

Exchanging on social power in health

Learning from international experience on approaches to community power, participation and decision-making in health

Case Study: Mental health in Makueni County, Kenya

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Produced within the Shaping Health programme led by the Training and Research Support Centre (TARSC).

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







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Cite as: Ndetei D, Musyimi C, Musau A, Matoke L, Mutiso V (2017) 'Case study: Mental health in Makueni County, Kenya,' in the Shaping Health programme on Learning from international experience on approaches to community power, participation and decision-making in health, AMHF, TARSC, July 2017.

Africa Mental Health Foundation (AMHF) is a registered non-governmental organisation whose main mandate is to conduct mental health research to inform policy and practice. It focuses on community mental health with the aim of providing innovative, appropriate, available and accessible mental health and substance use services to all (See <u>www.africamentalhealthfoundation.org/)</u>. The team leader for the case study is David M. Ndetei, Director, Africa Mental Health Foundation, Kenya, and Professor of Psychiatry, University of Nairobi, Kenya.

We wish to acknowledge Dr. Rene Loewenson who has continuously reviewed and edited the case study report, Prof. Mutuku A Mwanthi (internal reviewer), University of Nairobi, and Vera Coelho, CEBRAP, as external reviewer. We thank the Ministry of Health, national and county level (Makueni), faith and traditional healers and Africa Mental Health Foundation (AMHF) staff for their dedication and support towards the success of this case study. Thanks to V Tyson for copy edit.

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This case study report is produced within the 'Shaping Health' research programme led by Training and Research Support Centre (TARSC), supported by a grant from the Robert Wood Johnson Foundation Global Ideas Fund at CAF America. The views expressed here do not necessarily reflect the views of TARSC, CAF America or the Robert Wood Johnson Foundation.

Executive Summary

This case study was conducted in Makueni County, Kenya, by Africa Mental Health Foundation (AMHF) between January and May 2017. It was implemented within the 'Shaping Health' project led by Training and Research Support Centre (TARSC) entitled 'Learning from international experience on approaches to community power, participation and decision-making in health' with support from the Robert Wood Johnson Foundation Global Ideas Fund at CAF America.

Although the number of chronic conditions of mental illness is rising in the country, mental disorders are poorly documented and treated. In Makueni County, stigma and negative perception of mental health in the community and poor recognition of mental illness in the health system mean that mental health has received little attention and has been treated as a personal issue or attributed to witchcraft. Community and primary care providers provide little or no diagnosis and treatment for mental disorders, so people visit referral hospitals for care. Because of this, those suffering from mental illnesses have preferred to seek treatment from traditional health practitioners (THPs) (traditional and faith healers) in their communities and not from healthcare workers.

To improve mental health services and reduce social stigma to support uptake, collaboration among healthcare workers, THPs and community members should be strengthened. There is no specific policy guidance for this in Kenya, but the 2015-2030 mental health policy promotes integration of THPs into the mental healthcare and support system. The Traditional Health Practitioners' Act, 2014, provides for training, registration and licensing of THPs to formalise their practice.

The case study aimed to gather and report evidence on promising practices in and models of meaningful community participation, power and decision-making in health systems in Makueni County, particularly in relation to the community-level actors in mental health. The case study focused mainly on THPs and CHWs as key community actors in linking the wider community to services and addressing community awareness and support. It described the approaches used to promote dialogue between health workers and local community-level actors – THPs and community health workers (CHWs) and community members -- to support delivery and uptake of mental health services in the community. These approaches supported collaborative referrals for uptake and inclusion of mental health services in primary care and community roles in follow up of clients.

A first step in the collaboration with THPs and community members was to build a common language on mental disorders for the community and services. A qualitative approach in eight separate focus group discussions with traditional healers, faith healers and healthcare workers discussed the perceptions among the different groups of mental illnesses, their causes and management to identify the barriers within each group of practitioners. The social dialogue found that THPs often attributed mental illness to witchcraft, while clinicians attributed it to poor life histories and conditions, substance abuse, physical illness, injury and old age. The dialogue exposed hostility between THPs and healthcare workers, with the latter looking down upon traditional healers and their herbal treatment and work, discouraging their patients from seeking care from them. THPs referred patients amongst themselves, with faith healers seeing referral to health services as being in conflict with their religious beliefs. THPs, however, were referring to health services, but the health care workers did not refer patients back to THPs for ongoing care.

In a second phase of discussions, healthcare workers were split into two groups, one group joining the THPs and another joining the faith healers, to explore shared solutions to identified barriers. The process helped reduce mistrust, enhance mutual respect and address barriers identified in referrals between the different groups. In the dialogue, both groups resolved that collaboration be strengthened, with shared training as one of the means to bridge the gap between the formal and informal health providers. THPs received training on identification and delivery of evidence-based

psychosocial interventions using the WHO mhGAP-IG, after translating and ensuring its cultural suitability. Community health workers were also trained to support follow-up care and recordkeeping to trace defaulters. Reduced stigma of mental illness and awareness of mental health issues and services were supported by road shows with promotional campaigns and public meetings with locally elected leaders, area chiefs and their assistants. Participation in these processes was supported by phone calls, announcements in public gatherings, county public participation structures, and local mass media (radio stations, print media and posters).

The dialogue, collaboration and awareness promotion were reported to have improved uptake of mental health services, to have led to community-level health providers and members feeling more recognised and appreciated by services, improved trust between THPs and healthcare providers and strengthened capacities for identification and delivery of psychosocial interventions, referral and follow-up of patients. Nevertheless, challenges remained that needed to be addressed. The community did not always appreciate community-level providers and patients were sometimes violent. There were cost barriers to uptake of and referrals to services. Some community members still stigmatised mental disorders. However, the increased uptake and referrals, reports of improved wellbeing in those suffering from mental illness, improved situations such as work resumption for patients' families, and improved trust and communication across those involved suggest the value of such 'bottom up' initiatives that recognise that community cultures and perceptions can facilitate dialogue across community and health service actors.

