

Can communities influence national health research agendas?

A learning process leading to a framework for community engagement in shaping health research policy

Country experiences

Bolivia
Cambodia
India
Kenya
Pakistan
Tajikistan
Zimbabwe

Acknowledgement

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**ANNEX 1 - Briefing note circulated for consultation, including list of participants
Making health research work ... for everyone: Communities matter!**

Key messages from the consultation

The expert group noted that:

Good health research is done with the community; community research is good research; and research projects that value the importance of community engagement should be promoted.

The group examined and discussed the rich experiences of the experts around the table, and the case studies highlighted some important strategies that can be applied to strengthen community engagement in health research, focusing on forming alliances and developing capacity.

Community participation in research is usually interpreted as the participation of patients, consumers, or the public, as the subjects of research. There is not sufficient expertise and knowledge today to take action in supporting community engagement in national health research and national health research systems in developing countries.

There is experience available from developed nations, but this cannot automatically be translated to developing countries, as supporting systems (i.e.: organized civil society, press freedom, democracy) is often not sufficiently developed to support community engagement in health research. A better understanding is needed of existing practices and approaches in developing countries, and of values and principles that support community action.

A framework or approach is needed to enable countries to respond appropriately to the needs of their populations, and to better understand the importance of communities' roles in needs assessment and priority setting for health research. The central questions to be addressed include: who is influencing the research agenda and how can communities play a meaningful role in this?; and how can research be more responsive to the needs of the community?

As a next step in its learning process on community influence on health research agendas, COHRED is preparing an extensive review of literature and of existing experiences from projects and partners. This will help map the current situation, extract a set of principles and values for good community engagement in health research and use this new perspective to develop a conceptual approach that countries can use to enhance the engagement of communities in health research, health research agenda setting and health research policy making.

The approach will be used, tested and continuously updated. The learning will be structured through a series of exchanges and consultations. It is expected that this Learning Spiral will result in ideas for approaches that can be used by various stakeholders to enhance community engagement in health research.

COHRED will work to include community engagement as core element in its work and adjust its project guidelines and operating principles to reflect and support good community engagement in research for health. This includes influencing the thinking of COHRED partners and other development actors who do not yet recognize community engagement as a key factor for achieving health through research.

Executive summary

How can communities become active players in the health research process - as clients, policy shapers and as researchers?

There are many examples and much practical thinking on community engagement in research in the development context. This includes activities such as participatory research methods for rural development programmes, or environmental, social and educational projects. It is curious, in contrast, to note the dearth of substantive literature and thinking on how communities can influence national health research agendas and national health research policies in developing countries.

This paper is the first step in a process of learning and consultation for the Council on Health Research for Development (COHRED) and a number of partners that have an interest in how communities can shape national health research agendas. The paper and the ongoing investigation address the question: *how can communities become active players in the health research process - as clients, policy shapers and as researchers*. COHRED's learning process on community engagement in health research started in 2005 with an expert consultation between 15 practitioners from Africa, South Asia, Europe and North and South America¹, who came together to share experiences and offer advice. Useful perspectives from outside the health sector were offered by members of an environmental NGO, two anthropologists and people experienced in running social programmes.

People in villages and specific groups in developing countries do 'participate' in health research. But this is primarily as providers of data for studies or as participants in trials of new medicines and health interventions. What is not considered in the picture of community engagement in health research is how the power of communities to focus national research agendas on their priorities can be harnessed, especially in developing countries, and how communities can better use and impact health research. The US and Europe have cases of communities impacting health research - increased investments in breast cancer research by the NIH in the United States is a shining example. But there are few, if any, in the south. The COHRED initiative *Communities Matter!* is concerned with improving the understanding of how communities can matter and become relevant players in influencing national research agendas and national research policies.

There are several documented levels of community involvement²:

- **Co-option and compliance** - people participate by being dutiful subjects of research.
- **Consultation** - the community is invited to present the people's perspective on matters of interest to researchers.
- **Cooperation** - members of the community are involved in the planning and execution of research.
- **Co-learning** - the community acquires new knowledge and skills from the research.
- **Collective action** - together, researchers the community and policy makers, take action to bring about change.

