) in *Section 3.5*.

3.8 Measures and meso level mechanisms[2] supporting community and system resources and capabilities for participation

Citation: Berger M, Otago F (2010) 'Poblaciones expuestas a agrotóxicos: autoorganización ciudadana en la defensa de la vida y la salud, Ciudad de Córdoba, Argentina,' [Populations exposed to pesticides: citizens' self-organisation in the defense of life and health, Cordoba City, Argentina] *Physis*. 20(1):119–43.
URL: www.scielo.br/readcube/epdf.php?doi=10.1590/S0103-73312010000100008&pid=S0103-73312010000100008&pdf_path=physis/v20n1/a08v20n1.pdf&lang=es
Country: Argentina
Community: Urban residents
Health system area: Meso-level supporting mechanisms; Oversight, monitoring and evaluation.
Summary: This paper presents a study of the political action group "Madres de Barrio Ituzaingó Anexo" in Cordoba, Argentina acting in response to more than 200 cases of morbidity and mortality in a district with a population of 5,000 inhabitants due to pesticides sprayed near to residents' houses. Regulations established by the National and Provincial Constitutions, National Environmental Law, Provincial Law Environment and Agrochemicals were not updated and the institutions responsible for control and regulation the use of these chemicals, had been dismantled. The public health sector did not have the infrastructure, administrative or intervention protocols for pesticide related morbidity. Action by the Mothers began at the end of 2001 with their request to authorities to clarify the causes of the pollution, and its effects on the health of the population. In parallel to petitioning the authorities, the Mothers and neighbours began to develop the "mortality map" using their own resources showing homes in the neighbourhood identifying patients, the type of pathology, and the deaths. The results were available weekly. The health authorities responded confirming the Mothers' assessment and sent health professionals to address the situation, including to "contain" the psychological consequences. The authorities hired an environmental consulting service who found no environmental contaminants or sign of ongoing contamination. The State denial of the problem and attempt to disqualify the Mothers deepened their efforts. This process continued for nearly 10 years despite obstacles by the State, including threats of violence. Perseverance by the Mothers finally led to: the enactment of provincial laws and municipal ordinances regulating the spraying of pesticides; state welfare measures creating municipal health centres and areas of environmental epidemiology at the Ministry of Health of the province and intervention protocols for populations exposed to pesticides by the national government.
Keywords: pesticides; accountability; social protest; civil society; activism; Argentina

Citation: Bispo Júnior JP, Martins PC (2012) ' Envolvimento comunitário na Estratégia de Saúde da Família: dilemas entre institucionalização e efetiva participação,' [Community engagement in Family Health Strategy: dilemmas between institutionalization and effective participation] *Physis: Revista de Saúde Coletiva* 22(4):1313-32.
URL: www.scielo.br/pdf/physis/v22n4/a04v22n4.pdf
Country: Brazil

---

[2] Refers to the next level up [in governance, health system, civil society organisation, other actors]. It doesn't include national / international actors unless in decentralized forms in that community.

Community: Urban residents
Health system area: Meso-level supporting mechanisms; Health policy deliberation;
Summary: Health councils and boards in Brazil bring together thousands of representatives of social segments, to discuss with managers and professionals the most appropriate direction for the health system. As a means of expanding the participation channels, some municipalities decided to establish local health councils (CLS). These usually operate in the area of a given unit of health – for example, a family health unit– and aim to discuss and define the main health problems of the local community, the forms of intervention and community involvement. In Vitoria da Conquista, Bahia in 2009, the municipality established a Health Council for each health unit with representatives of all teams and users belonging to the area of operation. The municipality maintains a coordination of the councils via the Municipal Health Secretariat to assist and monitor the performance of the local councils. A signed commitment is made with each CLS setting out the goals and targets to be met by the boards and reflecting community needs. Analysis of the agenda, follow-up forms, minutes of meetings of the council and semi-structured interviews with key informants found that the local health councils have limited performance, with a low frequency of meetings. Low levels of social mobilisation and community engagement; poor representativeness, lack of motivation to perform voluntary tasks and feeling unprepared due to poor training weakened performance of local councils, despite their potential.
Keywords: Primary health care; health councils; effectiveness; Brazil

Citation: Brooks F (2008) 'Nursing and public participation in health: an ethnographic study of a patient council,' *International journal of nursing studies* 45(1):3-13
URL: http://www.sciencedirect.com/science/article/pii/S0020748906002537
Country: United Kingdom
Community: Health service users.
Health system area: Meso-level supporting mechanisms; Implementing and co-ordinating health action.
Summary: A patient and public council was established in a non-teaching acute hospital trust in England by senior nursing staff as part of a locally initiated patient and public participation strategy and not the wider government initiative for 'patient forums'. It was the stated intention that as the council developed a patient councillor would ultimately chair the council. All three staff members attended all meetings. The 16 councillors were all members of the public, and not paid but expenses were reimbursed. Councillors were recruited via internal and external advertisements in the hospital and local press, with membership drawn entirely from the local community of the hospital. The only inclusion criterion was that applicants had to have been a patient at the hospital or a carer for someone who was a patient. Recruitment was by a brief letter of application. All 16 applications were accepted and appointed for 18 months. Training was provided for the councillors over several sessions covering health service policy and structures and team building. A study of the council over two years highlighted initial challenges including: differences in priorities over the focus of the work where councillors felt that they were only confirming decisions already taken; the view of the experiential knowledge of councillors by nursing staff as not relevant to service development; and professional nurse resistance to integrate councillors in decision making despite other managers viewing the contribution of council members in a more positive light. Patient participation schemes often emphasise training for patient participants however this experience illustrates the need for staff training, to enable nurses to work constructively with members of public participation initiatives.
Keywords: health councils, professional resistance; United Kingdom