Scaling up these practices depends in part on how well they link with wider mechanisms for social participation. Social participation is enshrined in the Kenyan Constitution. To operationalise this, the public is represented in development committees, project management committees and thematic groups from village (community) to county level and they propose, make input to and prioritise activities for infrastructure development. Those that reach county level may be approved at the County Peoples' Forum and have budgets set for them. Project management committees supervise their implementation to completion. Village health committees (VHCs) are used as vehicles for social participation in the health sector. While these mechanisms provide useful channels for social participation in health, they commonly focus on infrastructure and environment issues, and rarely take up less visible issues such as mental health. They may be more likely to raise and act on mental health after a process to raise awareness, address stigma and strengthen service delivery, as outlined in the case study. The process in Makueni raised awareness of these concerns in the county, and participants recommended that the government, through VHCs, invest in mental health at the primary healthcare level and that government, in collaboration with non-governmental organisations, promote mental health advocacy groups at community level.

This case study indicated that: dialogue and information sharing are essential in mental health, as a means to strengthen collaboration between community-level actors and health systems. In relation to such chronic and sometimes buried issues in communities, these community actors and informal providers are essential contributors to supportive responses and need to be involved. This calls for shared language, clearly defined roles between different actors and joint dialogue and capacity building to identify and address barriers to their interaction. These investments are a basis for next steps to increase participation of directly affected families in the process and to bring issues to formal mechanisms for participation that had not yet addressed them. Some features could be adapted/adopted elsewhere. The (informal) processes may have relevance to other buried and stigmatised health issues to facilitate the interactions and awareness needed for application within more formal mechanisms for social participation. These processes may include building common terms, a structured dialogue on barriers, roles and actions and evidence-based training using the <u>WHO mhGAP-IG</u> and wider community awareness to support collaboration between community-level and system actors.

1. The site

This case study was conducted in Makueni County. Makueni County is one of the 47 counties of Kenya and is among the poorest counties in the country. Over 60% of the population live below the poverty line, above the national average of 46% (County Government of Makueni, 2017a). The county is located in the lower eastern part of Kenya and borders counties shown in the map in *Figure 1.* It lies in the arid and semi-arid zones of the eastern region of the country and is usually prone to droughts due to insufficient rainfall (County Government of Makueni, 2013). Administratively, Makueni County consists of six sub-counties, namely: Mbooni, Kilome, Kaiti, Makueni, Kibwezi West and East with Makueni sub-county having the largest number of wards.



Figure 1: Location of Makueni County

Source: County Government of Makueni, 2015

2. The context for the work

Makueni County is mainly inhabited by the Kamba ethnic community and has a total population of 1 033 398 people, of whom 48.6% are men and 51.4% women (Ministry of Health, 2015b). According to the County Government of Makueni (2013), the population is generally youthful, with those aged below fifteen years accounting for 44% of the total population (Population Action International, 2014; County Government of Makueni 2013). The population growth in Makueni is rapid due to the high fertility rate, which is currently 6 children per woman, compared to a national average of 5 children per woman (Kenya National Bureau of Statistics, 2015; Population Action International, 2014).

Despite Makueni County being prone to drought, its residents mostly depend on agriculture. This has led the county to be one of the poorest in Kenya (County Government of Makueni, 2017a). Community solidarity networks exist within the area to address basic needs. Given high levels of poverty, social groups in the area improve their financial status by joining informal co-operative societies or micro-savings groups, known as *chamas*

Yes. There are many chamas. I can't remember all their names...What I know is that they are all for economic purposes to uplift their members' financial status—KI health management Makueni County 2017.

In these micro-savings' groups, members contribute a specific amount of money at each meeting for a fixed time, which is then paid in full to one member on a rotating schedule, known as 'Merry Go Round'.

County safety net programmes support community-level processes. For example, the government has supported transport service provider members of the motor cycle transport (*bodaboda*) Savings and Credit Co-operative Society (SACCO) with free driving licenses after free training, provided motorbikes as seed capital and training on entrepreneurship skills. Youth and women's' groups access loans at low interest rates to start small- and medium- sized enterprises (County Government of Makueni, 2017a). The county government also waives hospital bills in all public hospitals for elderly and vulnerable people in the county (County Government of Makueni, 2015a).

Kenya has four tiers of health services shown in the diagram in *Appendix A1*. These include: community services, primary health care services, county referral services and national referral services.

- Tier 1 (community services) comprises all community-based health activities and a community unit made up of 25 trained community health workers (CHWs), appointed by a primary healthcare management team and endorsed by a local village health committee that includes community members (discussed later). It serves a population of about 5 000. A community health extension worker (CHEW) supervises this unit, linking community services to the second tier, and provides technical support. CHEWs are trained public health employees certified in nursing or public health and are government employees. The community unit assists in: identifying potential problems for referrals to health facilities, providing health education, reproductive health services and home visits.
- 2. Tier 2 (primary care services) comprises dispensaries, maternity and nursing homes and health centres in public and private sectors, serving populations in the same geographical location. Profit-making institutions or individuals operate the private services and charge fees; they have a lower provider-to-patient ratio compared to that in public sectors. Public services co-ordinate the community units and provide primary care services through clinical officers, nurses, laboratory technicians, CHEWs and other health cadres. They manage referrals from communities and refer where needed to the nearest county referral service. They provide basic outpatient care, minor surgical services, basic laboratory services, maternity care and limited inpatient services.
- 3. Tier 3 (county referral services) includes all former district and provincial (referral) hospitals in the county. Counties are administrative units of the devolved government and are enshrined in the 2010 Constitution of Kenya.
- 4. Tier 4: (national referral services) includes all service units providing tertiary/highly specialised services, including high-level specialised medical care, reference laboratory support, blood transfusion services and research. The units are semi-autonomous and operate under a defined level of self-autonomy from the national health ministry (Ministry of Health, 2012; Ministry of Health, 2014; County Government of Makueni, 2013).

At county level, the governance units include a county department of health, hospital boards, primary care management committees and community/village health committees (as shown in *Appendix A2*). Currently the county has 156 health facilities, with an immunisation coverage of 62.26%, and a contraceptive acceptance level of 30.75% (County Government of Makueni, 2013). By 2013 the county had an infant mortality rate (IMR) of 53 per 1 000 live births and an under-five mortality rate (U5MR) of 61 per 1000 live births. The maternal mortality rate (MMR) is 400 per 100 000 live births (County Government of Makueni, 2016), (See Table 1, Appendix A1). According to the Makueni County Integrated Plan of 2013, malaria/fever is the most common disease for all populations, followed by flu, stomach ache, diarrhea and respiratory diseases (County Government of Makueni, 2013).