¹ Aga Khan University, Pakistan; Institute of Anthropology, Copenhagen University, Denmark; PROCOSI, Bolivia; Ministry of Health, Bolivia; Chitra Tirunal Institute for Medical Sciences and Technology, India; Centre for Science and Environment, India; Community Working Group on Health, Zimbabwe; Monash University, Australia; AfriAfya, Kenya; National University of Ireland; Exchange, UK; Harvard University, USA; and Swiss Development Corporation, Tajikistan.

² Cornwall, A. (1996). Towards Participatory Practice: Participatory Rural Appraisal (PRA) and the Participatory Process. In: de Koning K. & Martins M. (Eds)

In the first level of involvement community members are the subjects of research. The following four levels indicate an increasing level of ownership by the community, with people taking charge of their own issues.

The consultation examined several cases of how community engagement makes research work for their populations:

- **Zimbabwe - Clear information helps move authorities to action.**
In Zimbabwe, where the government sees NGOs as obstacles, the Community Working Group on Health (CWGH) uses the collection and dissemination of clear information on the national health care situation related to HIV-AIDS as its main force to demand government action. To *encourage* the circulation of accurate information on the health situation, CWGH trains community groups in basic research skills. The Zimbabwe Network for Women, for example, has become a powerful group, collecting information that it shares with the authorities and the media. In some cases the government conducted 'counter'-research in response to the information and questions from the community. CWGH comprises some 25 member organizations, which are a link between authorities and community groups and train community members in basic research skills.
- **India - Environmental health concerns lead to demand driven research.** The Centre for Science and Environment (CSE), an independent, public interest organization, leads the search for solutions to environmental challenges in the country. It pushes the government to create frameworks that allow communities to act on their own. With the help of CSE's Pollution Monitoring Laboratory, Endosulfan Spray Protest Action Committee, a local NGO in Kerala could link the use of the pesticide, endosulfan to the various health problems in the area. The organisation could then lobby with the authorities to stop the use of this pesticide. Public pressure helped translate protest into policy. In Punjab, a local NGO requested help to better understand the health risks of pesticides used in cotton farming. This experience suggested the need for regular monitoring of pesticides in human bodies for the whole country and a policy to protect the people from this kind of trespass.
- **Pakistan - Academics involve poor communities.** This example illustrates how academia has examined ways of involving specific communities in a meaningful way. Rather than making a judgment based on economic and social indicators, researchers of the Community Health Sciences Department of the Aga Khan University (Karachi) asked the poor to define what constitutes poverty, in order to create the opportunity for the community to identify health related problems that it could address together with the district health care teams.
- **Tajikistan - For community consultation - 'unlearning' the habits of the socialist system.** Under the past socialist system, the community's role was to accept the decisions taken by the central authority. Today there are many initiatives to devolve decision making to the regional and local levels, but many local authorities find it difficult to relate to the central government. International organizations have turned to communities and NGOs in building their projects, including the conduction of surveys.
- **Kenya - Bringing communities on-line as partners in providing research inputs.** The NGO, AfriAfya, works with NGOs to increase communities' involvement and access to health information. It gives NGOs working at the district level and community groups access to health data through information systems. This access allows communities to identify and address problems and see morbidity and mortality data, on a monthly basis. The advantage of involving the community in the data collection is that non-health service data, i.e. on home deliveries, are also recorded.

- **Europe-US - ‘Science shops’ to increase demand for community-level information.** A Science Shop is a small resource center that does research on a wide range of disciplines - usually free of charge - on behalf of citizens and local civil society. This approach is different from other knowledge transfer mechanisms as it responds directly to civil society’s needs for expertise and knowledge. It is often directly linked with civil society groups as partners and customers.
- **Cambodia - Research done by community members- the example of sex workers.** Much research has been done on the plight of sex workers and intravenous drug user populations. Most of these researcher-initiated activities assume wrongly that the primary concerns are HIV or Hepatitis. These communities mostly value safe working and living environments and the respect of service providers and local authorities. In this case, sex workers designed a study themselves and also conducted stakeholder interviews.
- **Bolivia - Understanding local cultural values helps prevent Chagas disease.** PROCOSI, a Bolivian NGO, describes the delicate task of fighting Chagas disease, a major national health problem. The Chagas vector is seen as a good luck omen in rural areas. So a top-down public health campaign to eradicate it has little chance of gaining public support. PROCOSI involved communities in the problem solving process, resulting in a shared perception of the problem and how each household can solve it.