Citation: Cross CR, Kiry LV, UNICEF (2008) 'Community participation policy for health.' UNICEF: Cambodia.
URL:http://elibrary.kiu.ac.ug:8080/jspui/bitstream/123456789/2101/1/Community%20Participation%20Policy%20%20for%20Health.pdf
Country: Cambodia
Community: General public
Health system area: Meso-level supporting mechanisms; Health policy deliberation
Summary: The Cambodian Community Participation Policy for Health (CPPH) has been revised through a participatory process. The main objectives of the CPPH include: involving the community, through the Village Health Support Group (VHSG) and the Health Centre Management Committee (HCMC) in the process of health centre management; and increasing

Health Centre accountability to users for quality services by supporting and working with the VHSG and other community participation structures. It also involves enabling the VHSG to promote informed health seeking behaviour and sustainable participation, including by identifying funding for community participation structures. The VHSG has one VHSG Leader per village elected by community members. A revised process for information and communication has been established to improve transparency and facilitate exchange between the community and the Health Centres. The strategy sets out the working arrangements for the VHSG and the HCMC including: membership and representation; roles and responsibilities; the scope of work; the meetings that the leader or members are responsible to attend or hold. Community participation supportive mechanisms are also detailed, including the training and capacity building of health centre staff and the VHSG, and financing mechanisms. The HCMC is meant to advocate for appropriate financial resources in its Annual Operation Plan to cover costs associated with fulfilling VHSG roles, including implementation of the VHSG Scope of Work.

Keywords: community health; CHWs, health volunteers, support groups; Cambodia

Country: Tanzania
Community: Rural residents
Health system area: Meso-level supporting mechanisms; Implementing and co-ordinating health action
Summary: Council Health Service Boards (CHSBs) and health facility committees in Tanzania are tasked with strengthening community-level decision-making about facility matters, including funding. The health facility committees are a mechanism for the community members to get involved in advocating for enhanced service delivery. The CHSB have four elected community members, all with voting rights, and the hospital, health centre and dispensary committees have 2-3 service user members, also voting members. Qualification for all these structures is secondary education and above, ages 21+ and or 25-70 years. Studies have reported variations in the performance of the committees. An exploratory case study focusing on two districts - one in a well-functioning district and one not – found that community members with stronger capacities were not always interested in participating in the councils. The health committees largely assisted in the clinic day-to-day running, and had limited influence on policy, planning and budgeting. Some few success storeys were reported in Lindi and in Iramba Districts, where the CHSB and other committees were perceived to be useful in sensitising community members on community health funds, on supervising construction and rehabilitation of the health facilities, managing health facility bank accounts and monitoring the provision of health services at the facility, including drugs and medical supplies. Analysis suggests that managerial and leadership practices of the district health managers, including effective supervision and personal initiatives of the top-district health officials coupled with incentives, positively influence the performance of the health facility committees and the boards. To achieve impact, the authors recommend that health committees get adequate training on their roles and functions; on the interaction between the committees, the communities and the health workers; on development of health plans and budgets at the local and district level; and on monitoring and tracking.

Keywords: health committees; councils; capacities; roles; Tanzania

Other publications including information on *measures and meso level mechanisms supporting community participation* listed elsewhere in this document include:
1. Mubyazi et al (2008) in *Section 3.2*;
2. Howe et al (2011); Kamuzora et al (2013); Kessy and Ramsey (2014); and Lockett-Kay (2005) in *Section 3.3*;
3. Freile-Gutiérrez (2014); Jakubowski et al (2006); Quantz and Thurston (2006); and Rasanathan et al (2012) in *Section 3.4*;
4. Lee et al (2009) and Lemos et al (2010) in *Section 3.5*;
5. Duarte and Machado (2012); Mosquera et al (2009); Vasquez et al (2005) in *Section 3.6*; and
6. Nathan et al (2013; 2014); Ruano et al (2014); and Serapioni and Matos (2014) in *Section 3.7*.

4. Reference list

1. Adindu A, Ndep AO and Peter A (2012) 'Advancing participation in primary health care through community health management information systems in rural Africa,' *International journal of development studies* 5(4):132-44.

2. Ahmed S, Kim MH, Dave AC, Sabelli R, Kanjelo K, Preidis GA et al. (2015) 'Improved identification and enrolment into care of HIV-exposed and -infected infants and children following a community health worker intervention in Lilongwe, Malawi,' *Journal of the international AIDS society* 18(1):19305. 10.7448/IAS.18.1.19305 [doi]

3. Akhtar T, Khan Z and Raoof S (2014) 'Community participation eludes Pakistan's maternal, newborn and child health programme,' *Eastern Mediterranean health journal* 20:10-16.