Traditional health practitioners (THPs) are people recognised by the community members as competent to provide healthcare by using either plant, animal, mineral-based medicines or methods based on social, cultural and religious beliefs and knowledge on the causation of disease and disability in the community (Musyimi et al., 2017a). Many people in Kenya seek treatment from THPs, although their total number is unknown because they are all not registered. The ratio of THPs to patients in sub-Saharan Africa is about 1:500 (Truter, 2007). THPs are classified into traditional healers/herbalists, diviners and faith healers (Van Niekerk et al., 2014). Diviners use ancestral spirits to identify the cause of illness, while herbalists/traditional healers use herbs, massage and dietary advice to treat a disease. Faith healers use Christian practices such as prayers, laying on of hands or providing holy water for treatment (Musyimi et al., 2017a).

Within this health and service context, clinical detection of mental disorders is poor, leaving most mental health problems undiagnosed and unmanaged (Ndetei et al., 2009). Previous studies have estimated that up to 25% of outpatients and up to 40% of inpatients in health facilities suffer from mental conditions, particularly depression, substance abuse, stress and anxiety disorders (Ndetei and Muhangi 1979; Dhadphale, 1984; Lipowski, 1977). In 2015 Makueni County reported 1 516 cases of mental disorders (0.15% of the total population), with the most common condition being psychotic cases at 0.1% of the total population (983 cases) (County Government of Makueni, 2015b). A recent study in Makueni County at primary care level detected a 25% prevalence of depression (Musyimi et al., 2016a). However, tier 1 and 2 facilities provide little or no services for diagnosis and treatment of people with mental disorders, and inpatient mental health services are only available in tiers 3 and 4 (Jenkins et al., 2010). This is largely due to the limited number of mental health specialists in tiers 1 and 2.

THPs are thus often the first line of contact for mental illness in Kenya, because they are readily available and accessible in the community and form part of the community's cultural belief system (Ndetei et al., 2008). Communities prefer seeking treatment from THPs rather than health facilities. This is because of dissatisfaction with treatment and services at the local health facility, THPs being seen as kind and having more time to listen to their patients, and THPs having more flexible payment arrangements for treatment, with payments at a later date or in kind (Mbwayo et al., 2013). Despite their larger clientele, THPs recognise a limited number of mental illnesses based on one's behaviour and miss co-morbidities (Mbwayo et al., 2013). Collaborative referral between THPs and western healthcare providers is needed to ensure effective treatment of mental illnesses. No specific policy is guiding this, although the 2015-2030 mental health policy encourages integration of THPs into mental healthcare and support community leaders to participate in referral of persons with mental illness for treatment (Ministry of Health, 2015a). To regulate THP practices, the Traditional Health Practitioners Act, 2014, makes provision for training, registering and licensing, and provides for the establishment, powers and functions of THPs Council of Kenya (Republic of Kenya 2014). Recent studies in Makueni County have indicated that THP associations such as National Traditional Health Practitioners' Association and Herbalists' Society of Kenya provide an infrastructure for capacity building for evidence-based and integrated practice (Musyimi et al., 2017a; Musyimi et al., 2017b).

3. The aims and methods

The case study aimed to gather and report evidence on promising practices in and models of meaningful community participation, power and decision-making in health systems management of mental health in Makueni County. A document review was followed by key informant interviews and focus group discussions, using a shared framework for the project.

The documents reviewed included: published and grey literature, official documents, site documents, statements and reviews and operational documents, reports and evaluations, 'how to' guides, information briefings, newsletters of sites, and meeting reports. Documents were also sourced from an internet search of published literature on Google scholar, PubMed, Medline and other online journals post-2000. Important antecedent documents published in the 1970s and 1980s on mental illness in Kenya were also included. The search and review experienced some limitations in that most of the information on community participation in Makueni was not available online and materials had to be sourced from county personnel and community representatives. Ten key informant (KI) interviews were conducted involving county Ministry of Health personnel, THP, CHW and community representatives involved in community participation and decision making at the primary healthcare level. Two focus groups were held with members of the community. Videos and photograph images were also taken to capture evidence of key contexts, processes, actions and groups. Data from interviews were analysed using NVIVO qualitative software for emerging themes and the results presented in form of quotations.

Maseno University Ethical Review Committee reviewed and approved the study. Participation in the study was voluntary, and anyone was free to drop out of the study at any time or decline answering any question without being penalised. Interview transcripts and data gathered were held under secure electronic access and confidentiality protected. Participants provided written consent.

4. The participatory work

4.1 The organisation of social participation

Public participation is one of the foundational principles of democracy in Kenya (Govt of the Republic of Kenya, 2010). Democracy is pegged on the idea that all citizens are equally entitled to have a say in decisions affecting their lives. In Kenya, public participation is a right enshrined in the Kenyan Constitution. Article 1(2) of the constitution vests all sovereign power to the people of Kenya (Govt of the Republic of Kenya, 2016). This power can be expressed through direct participation or indirectly through elected representatives (Kenya Law Reform Commission, 2017). Other legislative provisions available in various platforms for citizen participation in devolved governance include the County Government Act and the Public Finance Management Act that were developed in 2012

Figure 2: Structure of the different levels of public participation





(Govt of the Republic of Kenya, 2012a; 2012b). Citizens are entitled to make choices in development projects based on their priorities. Public participation is seen to generate new, diverse and innovative

ideas and actions, improve delivery of public services and government responsiveness, and enhance relations between citizens and government (Oduor et al., 2015).

With respect to infrastructural development projects, public participation in Makueni County starts at the village level (Village People's Forum) (See *Appendix A3*). It involves community members, county government representatives and various elected leaders who meet in various committees to prioritise on the development agendas of the community. These agendas would then be debated in the different forums up to the county level as illustrated in *Figure 2* above. Those projects at county level are tabled and approved at the County Peoples' Forum and budgets are set for them. Project management committees supervise their implementation to completion.

With Makueni located in an arid and semi-arid area, most of the infrastructural development projects to date from these mechanisms for public participation have been in water and sanitation infrastructure.