The expert group noted that: *good health research is done with the community, community research is good research, and research projects that value the importance of community engagement should be promoted.* The discussions of the case studies highlighted some important strategies that can be applied to strengthen community engagement in health research, focusing on forming alliances and developing capacity. However, it also became clear that today there is not sufficient expertise and knowledge to take action in supporting community engagement in national health research and national health research systems in developing countries. There is experience available from developed nations, but this can not automatically be translated to developing countries, as the supporting systems (for example: organized civil society, press freedom, democracy) are often not sufficiently developed to support community engagement in health research. A better understanding is needed of existing practices and approaches in developing countries, and of values and principles that support community action.

A framework or approach is needed to enable countries to respond appropriately to the needs of their populations, and to better understand the importance of communities' roles in needs assessment and priority setting for health research. The central questions to be addressed include: who is influencing the research agenda and how can communities play a meaningful role in this?; and how can research be more responsive to the needs of the community? As a next step COHRED is preparing an extensive review of literature and of existing experience from projects and partners.

The learning exchange will in the meantime continue and engage more interested players in 2006. It is expected that this learning spiral will result in ideas for approaches that can be used by various stakeholders to enhance community engagement in health research. **Communities Matter! learning spiral** www.cohred.org/communities

The planned outcomes of this process are: the creation of an approach and examples to guide communities, community based organizations, researchers, development professionals and government officials on how to influence national health research agendas from the local perspective.

1. Introduction and background

In the health research triangle of researchers, policy makers and users/communities, the latter is often mentioned, but it is not well understood how these groups of people can have an impact on research for health. 'Community participation in research' is often seen as how community members should be made partners in research projects. What is not considered is how the power of communities to focus national research agendas on national priorities can be harnessed and how communities can better enhance the use and impact of health research. There are good examples of local interests influencing research agendas in the US and Europe³, but few, if any, in the south. The initiative started by COHRED and experts from South Asia, Latin America, Africa, Europe and the United States, focuses on improving the understanding of how 'communities can matter' in setting national research agendas and in national health research.

In September 2005, COHRED organized a consultation on "Communities matter", which took place in Mumbai (India), and involved 15 participants from several regions of the world. The consultation, of which this paper provides a record, reviewed case studies of successes and failures of community and civil society engagement, participation and action in health research. The group discussion focused on opportunities and obstacles for communities to engage in health research. It analyzed strategies that can be applied to increase a community's voice in health research, and looked at the concepts, definitions and frameworks that can be used for promoting, advocating and supporting community engagement in health research.

The issues raised include the need to redefine research in the community context (what research is useful where and for what? who decides? who benefits?); understanding how community engagement can work at a national level (in developing health research policies, setting the national health research agenda, determining how community engagement can be mainstreamed into national health research); the importance of research methods (developing ownership and credibility through the methods chosen); understanding the environment, and developing guidelines or frameworks (specific reference was made to the human rights framework, and to equity).

³ See for example publications by Oliver et al (analysing examples from the UK) and O'Fallon et al (examining environmental health research in the US):

Oliver, S., L. Clarke-Jones, et al. (2004). Involving consumers in research and development agenda setting for the NHS: developing an evidence-based approach. *Health Technol Assess* 8(15): 1-148, III-IV.

O'Fallon, L. R., G. M. Wolfle, et al. (2003). Strategies for setting a national research agenda that is responsive to community needs. *Environ Health Perspect* 111(16): 1855-60.