4. Alazab R, Elsheikh R and Kamal I (2008) 'Child-to child health as a model of community participation for combating Avian influenza in selected slum and rural areas, Egypt,' APHA 136th Annual Meeting, October 25-29, 2008: San Diego, CA.

5. Amerson R (2013) 'Contributing to family health using a promotora programme in Guatemala,' *Journal of community engagement and scholarship 6*(1):3.

6. Andrade GR and Vaitsman J (2013) 'A participação da sociedade civil nos conselhos de saúde e de políticas sociais no município de Piraí en 2006, [The participation of civil society in health and social policy councils in the city of Pirai, State of Rio de Janeiro in 2006] *Ciencia & saude coletiva*, 18(7):2059-68.

7. Aston M, Meagher-Stewart D, Edwards N and Young LM (2009) 'Public health nurses' primary health care practice: Strategies for fostering citizen participation,' *Journal of community health nursing* 26:24-34.

8. Atanasova-Pieterse D, Kerekovska A and Popova S (2013) 'Citizen participation in healthcare in Bulgaria: The gap between citizens, health experts, and local officials,' *Scripta scientifica medica* 45(3):82-5.

9. Avard D, Bucci LM, Burgess MM, Kaye J, Heeney C, Farmer Y and Cambon-Thomsen A (2009) 'Public health genomics (PHG) and public participation: Points to consider,' *Journal of public deliberation* 5(1):7.

10. B-Lajoie MR, Hulme J and Johnson K (2014) 'Payday, ponchos, and promotions: A qualitative analysis of perspectives from non-governmental organization programme managers on community health worker motivation and incentives,' *Human resources for health 12*:66-4491-12-66. 10.1186/1478-4491-12-66 [doi]

11. Baatiema L, Skovdal M, Rifkin S and Campbell C (2013) 'Assessing participation in a community-based health planning and services programme in Ghana,' *BMC health services research* 13:233.

12. Banerjea N (2011) 'Voluntary participation and self-governance: A study of community health volunteering in Kolkata, India,' *Cultural dynamics* 23(3):197-218.

13. Bang C (2015) 'Promoting mental health and community participation: A study on participatory arts practice, creativity and play in the city of Buenos Aires, Argentina,' *Health, culture and society* 8(1):61-71.

14. Batten LS (2008) 'Lady, is this civilisation?: A case study of community participation in a health development programme in Aotearoa, New Zealand,' thesis presented in fulfilment of the requirements for the degree of Doctor of Philosophy in Development Studies at Massey University: Palmerston North.

15. Berger M and Otago F (2010) 'Populations exposed to pesticides: Citizens' self-organization in the defence of life and health, Cordoba City, Argentina,' *Physis* 20(1):119-43.

16. Bhatia K (2014) 'Community health worker programmes in India: A rights-based review,' *Perspectives in public health 134*(5): 276-82. 10.1177/1757913914543446 [doi]

17. Bhengu BR (2010) 'An investigation into the level of empowerment of rural women in the Zululand district of KwaZulu-Natal province of South Africa,' *Curationis* 4-12.

18. Bispo Júnior JP and Martins PC (2012) 'Envolvimento comunitário na Estratégia de Saúde da Família: Dilemas entre institucionalização e efetiva participação' [Community engagement in Family Health Strategy: Dilemmas between institutionalization and effective participation], *Physis: Revista de saúde coletiva* 22(4):1313-32.

19. Bispo Junior JP and Sampaio JJ (2008) 'Participação social em saúde em áreas rurais do Nordeste do Brasil' [Social participation in health in rural northeastern Brazil], *Revista panamericana de salud publica* 23(6):403-9.

20. Blakey H (2005) 'Participation - why bother? The views of black and minority ethnic mental health service users on participation in the NHS in Bradford,' report of a community research process undertaken by the International Centre for Participation Studies, University of Bradford, and Sharing Voices (Bradford).

21. Brooks F (2008) 'Nursing and public participation in health: An ethnographic study of a patient council,' *International journal of nursing studies* 45:3-13.

22. Bryant J, Saxton M, Madden A, Bath N and Robinson S (2008) 'Consumer participation in the planning and delivery of drug treatment services: The current arrangements,' *Drug alcohol review* 27:130-37.

23. Chilaka MA (2015) 'Drawing from the well of community participation: An evaluation of the utility of local knowledge in the health impact assessment process,' *Community development* 46(2):100-10.c.

24. Chilundo BG, Cliff JL, Mariano AR, Rodriguez DC and George A (2015) 'Relaunch of the official community health worker programme in Mozambique: Is there a sustainable basis for iCCM policy?' *Health policy and planning 30 suppl 2*: ii54-ii64. 10.1093/heapol/czv036 [doi]

25. Condo J, Mugeni C, Naughton B, Hall K, Tuazon MA, Omwega A et al. (2014) 'Rwanda's evolving community health worker system: A qualitative assessment of client and provider perspectives,' *Human resources for health 12:71*. 10.1186/1478-4491-12-71 [doi]

26. Cornwall A and Leach M (2010) 'Putting the politics back into 'public engagement': Participation, mobilization and citizenship in the shaping of health services,' Institute of Development Studies: Brighton.