... we normally consider priority projects that the government might fund. One of them we saw as a priority was access to water. Currently, a dam and a borehole where people would get water are under construction. The other thing concerning health was another organisation that came called Kitise Rural and they were under the Ministry of Health, theirs was on community sanitation, which was also considered a priority. ... they would inspect the cleanliness in homes, check whether they had a dustbin, a sink (area) for washing utensils even if the home had grass thatch. They even made sure people don't use the bush as latrines -- KI community member, Makueni sub-county, 2017

In health services, the village health committee (VHC) acts as the vehicle for social participation at the primary healthcare level. This committee consists of eleven to thirteen people, with at least onethird of the committee drawn from women's groups, faith-based organisations, youth groups and from people living with disabilities (TARSC, 2014). The committee represents the community in local development forums and various health committees at other levels; they oversee the recruitment of CHWs; mobilises resources for health activities, including outreach and referral; facilitates regular dialogue within the community based on the community and facility information system; organises the community for collective health actions and addresses priority problems; ensures community involvement in decision-making and in decisions and priorities for interventions (Government of Kenya 2006) (see Appendix A2). Through this committee, the chair, who is a member of the community, is responsible for mobilising community resources and reports to the dispensary committee in all matters of Tier 1 services. The VHC chairpersons are selected/elected by the community under the leadership of the village administrator, and they must be people of integrity and good moral standing in the community (Government of Kenya, 2006). CHWs working in the village report to the chair of this committee on their day-to-day activities, with the technical support of the community health extension worker (CHEW). Major health challenges affecting the community are reported to this committee, as reported below by a CHEW from Makueni County.

...If there is any problem it is managed from the grassroots and, depending on the reports we receive, we try to categorise the problems and if there is any major health problem, we plan for interventions. These may include organising barazas [public meetings] to address those problems if it is a major problem and will affect many people. If it is an individual problem, it is handled at the facility level — KI CHEW, Makueni County Referral Hospital, 2017.

As discussed later in the case study, these formal mechanisms for social participation, while providing for community voice in decisions on services and development activities, have not taken up mental health issues in the past. THPs are also not members of this committee, given their lack of formal status in the system and their role in managing such psychosocial problems. The next section explores the work done in Makueni to strengthen the role of these and other community actors in the local responses to mental health problems, and later reviews what this means for these formal mechanisms for participation.

4.2 Social participation in addressing mental health issues

In Kenya, generally the VHCs' role should encompass all issues of public health significance. However, in practice CHWs mainly focus on physical health matters (Jenkins et al., 2010), thus neglecting mental health issues despite mental healthcare being integrated into general healthcare at the community level (Tier 1) (Kiima et al., 2004). This is also the case in Makueni County, where the VHC has neglected mental health issues since they believe that mental health problems are personal issues that should be dealt with privately. A member of the VHC from one of the health facilities in Makueni reports that: *It is very rare to find the VHC discussing mental health issues. They consider it a family problem* – KI CHW, 2017.

Community members in Makueni County also generally believe that one's poor mental condition is mainly a result of witchcraft. That the condition is not curable and if 'cursed', the curse can be passed down one's lineage. This attribution to mental illness results into seeking services from THPs.

The Kamba community has actually ignored mental health because of the belief that if you are below 35 years of age and you have a mental problem, it did not just come by itself. It is either that you or your ancestors wronged somebody. They don't believe there is a sickness called madness. Instead, they believe it is brought by something...It is not curable and one has to ask for forgiveness from the offended to be healed – KI ward representative, Makueni County, 2017.

These beliefs have led to limited attention given to mental health challenges compared to other diseases such as malaria that are often discussed in VHCs.

... The government has not yet implemented a plan for the mentally ill patients, because when you look at it, you find that the government has implemented good programs for treatment of malaria. They have malaria drugs readily available in hospitals and they also do campaigns for malaria. They even issue mosquito nets in schools. But mental illness has not yet been given priority, it is like they have not realised that it is also a problem -- KI faith healer, 2017.

Few people seek treatment for mental disorders in dispensaries and health centres as confirmed in focus group discussions with different categories of participants. People in Makueni prefer THPs to healthcare workers, and they only visited the health facilities if all the other options failed.

...mental illness doesn't have a direct treatment since it's both cultural and spiritual. So those who take care of them always bring them to us [faith healers] and we pray for them... those who don't believe in God or don't have faith they always go to the traditional healers... – KI faith healer, 2017.

There are healers who treat people in the community with herbs. They are also taken to priests for prayers and after going round they are brought to the hospital - -KI health worker, Makueni County Referral Hospital, 2017.

Health services at the health facility level (dispensaries and health centres) provided by registered nurses and clinical officers lack adequate training in mental health. Psychiatric nurses from Tier 3 facilities have high workloads to visit these dispensaries to offer counseling services for common mental health disorders and to give health education on drug and substance abuse both in schools and in the community.

Currently, primary school programmes on mental health education and prevention on the same are there, like we talk on substance and drug abuse to the young people who are in school because they are very vulnerable and if they are left without knowing the effects, they will find themselves in problems with mental disorders...I have 13 dispensaries where I go monthly to give curative services – KI health worker, Makueni County Referral Hospital, 2017.

Consequently, THPs believe that they are the right people to deal with patients suffering from mental disorders. Residents in fact prefer visiting healers outside their respective communities, perhaps due to the stigma associated with mental illness and the assumed incurable nature of the illness.

> ... the best person who can help is either a pastor or a traditional healer, because these things are ancestral and traditional and so they are related to a lot of traditional beliefs. So I think the faith and traditional healers have a lot of work taking care of these people with mental illnesses... -- KI faith healer, 2017.

Even in the bible, Jesus was rejected in his area, like for me I cannot treat in my area because people will not respect me, but I treat



Faith healer's common mode of treatment (prayer) © DM Ndetei 2017

a lot of people outside my community. I go so many places to treat but in my area nobody can even bother to consult me on anything. -- KI traditional healer, 2017.

Through dialogue, both THPs and health care workers identified problems and terms used for common mental health problems in the community. Some of the common mental health problems identified include psychosis, locally referred to as *mundu wa nduuka* (a mad person) or *mbusu* (a person in a confused state), depression, locally known as *theva* (sadness or mourning), and epilepsy, referred to as *mung'athuko* (unnecessary falls). These conditions were named according to their symptoms. For instance, a traditional healer used the term *mbusu* to refer to psychosis, while a CHW referred to it as *mundu wa nduuka*. Both terms referred to psychosis since the individuals manifested with unusual symptoms such as walking naked and talking to themselves in a confused state:*doesn't know if he/she is naked, he/she cannot know a child, he/she can walk in the streets naked that's why they are called andu ma nduuka*. – KI CHW, 2017.