27. Costa Sde M, Araujo FF, Martins LV, Nobre LL, Araujo FM and Rodrigues CA (2013) 'Agente comunitário de saúde: Elemento nuclear das ações em saúde' [Community health worker: A core element of health actions], *Ciencia & saude coletiva 18*(7): 2147-56. S1413-81232013000700030 [doi]

28. Coyne P (2011) 'Ecocultural health and resilience in regional Australian communities: Mitigating the psychological distress of environmental crisis through community arts participation,' thesis presented as part of the requirement for the Degree of Bachelor of Arts in Community Development with Honours in Sustainable Development. Murdoch University: Western Australia.

29. Cross CR, Kiry LV, UNICEF (2008) 'Community participation policy for health,' UNICEF: Cambodia.

30. de Freitas C and Martin G (2015) 'Inclusive public participation in health: Policy, practice and theoretical contributions to promote the involvement of marginalised groups in healthcare,' *Social science & medicine* 2015;135:31-9.

31. Delgado-Gallego ME and Vazquez-Navarrete L (2006) 'Barreras y oportunidades para la participación social en salud en Colombia: Percepciones de los actores principales' [Barriers and opportunities for social participation in health: The main social actors' perceptions], *Revista de salud publica* 8(2):128-40.

32. Draper AK, Hewitt G and Rifkin S (2010) 'Chasing the dragon: Developing indicators for the assessment of community participation in health programmes,' *Social science & medicine* 71:1102–09.

33. Duarte EB and Machado MdFAS (2012) 'O exercício do controle social no âmbito do Conselho Municipal de Saúde de Canindé, CEm' [The exercise of community participation in the sphere of Canindé's Municipal Council of Health], *Saúde e sociedade* 21:126-37.

34. Edward A, Branchini C, Aitken I, Roach M, Osei-Bonsu K and Arwal SH (2015) 'Toward universal coverage in Afghanistan: A multi-stakeholder assessment of capacity investments in the community health worker system,' *Social science & medicine* 145:173-83. 10.1016/j.socscimed.2015.06.011 [doi]

35. Eftekhari MB, Mirabzadeh A, Forouzan AS, Dejman M, Afzali HM, Djalalinia S, Peykari N and Roshanfekr P (2014) 'A qualitative study of community-based health programmes in Iran: An experience of participation in Iran,' *International journal of preventive medicine* 5(6):679.

36. Elstad TA (2014) 'Participation in a "low threshold" community mental health service: An ethnographic study of social interaction, activities and meaning,' thesis for the degree of Doctor of Philosophy, Norwegian University of Science and Technology: Trondheim.

37. Elstad TA and Eide AH (2009) 'User participation in community mental health services: Exploring the experiences of users and professionals,' *Scandinavian journal of caring sciences 23*(4): 674-81. 10.1111/j.1471-6712.2008.00660.x [doi]

38. Findley SE, Uwemedimo OT, Doctor HV, Green C, Adamu F and Afenyadu GY (2013) 'Comparison of high- versus low-intensity community health worker intervention to promote newborn and child health in northern Nigeria,' *International journal of women's health* 5:717-28. 10.2147/IJWH.S49785 [doi]

39. Freile-Gutiérrez B (2014) 'Participación ciudadana en el contexto de la evaluación de tecnologías sanitarias' [Citizen participation in the context of health technology assessment], *Revista medica de Chile* 142:S27-32.

40. Galaa S (2008) 'Community participation in health delivery and management in Ghana: Lessons from selected districts in Northern Ghana,' *Ghana journal of development studies* 5(1):39-57.

41. Give CS, Sidat M, Ormel H, Ndima S, McCollum R and Taegtmeyer M (2015) 'Exploring competing experiences and expectations of the revitalized community health worker programme in Mozambique: An equity analysis,' *Human resources for health 13*: 54-015-0044-0. 10.1186/s12960-015-0044-0 [doi]

42. Goodwin V and Happell B (2006) 'In our own words: Consumers' views on the reality of consumer participation in mental health care,' *Contemporary nurse* 21:4-13.

43. Gray K, Elliott K and Wale J (2013) 'A community education initiative to improve using online health information: Participation and impact,' *Inform health soc care* 38:171-81.

44. Greenspan JA, McMahon SA, Chebet JJ, MpungatM, Urassa DP and Winch PJ (2013) 'Sources of community health worker motivation: A qualitative study in Morogoro region, Tanzania,' *Human resources for health 11*:52-4491-11-52. 10.1186/1478-4491-11-52 [doi]

45. Guizardi FL and Pinheiro R (2008) 'Novas práticas sociais na constituição do direito à saúde: A experiência de um movimento fitoterápico comunitário' [New social practices constituting the right to health: The experience of a community phytotherapy movement], *Interface - Comunic, saúde, educ* 12(24):109-22.

46. Hassan MM (2005) 'Arsenic poisoning in Bangladesh: Spatial mitigation planning with GIS and public participation,' *Health policy* 74:247-60.

47. Haworth R and Melling B (2010) 'From rhetoric to reality: Breaking down the barriers. To what extent are service users collaborating in decision making processes within the NHS?' paper presented at Breaking down the barriers. Proceedings of the 13th International Research Conference, Staffordshire University (10-11 September 2009).

48. Howe D, Batchelor S and Bochynska K (2011) 'Finding our way: Youth participation in the development and promotion of youth mental health services on the NSW central coast,' *Advances in mental health 10*(1): 20-28.

49. Jakubowski E, Lister G and Skavron R (2006) 'Ninth Futures Forum on health systems governance and public participation: Amsterdam, 10-11 October 2005.' WHO Regional Office for Europe: Copenhagen.

50. James AM (2007) 'Principles of youth participation in mental health services,' *Medical journal of Australia* 187(7 Suppl): S57-60. jam10307_fm [pii]

51. Jara CEM and Andrade MCT (2015) 'Participación en salud y desarrollo territorial: Experiencia sanitaria en una comuna del Sur de Chile' [Health participation and territorial development: Health experiences in a commune in Southern Chile], *Cienc enferm* 4PY:115–25.

52. Jaskiewicz W and Tulenko K (2012) 'Increasing community health worker productivity and effectiveness: A review of the influence of the work environment, '*Human resources for health 10*:38-4491-10-38. 10.1186/1478-4491-10-38 [doi]

53. Javanparast S, Baum F, Labonte R, Sanders D, Heidari G and Rezaie S (2011) 'A policy review of the community health worker programme in Iran,' *Journal of public health policy 32*(2):263-76. 10.1057/jphp.2011.7 [doi]

54. Jeffery V and Ervin K (2011) 'Responding to rural health needs through community participation: Addressing the concerns of children and young adults,' *Australian journal of primary health* 17:125–30.

55. Kamanda A, Embleton L, Ayuku D, Atwoli L, Gisore P, Ayaya S, Vreeman R and Braitstein P (2013) 'Harnessing the power of the grassroots to conduct public health research in sub-Saharan Africa: A case study from western Kenya in the adaptation of community-based participatory research (CBPR) approaches,' *BMC public health* 13:9.1.

56. Kambou SD, Magar V, Hora G and Mukherjee A (2007) 'Power, pleasure, pain, and shame: Assimilating gender and sexuality into community-centred reproductive health and HIV prevention programmes in India,' *Global public health* 2:155–68.

57. Kamuzora P, Maluka S, Ndawi B, Byskov J and Hurtig AK (2013) 'Promoting community participation in priority setting in district health systems: Experiences from Mbarali district, Tanzania,' *Global health action* 6:22669.

58. Karwalajtys T, Kaczorowski J, Chambers LW, Hall H, McDonough B, Dolovich L, Sebaldt R, Lohfeld L and Hutchison B (2013) 'Community mobilization, participation, and blood pressure status in a cardiovascular health awareness program in Ontario,' *American journal of health promotion: AJHP* 27(4):252-61.

59. Kema KM, Komwihangiro J and Kimaro S (2012) 'Integrated community-based child survival, reproductive health and water and sanitation programme in Mkuranga district, Tanzania: A replicable model of good practices in community-based health care,' *Pan African medical journal 13 Suppl 1*:11.

60. Kessy FL and Ramsey D (2014) 'Improving health services through community participation in health governance structures in Tanzania,' *Journal of rural and community development* 9(2):14-31.

61. Kieler B (2008) 'Community participation in health, safety, and development projects in South India,' final report for Fulbright-sponsored research project in India, Fulbright programme, New Delhi.

62. Lee SK, Thompson SC and Amorin-Woods D (2009) 'One service, many voices: Enhancing consumer participation in a primary health service for multicultural women,' *Quality in primary care* 17:63–69.

63. Lehmann U and Gilson L (2013) 'Actor interfaces and practices of power in a community health worker programme: A South African study of unintended policy outcomes,' *Health policy and planning* 28:358-66.

64. Lehmann U and Matwa P (2008) 'Exploring the concept of power in the implementation of South Africa's new community health worker policies: A case study from a rural sub-district,' EQUINET Discussion Paper Series 63. EQUINET, CHP: Harare.

65. Lemos PN, Hirooka LB, Nunes SA, Arantes R, Mestriner SF, Mestriner Junior W (2010) 'O modelo de atenção a saúde bucal no Médio e Baixo Xingu: Parcerias, processos e perspectivas,' [The oral health care model in Middle and Low Xingu: Partnerships, processes, and perspectives] *Ciencia & saúde coletiva* 15 Suppl 1:1449-56.

66. Lewis L (2014) 'User involvement in mental health services: A case of power over discourse,' *Sociological research online 19*(1):6.

67. Little A, Medhanyie A, Yebyo H, Spigt M, Dinant GJ and Blanco R (2013) 'Meeting community health worker needs for maternal health care service delivery using appropriate mobile technologies in Ethiopia,' *PloS one 8*(10):e77563. 10.1371/journal.pone.0077563 [doi]

68. Llovet I, Dinardi G and De Maio FG (2011) 'Mitigating social and health inequities: Community participation and Chagas disease in rural Argentina,' *Global public health* 6:371-84.