The terms were based on characteristic behaviours and were deemed appropriate by the community and by THPs and CHWs.

Most of us were born and we found those names already in place. And therefore, I can't really tell how the names came into being....what I can say, they are named according to the symptoms manifested--- KI faith healer, 2017.

As a first step to strengthen collaboration between healthcare workers and THPs in Makueni County, AMHF, in collaboration with Makueni County government and National Traditional Health Practitioners' Association, initiated dialogue between the two groups. Each group held separate discussions; then the different groups of practitioners together identified and addressed barriers to collaboration and factors leading to mistrust.



THPs and Health care workers after a dialogue meeting © DM Ndetei 2017

When the dialogue was evaluated, it was noted that:

- THPs mainly attributed mental illness to witchcraft while clinicians attributed it to poor upbringing. Other causes of mental illness included substance abuse, physical illness, injury and old age.
- Healthcare workers looked down on traditional healers, creating hostility between the two. They discredited traditional healers' work and discouraged their patients from seeking treatment from them, since they used herbal medicine for treatment.
- Traditional healers referred patients amongst themselves.
- Some faith healers felt that God should heal those suffering from mental illness and saw referral to health facilities as being in conflict with their religious beliefs.
- Although THPs referred patients to clinicians, health facilities did not receive this well because clinicians felt that patients only sought their help when their conditions worsened.
- Clinicians seldom referred patients to THPs as there was no structure in place to allow for cross referral.

In the dialogue, all the three groups (faith healers, traditional healers and healthcare workers) resolved to strengthen their collaboration. They saw training as important to bridge the communication and referral gap between formal and informal health providers, and all stakeholders saw the need for training on how to identify and manage priority mental health problems. THPs and clinicians shared a goal in improving the lives of their patients and thus resolved to work together, show mutual respect for one another, and strengthen referral of patients with severe mental illnesses to clinicians (Musyimi et al., 2016b).

Arising from the recommendations, THPs were trained to identify and manage depression using the depression psychosocial component of the WHO mental health Global Action (mhGAP-IG) (World Health Organisation, 2010). Before the training, the mhGAP was translated into the local language, back translated into English and any inconsistencies between the two versions discussed by a team of health experts, an anthropologist and lav persons, fluent in both languages until a consensus was reached (Musyimi et al., 2017b). Traditional and faith healers found it suitable for use, except for the pharmacological interventions delivered by prescription at primary care settings. The training involved:



Training of THPs on mental illness detection © DM Ndetei 2017

- Identification and delivery of evidencebased mhGAP-IG psychosocial interventions to patients who scored positive for depression.
- Training on the causes of depression and mental illness in order to alleviate any misconceptions about the cause of mental illness that might interfere with their new mode of treatment.

The training was conducted over two days and involved interactive experiential learning, including demonstrations, small group work, question and answer sessions and role-plays. The psychosocial interventions in mhGAP-IG educated patients and caregivers on common symptoms and causes of depression, on improving wellbeing, sleep, exercise, reducing stress, strengthening social support and promoting functioning in daily activities and community life. The training also discussed conceptions of the causes of depression and mental illness and how they are managed (WHO, 2010).

All trainees were supported and supervised for three months to ensure mastery of concepts and confidence in practice. The participants were evaluated at the end of three months after training. They showed a 12.27% statistical improvement in the practice of confidence, knowledge and skills (p<0.0005). Additionally, 58% and 78% of THPs' patients also showed a reduction in symptoms of depression ranging from a score of 3.5-9.3 at 6 and 12 weeks after intervention respectively (Musvimi et al., 2017a).

CHWs were also involved in mental health activities. Unlike THPs, CHWs are attached to health facilities and regularly conduct home visits. They are selected by the community through a *baraza* (meeting with community elders) with input from community members through the VHC and CHEWs based at health facilities (Rachlis et al., 2016). The CHWs were trained for two days on:

- Recordkeeping, tracing defaulters by collecting relevant personal information at the initial contact;
- Follow-up to evaluate patients' health outcomes after receiving treatment from the health providers (Musyimi et al., 2017a).



CHWs training on record keeping and defaulter tracing © DM Ndetei 2017

In addition to treating and conducting follow-up visits, all these community health providers also referred patients to health facilities to receive further treatment:

...they [herbalists, faith healers and community health workers] are the people who refer these people to the satellite clinics. So we are collaborating.... Research shows that it has been working well. Moreover, through interacting with the Africa Mental Health Foundation, it has been realised that if we involve them [traditional healers, faith healers and community health workers], the results are always better -- KI management, Makueni County Referral Hospital 2017.

After talking to this person and you get to know their problem, we write them referral letters and then send them to the nearest hospital providing these services. After which we contact someone at the facility who then takes over -- KI, faith healer, 2017

AMHF staff used various avenues such as phone calls to mobilise healthcare workers, CHWs, traditional healers and faith healers to participate in the dialogue meetings and trainings. Phone calls were also used by the health providers during patient follow-up to confirm arrival of patients and availability of a mental health professional at the health facility, as well as during patient follow-up assessments.

We sometimes called the facilities just to confirm their availability before sending patients to them. Since sometimes they [the patients] would go and miss them — KI faith healer, 2017.

Once patients have undergone treatment, you must have their contacts to make follow-ups. We always call their family members to remind them of the return date and find out how the patients are faring on. On the day the patients are supposed to return for follow-up, we again call the nurses to find out if the patients came back for treatment. If they didn't return for treatment, you have to go look for them – KI CHW, 2017.

Other avenues used to increase public awareness and encourage participation in health in Makueni County include use of local mass media such FM radio stations, county print media, and posters as cited below by an official from Makueni Subcounty. The mobilisation and sensitisation methods used approaches relevant to specific populations to make announcements to the public, such as through churches, in market places and through public structures such as village, ward, sub-county and county administrators' meetings.





Poster of 2015 World Mental Health day © DM Ndetei 2017

public participation. So we communicate to the delegates and members of the community -- KI official, Makueni sub-county, 2017

Bearing in mind where we are, we still use the old way (of communication) such as making announcements in churches and market places – KI management, Makueni County, 2017

In addition, the State of the County address is a forum that was used to address upcoming mental health activities in Makueni County, as for example at

https://www.makueni.go.ke/state-of-thecounty-address-12-2015.