69. Lockett-Kay JE (2005) 'Community participation in the establishment of a primary health organisation in the Horowhenua: A longitudinal case study,' thesis presented in partial fulfilment of requirements for the degree of Doctor of Philosophy in Management at Massey University, Turitea, Palmerston North, New Zealand.

70. Luis IP, Martinez S and Alvarez A (2012) 'Community engagement, personal responsibility and self help in Cuba's health system reform,' *MEDICC review* 14(4):44-47.

71. Magnezi R, Bergman YS and Grosberg D (2014) 'Online activity and participation in treatment affects the perceived efficacy of social health networks among patients with chronic illness,' *Journal of medical internet research* 16:e12.

72. Maluka SO, Bukagile G (2015) 'Community participation in the decentralised district health systems in Tanzania: Why do some health committees perform better than others?' *International journal of health planning and management,* DOI:10.1002/hpm.2299.

73. Marston C, Renedo A, McGowan CR and Portela A (2013) 'Effects of community participation on improving uptake of skilled care for maternal and newborn health: A systematic review,' *PloS one* 8:e55012.

74. Matos AR (2011) 'A importância da participação cidadã nas políticas de saúde: o caso da reestruturação dos serviços de saúde materno-infantil em Portugal' [Citizen participation relevance in health policies: The case of the maternal and child health services restructuring in Portugal], *Saúde e sociedade* 20(3):604-16.

75. McHunu GG (2009) 'The levels of community involvement in health (CIH): A case of rural and urban communities in KwaZulu-Natal,' *Curationis* 4-13.

76. Mendez CA and Lopez JJ (2010) 'La participación social en salud: el desafío de Chile' [Community participation in health: The challenge in Chile], *Revista panamericana de salud publica* 27(2):144-48.

77. Mercader HF, Kyomuhangi T, Buchner DL, Kabakyenga J and Brenner JL (2014) 'Drugs for some but not all: Inequity within community health worker teams during introduction of integrated community case management,' *BMC health services research* 14 Suppl 1:S1. Epub 2014 May 12. 10.1186/1472-6963-14-S1-S1 [doi]

78. Micikas M, Foster J, Weis A, Lopez-Salm A, Lungelow D, Mendez P and Micikas A (2015) 'A community health worker intervention for diabetes self-management among the Tz'utujil Maya of Guatemala,' *Health promotion practice 16*(4):601-08. 10.1177/1524839914557033 [doi]

79. Mitsunaga T, Hedt-Gauthier B, Ngizwenayo E, Farmer DB, Karamaga A, Drobac P et al. (2013) 'Utilizing community health worker data for programme management and evaluation: Systems for data quality assessments and baseline results from Rwanda,' *Social science & medicine (1982) 85*:87-92. 10.1016/j.socscimed.2013.02.033 [doi]

80. Molale MG (2012) 'Community participation in health education programmes: A case of study of a tuberculosis programme in the rural communities of Thabana-Morena, Lesotho,' dissertation submitted to the Department of Sociology, Anthropology and Social Work in partial fulfilment of the requirements for the Degree of Master of Science in Sociology, National University of Lesotho: Roma.

81. Monson K, Thurley M (2011) 'Consumer participation in a youth mental health service.' *Early intervention in psychiatry* 5:381-88.

82. Morrison C and Dearden A (2013) 'Beyond tokenistic participation: Using representational artefacts to enable meaningful public participation in health service design. *Health policy* 112:179-86.

83. Mosquera J, Gutiérrez A and Serra M (2009) 'La experiencia de participacion ciudadana en el control social a la gestion en salud en Cali, Colombia' [Citizen participation in accountability to health management in Cali, Colombia], *Colombia médica* 40(1):95-102.

84. Mubyazi GM, Mushi A, Kamugisha M, Massaga J, Mdira KY, Segeja M and Njunwa KJ (2007) 'Community views on health sector reform and their participation in health priority setting: Case of Lushoto and Muheza districts, Tanzania,' *Journal public health* 29:147-56.

85. Murakami JK, Petrilli Filho JF, Telles Filho PC (2007) 'Conversando sobre sexualidade, IST e AIDS com adolescentes pobres' [Talking about sexuality, STI and AIDS with poor adolescents], *Revista latino-americana de enfermagem* 15 Spec No:864-66.

86. Murray ZK (2010) 'The nature of community participation in municipal public health planning in Queensland,' thesis for PhD, Griffith School of Environment Science, Environment, Engineering, and Technology, Griffith University: Queensland.

87. Naimoli JF, Perry HB, Townsend JW, Frymus DE and McCaffery JA (2015) 'Strategic partnering to improve community health worker programming and performance: Features of a community-health system integrated approach,' *Human resources for health 13*:46-015-0041-3. 10.1186/s12960-015-0041-3 [doi]

88. Nandi S and Schneider H (2014) 'Addressing the social determinants of health: A case study from the Mitanin (community health worker) programme in India,' *Health policy plan 29 Suppl 2*: ii71-81. 10.1093/heapol/czu074 [doi]

89. Nathan S, Braithwaite J and Stephenson N (2013) 'Facilitating the action of community representatives in a health service: The role of a community participation coordinator,' *BMC health services research* 13:154.