Although mobile phone coverage in Makueni County stands at 85%, and the illiteracy level at 22.4% (County Government of Makueni, 2013), internet access in the county was still low, limiting the use of emails, social media



Members of the public in a sensitisation programme on mental health © DM Ndetei 2017

and other internet-based communication strategies to relay information to the public. To address the stigma of mental illness and help create awareness on the project activities, road shows (promotional campaigns) and public meetings with local elected leaders and area chiefs and assistant chiefs were conducted by AMHF in collaboration with the county government.

Various groups recommended specific actions to further strengthen community participation in mental health such as:

 Government, through VHCs, investing in management of mental diseases at the primary healthcare level: If possible the government should also invest in mental health not only diseases like malaria, HIV and AIDS, TB and the likes. Because we normally have dialogue days, where we sensitise the community on issues affecting them... but you will not hear them discuss about mental health. So if possible, they should also include it [mental health]... -- KI CHW, 2017 Government collaborate with non-governmental organisations to encourage the community to set up mental health advocacy groups to represent people with mental health problems, including in VHCs and development forums: As a patient, I would ask the government in collaboration with NGOs, like you people [AMHF], to encourage us to come together with one voice so that we can also be heard in these development forums – FGD patient, 2017

5. Factors and conditions affecting the approaches

As a result of the collaboration, traditional and faith healers in the study reported feeling much appreciated and useful in the society when they were involved in the referral process (Musyimi et al., 2016b).

...even today many people come and appreciate what I did to them -- KI traditional healer, 2017

...Yes, I feel I served my purpose because there was a time I received a call from hospital to look for a certain lady who was needed in the hospital and I did and the patient was helped -- KI traditional healer, 2017

Information sharing in good time and co-operation among all the relevant stakeholders (patients and their caregivers, healthcare providers, traditional healers and faith healers) smoothed the referral process.

What made the project succeed was working together, and creating awareness and getting information in good time -- KI health worker, Makueni County referral hospital, 2017

After screening and referral of patients to health facilities, CHWs and the THPs were paid an incentive for their time and effort. This incentivised their practice but also provided income support to them.

The participatory processes brought a sense of unity/togetherness in the community as people from different backgrounds shared information in the community

...The other thing that makes me think it [community participation] is good for us is because it brings people together and they start to prepare themselves incase their proposal is approved. The other thing is that, it has created a good relationship because as people air their views, at times during break time, they continue to interact and even share other problems they might have at home among themselves. For instance, one can share if they have a mentally sick person at home and she is advised on how to take that person either to a THP or to the hospital – KI, community, Makueni sub-county, 2017

On the other hand, community members and community health providers experienced various challenges through their participatory role in mental health service delivery. Some community members mocked the traditional healers' new role of referring patients with mental illnesses to the health facilities. One elderly traditional healer experienced this at inception of the project, but later, the patients understood his role and benefited from the initiative.

Lack of respect in the community, some mocked me but others came later to know what I was doing and they got help –KI traditional healer, 2017

Traditional and faith healers also felt uncomfortable dealing with unaccompanied patients who were violent.

...the challenges are, like you get a sick person who is violent who might beat you and getting his people is not easy – KI traditional healer, 2017

...because sometimes you handle people who are not co-operative, there are so many risks. Only that God takes care – KI faith healer, 2017

To reduce self-injury some patients were restrained before referral to a hospital, but this was still harmful.

Like the patient is not willing to come and the patient has to be tied with ropes and he will get injuries on transport. So that is a problem because by the time he will be reaching us, he will be having other additional injuries –KI health worker, Makueni County referral hospital, 2017

Lack of transport to health facilities after referral was one of the main challenges experienced by patients and their caregivers. This explains the high number of patients who seek care from local health providers based in communities.

The main challenge was how to take the patient to the hospital -- bus fare was the challenge. If I don't have the money, I would do some casual jobs to get money and take the patient to the hospital – KI community caregiver, 2017.

There were also challenges in the ability of the health care services to manage demand. Healthcare workers in Tier 3 were not able to offer counseling services during outreach sessions due to lack of transport.

Transport is also a problem because you will find that we would like to go out (to satellite clinics) as many health workers but there are no vehicles – KI health worker, Makueni County referral hospital, 2017.

Inadequate number of mental health workers in health facilities resulted in patients waiting in long queues. This led to patients defaulting after referral by community health providers.

At times you can refer a patient and he goes queuing until he starts complaining because there is only one doctor (primary healthcare worker) serving them -- KI Faith healer, 2017.

Making a link between these processes for better management of mental health and the formal mechanisms for participation such as the village development committee and higher structures is thus important. The processes described in the case study suggest that mental health issues may be brought into formal mechanisms, linking formal measures with local processes, to institutionalise it. Community involvement in the discussion and decisions on actions put people in a stronger position to oversee and ensure social accountability on their implementation. The community observed that the new roles of CHWs, traditional and faith healers and the promotion of dialogue between these teams on mental health now needed stronger health facilities that encourage inclusion of mental health services during routine care and referral of patients:

What we are doing is a good thing because before we got the devolved government, we just used to see projects like for hospitals... we would see stones being delivered without the locals' knowledge. We would see a contractor brought and yet we were never involved. We would only be called on the day of the opening ceremony. But now the locals can sit back and identify a need. They can check the projects that have been done in the area and which ones have not been done in the area. Then prioritise all the needs and identify which one needs to be done first – KI community member, Makueni sub-county, 2017

6. Outcomes

While there is some caution on making direct attribution to the practices described, and while the roles of the community health providers, THPs and CHWs may be affected by other social factors, the participatory work was reported to contribute to various outcomes, including:

- County government contributions of financial and human resources and work with nongovernmental organisations contributing to reduction of symptoms for patients suffering from a priority mental illness (Musyimi et al., 2017b).
- Improved community health outcomes reported by THPs, for example: There was a certain sick old man who used to cover himself with a blanket; since he was healed, he threw that blanket away and is now doing well. I can say, whoever used the medicine well recovered KI traditional healer, 2017.
- Improved situation in the families and reduction in their caring load, enabling them to return to other work: ... Some could not leave their sick people unattended to go anywhere but now the families have peace... -- KI, traditional healer, 2017, and Yes, like one who never used to work because they were sick can now do something for their lives. ... Even the families came together. You would find that sometimes it had departed but now you can see socialism in the family and they are doing things together – KI health worker, Makueni County referral hospital, 2017.
- Increased knowledge about mental health amongst the personnel involved. Yes, like in my clinical line, the clinical officers gained a lot of information on the management of mental illnesses. When they got patients, they would consult and we managed together. If they got in patients with mental illnesses, they called us and we managed together KI health worker, Makueni County referral hospital, 2017.