90. Nathan S, Braithwaite J and Stephenson N (2014) 'The scope and impact of community participation: The views of community representatives in an Australian health service,' *Journal of health organization and management* 28:405-21.

91. Ndou T, van Zyl G, Hlahane S and Goudge J (2013) 'A rapid assessment of a community health worker pilot programme to improve the management of hypertension and diabetes in Emfuleni sub-district of Gauteng Province, South Africa,' *Global health action 6*:19228. 10.3402/gha.v6i0.19228 [doi]

92. Neupane S, Odendaal W, Friedman I, Jassat W, Schneider H and Doherty T (2014) 'Comparing a paper-based monitoring and evaluation system to a m-health system to support the national community health worker programme, South Africa: An evaluation,' *BMC medical informatics and decision making 14*:69-6947-14-69. 10.1186/1472-6947-14-69 [doi]

93. Nikniaz A and Alizadeh M (2007) 'Community participation in environmental health: Eastern Azerbaijan healthy villages project,' *Eastern Mediterranean health journal* 13(1):186-92

94. Nxumalo N, Goudge J and Thomas L (2013) 'Outreach services to improve access to health care in South Africa: Lessons from three community health worker programmes,' *Global health action* 6:19283.

95. Oh J, Ko Y, Alley AB and Kwon S (2015) 'Participation of the lay public in decision-making for benefit coverage of national health Insurance in South Korea,' *Health systems & reform* 1(1):62-71.

96. Otieno CF, Kaseje D, Ochieng' BM and Githae MN (2012) 'Reliability of community health worker collected data for planning and policy in a peri-urban area of Kisumu, Kenya,' *Journal of community health 37*(1):48-53. 10.1007/s10900-011-9414-2 [doi]

97. Ottmann GF and Laragy C (2010) 'Developing consumer-directed care for people with a disability: 10 lessons for user participation in health and community care policy and programme development,' *Australian health review 34:390-94.*

98. Paiva FS, Stralen CJ and Costa PH (2014) 'Participação social e saúde no Brasil: Revisão sistemática sobre o tema' [Social participation and health in Brazil: A systematic review on the topic], *Ciencia & saude coletiva* 19(2):487-98.

99. Park Y, Kim C-Y, You MS, Lee KS and Park E (2014) 'Public participation in the process of local public health policy, using policy network analysis,' *Journal of preventive medicine and public health* 47:298-308.

100. Pelletier JF, D'Auteuil S, Ducasse C and Rodriguez del Barrio L (2014) 'Participation publique et participation citoyenne des personnes utilisatrices de services en lien avec le Plan d'action en santé mentale 2005-2010: Leur rôle de porte-parole' [Public participation and civic participation of service users in relation to the mental health action plan 2005-2010: Their spokesperson function], *Sante mentale au Quebec* 39(1):175-93.

101. Perestelo-Perez L, Perez-Ramos J, Abt-Sacks A, Rivero-Santana A and Serrano-Aguilar P (2013) 'Promoción de la participación ciudadana en cuidados de salud a través de PyDEsalud.com' [Promoting citizen participation in healthcare through PyDEsalud.com] *Gaceta sanitaria* 27(5):466-67.

102. Quantz D and Thurston WE (2006) 'Representation strategies in public participation in health policy: The Aboriginal Community Health Council,' *Health policy* 75:243-50.

103. Rahmawati R and Bajorek B (2015) 'A community health worker-based programme for elderly people with hypertension in Indonesia: A qualitative study, 2013,' *Preventing chronic disease 12*:E175. 10.5888/pcd12.140530 [doi]

104. Ramirez NA, Ruiz JP, Romero RV and Labonte R (2011) 'Comprehensive primary health care in South America: Contexts, achievements and policy implications,' *Cad saúde pública* 1875-90.

105. Rasanathan K, Posayanonda T, Birmingham M and Tangcharoensathien V (2011) 'Innovation and participation for healthy public policy: The first National Health Assembly in Thailand,' *Health expectations: An international journal of public participation in health care and health policy* 15(1):87-96.

106. Ribeiro SM, Bógus CM and Watanabe HA (2015) 'Agricultura urbana agroecológica na perspectiva da promoção da saúde' [Agroecological urban agriculture from the perspective of health promotion], *Saúde e Sociedade* 24(2):730-43.

107. Robinson L, Newton J and Dawson P (2012) 'Professionals and the public: Power or partnership in health research?' *Journal of evaluation in clinical practice* 18:276-82.

108. Ruano AL, Sebastián MS and Hurtig A-K (2014) 'The process of social participation in primary health care: The case of Palencia, Guatemala,' *Health expectations: An international journal of public participation in health care and health policy* 17:93-103.

109. Schuttner L, Sindano N, Theis M, Zue C, Joseph J, Chilengi R, Chi BH, Stringer JSA and Chintu N (2014) 'A mobile phone-based, community health worker programme for referral, follow-up, and service outreach in rural Zambia: Outcomes and overview,' *Telemedicine journal and e-Health: The official journal of the American Telemedicine Association 20*(8):721-28. 10.1089/tmj.2013.0240 [doi]

110. Serapioni M and Matos AR (2014) 'Citizen participation and discontent in three southern European health systems,' *Social science & medicine* 123:226-33.

111. Silva EC and Pelicioni MC (2013) 'Participação social e promoção da saúde: Estudo de caso na região de Paranapiacaba e Parque Andreense' [Social participation and health promotion: A case study in the region of Paranapiacaba and Parque Andreense] *Ciencia & saude coletiva* 18(2):563-72.

112. Silveira AC, de Rezende DF, Nogales AM, Cortez-Escalante JJ, Castro C and Macedo V (2009) 'Avaliação do sistema de vigilância entomológica da doença de Chagas com participação comunitária em Mambaí e Buritinópolis, Estado de Goiás' [Assessment of an entomological surveillance system for Chagas disease with community participation in Mambai and Buritinopolis, State of Goias], *Revista da sociedade Brasileira de medicina tropical* 42(1):39-46.

113. Sirilak S, Okanurak K, Wattanagoon Y, Chatchaiyalerk S, Tornee S and Siri S (2013) 'Community participation of cross-border migrants for primary health care in Thailand,' *Health policy plan* 28:658-64.

114. Siriliang R (2013) 'People's health development in Tambon (sub-district) administrative organization (TAO.) Responsible areas by emphasis on community participation in LOEI Province, Thailand, 2012,' *Journal of biology, agriculture and healthcare* (15):47-54.

115. Small R, Taft AJ and Brown SJ (2011) 'The power of social connection and support in improving health: Lessons from social support interventions with childbearing women,' *BMC public health* 11 Suppl 5:S4.

116. Soe HHK, Somrongthong R, Moe S, Myint KT and Ni H (2012) 'Assessment of community participation in safe motherhood health education programme in Shan State, Myanmar,' *European journal of scientific research* 73(3):373-81.

117. South J, Kinsella K and Meah A (2012) 'Lay perspectives on lay health worker roles, boundaries and participation within three UK community-based health promotion projects,' *Health education research* 27:656-70.

118. Strachan DL, Kallander K, Nakirunda M, Ndima S, Muiambo A, Hill Z and inSCALE study group (2015) 'Using theory and formative research to design interventions to improve community health worker motivation, retention and performance in Mozambique and Uganda,' *Human resources for health* 13:25-015-0020-8. 10.1186/s12960-015-0020-8 [doi]

119. Swartz A (2013) 'Legacy, legitimacy, and possibility: An exploration of community health worker experience across the generations in Khayelitsha, South Africa, '*Medical anthropology quarterly 27*(2): 139-54. 10.1111/maq.12020 [doi]

120. Tallo VL, Carabin H, Alday PP, Balolong E, Jr., Olveda RM and McGarvey ST (2008) 'Is mass treatment the appropriate schistosomiasis elimination strategy?' *Bulletin of World Health Organization* 765-71.

121. Tempfer CB and Nowak P (2011) 'Consumer participation and organizational development in health care: A systematic review,' *Wien Klin Wochenschr* 123:408-14.

122. Thurston WE, MacKean G, Vollman A, Casebeer A, Weber M, Maloff B and Bader J (2005) 'Public participation in regional health policy: A theoretical framework,' *Health policy* 73:237-52.

123. Thurston WE, Vollman AR, Meadows LM and Rutherford E (2005) 'Public participation for women's health: Strange bedfellows or partners in a cause?' *Health care women international* 26:398-421.

124. Torri MC (2012) 'Multicultural social policy and community participation in health: New opportunities and challenges for indigenous people,' *International journal of health planning management* 27:e18-40.

125. USAID and MCHIP (2013) 'Community participation in large-scale community health worker programmes. Developing and strengthening community health worker programmes at scale: A reference guide and case studies for progam managers and policy makers,' Jhpiego Corporation. USA

126. Vázquez ML, Flores A. Gonzalez ESC, Diniz CdS, Campbell AP, van Heerden ICM and Ahmadi IKG (2005) 'Nível de informação da população e utilização dos mecanismos institucionais de participação social em saúde em dois municipios do Nordeste do Brasil' [Level of community information and use of mechanisms for social participation in health in two municipalities of Northeast Brazil], *Ciência & saúde coletiva* 10:141-55.

127. Vega-Romero R, Acosta-Ramirez N, Mosquera-Méndez and Restrepo-Vélez MO (2008) 'Health policy in Bogota (2004-2008): An analysis of the experience with primary health care,' *Social medicine* 3(2):126-44.

128. Wakefield PA, Randall GE and Richards DA (2011) 'Identifying barriers to mental health system improvements: An examination of community participation in assertive community treatment programmes,' *International journal of mental health systems* 5:27.

129. Yeboah-Antwi K, Hamer DH, Semrau K, Waltensperger KZ, Snetro-Plewman G, Kambikambi C et al. (2014) 'Can a community health worker and a trained traditional birth attendant work as a team to deliver child health interventions in rural Zambia?' *BMC health services research 14*:516-014-0516-2. 10.1186/s12913-014-0516-2 [doi]

130. Zulu JM, Kinsman J, Michelo C and Hurtig A (2014) 'Integrating national community-based health worker programmes into health systems: A systematic review identifying lessons learned from low-and middle-income countries,' *BMC public health 14*(1):1.