The social dialogue created a sense of belonging where formal and informal health providers could freely discuss issues and suggest possible solutions without necessarily looking down on each other.

7. Discussion

This report highlights public participation in both infrastructure development and service delivery at the primary healthcare level in Makueni County. At policy level, participation at the community level starts at the primary healthcare level (VHC level), however in practice, it is biased towards physical health thus neglecting mental health service delivery. As such, service delivery is limited, forcing the community to source for the service from informal health providers (THPs). The report also highlights that there are no policies supporting collaboration between THPs and healthcare workers. Hence, gaps have resulted in the provision of mental health services at the primary healthcare level resulting in a unidirectional referral system. This report therefore proposes laws and policies to support collaboration between THPs and healthcare level.

Collaboration among these key players provides an opportunity to reduce the huge mental health service gap using existing community resources. It also opens doors for dialogue that supports information sharing and facilitates the social, collective interactions needed to achieve service and community goals.

Continuous supervision and mentoring of the processes are needed to support healthcare workers and informal health providers. In addition, there is need to encourage evidence-based practice, while checking for concordance of suspected illnesses until informal health providers acquire skills and competencies for continuity of care. Little documentation exists on such participatory processes, and guidelines should be developed and documented for future use.

It is suggested, however, that the participatory approaches described in this case study could be adopted in Kenya, across all areas of intervention in the formal mechanisms for participation (shown

in *Figure A3.1*), to promote sustainability and ownership of acceptable health service delivery systems. As a participatory process, it takes into account the interest of involved parties to ensure sustainable service models in an area that may not be well recognised or that may be socially stigmatised, like mental health. It promotes trust, improves performance and provides clear roles for involved parties by preventing overlap or gaps and building co-operation.

7.1 Areas for shared learning

Insights from the case study indicate that:

- Dialogue and information sharing are key in the field of mental health to address mistrust and communication gaps between the formal and informal health practitioners, build mutual respect and allow shared learning for patient care at community and primary healthcare level.
- Integrating mental healthcare into primary healthcare, especially for resource-limited countries such as Kenya, through capacity building for informal health practitioners and CHWs is key to improving mental health service delivery at the community level and reducing the huge mental health treatment and care gap. Collaborative training and strategies at the community level through existing personnel and networks can strengthen the primary healthcare response in mental health.
- There is need to clearly define roles between THPs and the healthcare workers to prevent overlap and avoid unnecessary conflicts and to identify the role of compensating CHWs and THPs for their roles in the system.
- While the process has strengthened community awareness and provider collaboration, it is important that formal mechanisms for participation, like VHCs, invest in the capacities to address mental health disorders at primary healthcare level, and not only invest in physical infrastructure and infectious diseases.
- Community mental health advocacy groups can assist to engage formal mechanisms and ensure accountability for delivery of resources and programmes, including to more marginalised groups.

While the work is located in a specific context, features that could be adapted/adopted elsewhere include:

- 1. The (informal) processes used for building common terms.
- 2. Structured dialogue on barriers, roles and actions and evidence-based training using the <u>WHO mhGAP-IG</u> approach.
- 3. Wider community awareness to support collaboration between community level and system actors may have relevance to other buried and stigmatised health issues, to facilitate the interactions and awareness needed for them to be applied within more formal mechanisms for social participation.

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Appendices Table A1: Health profile of Makueni County, 2013

Category	Description %(County)		National (%)	
Immunisation coverage (% children 12-23 months who have received all basic vaccinations)	92.0		79.4	
Contraceptive Acceptance	65.0		53.2	
Female Fertility rate (Births per woman)	3.3		3.9	
Mortality rates	Infant Mortality Rate (IMR)	53/1000	54/1000	
	Under 5 Mortality Rate (U5MR)	61/1000	79/1000	
	Maternal Mortality Rate	400/100 000	495/100 000	
	Crude Birth Rate	44.7/1000	35/1000	
	Crude Death Rate	11.9/1000	10.4/1000	
Life Expectancy		67	62	
Five most prevalent diseases (%)	Malaria and/ or fever	51.1	Not available	
	Flu	12.7	Not available	
	Stomach ache	5.0	Not available	
	Diarrhea	2.5	Not available	
	Respiratory Infection -Upper	1.1	Not available	
	-Lower	2.2	Not available	
Doctor-Patient ratio	1: 22 217 against WHO recommended 1: 10 000			
Nurse-Patient ratio	1: 2 197 against WHO recommended 1: 1 000			

Source: Kenya National Bureau of Statistics 2015; World Bank Group 2016; Ministry of Health 2015b; County Government of Makueni 2013; County Government of Makueni 2016

Table A2: Prevalence of mental disorders in Makueni County, 2015

Type of mental disorder	Number of cases (N = 1 033 398)	% prevalence	
Psychosis	983	0.095	
Epilepsy	372	0.036	
Depression	50	0.005	
Neurosis	33	0.003	
Dementia	29	0.003	
Substance use disorder	9	0.0009	
Others	40	0.004	

Source: County Government of Makueni, 2015b

Table A3: Outline of activities showing how dialogue was organised

Phase	Type of practitioner	No. of FGDs	Aim	
1	Traditional healers	2	To discuss practitioners' perceptions on mental illness, causes and management.	
	Faith healers	2		
	Clinicians	2		
2	Traditional healers and clinicians	1	To deal with mistrust, enhance respect and address any barriers	
	Faith healers and clinicians	1	inherent during referrals between the formal and informal sectors.	
Evaluation phase for dialogue formation	Traditional healers, faith healers and clinicians	Questionnaire with 9 clinicians, 9 faith healers 12 traditional healers	To evaluate the process of dialogue formation.	

Source: Musyimi et al., 2016

Appendix A1: Organisation of Health Service Delivery System in Kenya



Source: Ministry of Health, 2012

Appendix A2: Management structure of Health Service Delivery System in Kenya



Source: Ministry of Health, 2012

Appendix A3: Organisation of public participation in Makueni County

For development projects in Makueni county, public participation is generally organised into:

- (a) A territorial framework: where people are organised within their geographical locations and along county administration levels at village, sub-ward, ward, sub-county, and county levels.
- (b) A thematic framework, where the interests of special groups with common characteristics such as youth, women, faith-based organisations, people with disabilities (PWDs), farmers and the like are taken into account. They include groups such



Figure A3.1 Forms of public participation

Source: Adapted by author from County Government of Makueni (2017a)

as minority and marginalised groups, Faith based organisations, Parents Teachers Associations and the likes as shown in the url link (<u>https://www.makueni.go.ke/public-participation-framework</u>). These groups are found at the sub-county or county level and are nominated into development committees from the sub-ward level to the county level. They meet from time to time to plan, budget and execute development along their social organisational level. In addition, they make up the County Budget and Economic Forum.

- (c) A pictorial framework, where the county government displays development information to the public on bill boards and white boards with the aim of promoting visual representation of public participation. The county government informs the public of on-going projects in terms of their budget allocation and time span with the purpose of ensuring transparency, accountability and openness between the government and the citizens.
- (d) A technical framework, involving professional groups and technical departments with special technical skills to support social participation. These lenses are shown diagrammatically in *Figure A3.1* (County Government of Makueni, 2017b)

To support public participation, the public is represented in the development committees and forums constituted along the territorial, thematic and the technical frameworks and in Project Management Committees (PMCs) and organised thematic groups. These development committees represent different forums (County Government of Makueni, 2017b; County Government of Makueni, no date) shown in *Figure 2*, including :

a. The Village Peoples' Forum: This is the lowest development forum and is present in each of the 3 455 villages. Each forum is represented by a village development committee which consists of eleven selected/elected members. The members are selected and/or elected by the community in the presence of a village administrator, although the criterion used for their selection is not clearly defined. The village development committee meets at least once quarterly. Its members represent the village people's forum in the village cluster forum, where they present the prioritised development agenda from the respective villages.

- b. The Village Cluster People Forum is found in 315 village clusters, with each cluster covering approximately thirteen villages. This forum is represented by the Village Cluster Development Committee consisting of eleven members elected/selected by those village development committee members who attend the first village cluster development committee members of this committee include a representative from both the national and county government, who are ex-officio members. This forum is co-chaired by the village administrator and a community member. The Village Cluster Development Committee debate on the different development agendas from the different village peoples' forums, with the selected agendas then presented to the sub-ward peoples forum.
- c. The Sub-Ward peoples' Forum covers 3-5 village clusters, with eleven members of the Village Cluster Development Committee in the sub-ward and representatives of the county/national government and the community at this level and ex-officio members from the sub ward advisory council and the village administrator. Meetings in this forum are held bi-annually. The forum is co-chaired and convened by the county/national representative and the community representative, who form the secretariat. It is represented by an eleven-member Sub-ward Development Committee elected/selected by members of the different sub-ward peoples' forums and another 15 to 25 representatives nominated from the three to five village clusters. Regional balancing is considered when electing/selecting the representatives. The committee represents the sub-ward peoples' forum at the Ward People's Forum. This forum debates the development agendas from the different village cluster forums, before sending the selected agendas to the ward level.
- d. The Ward Peoples' Forum consists of 72 92 members from the two sub-wards in a ward. Its membership includes; eleven members from each sub-ward development committee, at least fifteen members nominated from each of the sub-wards and ten members from each of the organised groups in each sub-ward. The ex-officio members at this level include; the elected leaders and the ward (village) administrators, and one person from each of the organised groups is nominated by the respective county government official to attend the forum. This forum meets bi-annually to debate the development agendas from the different sub-wards. It is represented at the sub-county people's forum by the ward development committee which consists of eleven members elected from each ward. The county government representative (ward administrator) and a community representative are incharge of the forum's secretariat.
- e. **The Sub-County Peoples' Forum**: exists in each of the six 6 sub-counties and consists of eleven elected persons from the ward development committees and twenty people nominated to the forum by the sub-county administrator. They meet bi-annually to debate on the development agenda from the different wards before passing them to the county peoples' forum.
- f. The County Peoples' Forum is the highest level of community participation in Makueni County. It consists of eleven members from each of the sub-ward development committees, 140 county government officers and ten persons from each of the organised groups per sub ward nominated by the participants in the forum. The county government official, as the county secretary, and a representative of the community run the secretariat. The forum is cochaired by the Governor and his deputy and a representative of the community. In attendance are other elected county leaders such as members of the county assembly, whose roles are to represent the different wards in the county assembly. The County People's Forum provides the county government with a means to consult on the preparation of county plans, the County Fiscal Strategy Paper and the County Budget Review for the county. The forum meets three times a year and deals with matters relating to budgeting, the economy and financial management at the county level (Ministry of Devolution and planning and council of governance. 2016). A media story of the forums describes the debates on how they have worked in Makueni (Musau, 2016).

Once proposed projects have gone through these forums and stages of public dialogue, and have been approved at the County Peoples' Forum, budgets are set for them, a project management committee (PMC) is formed, with its members either selected or elected at a public forum. In electing or selecting members of this committee, a village administrator ensures that all interested groups are considered such that women, men, youth, among whom the selection is to be made understand the field of interest and it is made up of at least two development committee members, and includes people with disability and faith-based organisations. The PMCs ensure the smooth running of the project in terms of implementation and provide the community with progress reports which are displayed on either bill boards or white boards for public consumption. They also ensure that the community owns the project and that it remains sustainable to the community soon after completion (County Government of Makueni, 2017b).

More information on this community participation framework in Makueni County is shown in a video on the work at https://youtu.be/IYC2eGsBe2k

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

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

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

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

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

This case study report is produced within the 'Shaping Health' research programme led by the Training and Research Support Centre (TARSC). The project is supported by a grant from the Robert Wood Johnson Foundation Global Ideas Fund at CAF America. The views expressed here do not necessarily reflect the views of TARSC, CAF America or the Robert Wood Johnson Foundation.



Exchanging on social power in health

AMHF and TARSC 2017