2. Setting the scene: concepts and definitions

Community participation in health has been a major policy theme since the 1970s and was a fundamental principle of the Alma Ata Declaration on Primary Health Care of 1978. Community participation has also been a guiding principle in the Essential National Health Research (ENHR) Strategy. In the late 1990s, the COHRED Working Group on Community Participation in ENHR worked on further developing the concept of community participation in national health research and concluded that ‘in the next decade of health research for development, it may be most fruitful to think of community-researchers relations as coalitions for defining problems and learning how to solve them’⁴. The concepts in this paper build on this past work, and on the experience of the professionals participating in an expert consultation convened by COHRED in 2005, with the aim of bringing to life the concept of community engagement in research for health.

The ultimate test of any research or intervention is the extent to which it has made a difference in the lives of those who it is designed to benefit. Findings from good research do not necessarily result in improvements of the services delivered to the community, or in health policies that have a positive effect on population health. It should not be assumed that there is a sound relationship between research, policies and programmes, or that those in power are committed to the wellbeing of the populations at large. In the developing country context the challenges of research include weak research capacity, weak policy-making processes, weak capacity to absorb and make optimal use of research, and a social and political context not conducive to the meaningful involvement of all stakeholders in research.

To gain a clearer picture of what can be done to enhance community engagement in health research, a framework or approach is needed to enable countries to respond to the needs of their populations. Such a framework will help them better understand the importance of communities' roles in assessing needs and setting priorities for the country's health research. Questions that need to be addressed include: who is influencing the research agenda, how can communities play a meaningful role in setting research priorities, and how can research be more responsive to the needs of the community?

The expert group questioned the motivation of groups of concerned professionals in social activism, health care and anthropology coming together with the idea of increasing community engagement in shaping health research. Assuming that such a group's intentions are genuine, questions to be considered include: what do we mean by community? Who defines what a community is and who can represent the people? Who should participate and why? Who decides what a community 'needs'? Once they have defined themselves and made their voice heard, should communities concern themselves with the definition of a country's health research strategies?

2.1 Defining the community

What is a community, who defines one, and what does community 'participation' mean?

A community is a group of people that shares a common interest, or has a common need - perhaps cultural, political, social, health, or economic. A community can also be the inhabitants of a certain geographic area - a neighborhood, people living in the same street or same village. Too often 'community' is seen as a target group by researchers, implementers of health projects or policy makers. While attaching a specific label or description to a community may be difficult, it is useful for research activities to name the group. A useful approach is to let communities define themselves. In a livelihoods

⁴ Susan Reynolds Whyte (2000). Community Participation in Essential National Health Research. COHRED, Geneva, 2000

programme in Pakistan, poor communities - not social workers - have defined what poverty is and who the poor are.

2.2 From co-option to collective action: what is participation?

Once 'community' is defined, various levels of participation of the community can be considered⁵:

- Co-option and compliance - people participate by being dutiful subjects of research.
- Consultation - the community is invited to present the people's perspective on matters of interest to researchers.
- Cooperation - members of the community are involved in planning and execution of research.
- Co-learning - the community acquires new knowledge and skills from the research.
- Collective action - together the researchers and community, as well as policy makers, take action to bring about change.

The first level (co-option and compliance) cannot be described as participation. These community participants are the subjects of research. The following four levels indicate an increasing degree of control by the community. They illustrate people taking charge of their own situations. True participation - or engagement - of communities in matters that affect them has a more equitable and rights-based focus.

2.3 Who is the policy maker?

If communities, then, are to influence policy that affects them, the elusive 'policy maker' mentioned throughout development and research literature, must also be more precisely described. Is it the local, regional or national politicians, or people with other kinds of power in society and community?

Who is the community precisely trying to influence through its involvement in research? The ultimate goal might be to change legislation or increase spending in a specific area. Influencing the health minister is a worthy goal. But addressing local council representatives, the mayor or the members of a specific committee concerned with the issue at hand is more likely to gain recognition - and a reaction.

2.4 Who are the researchers?

Equally, the type of research that a group of people might usefully do, feed into or call for needs to be clarified. In this context 'research' might be providing health statistics - incidence of disease, mortality, or data on access to services - from village level to local authorities or community-based organizations. Or it may mean learning together with technical specialists, to understand processes of analysis and decision making and gain the skills needed to conduct analyses. Participating in the translation of these findings into action points that improve the situation for the affected groups, should be a key aspect of community engagement.

Obstacles to community engagement in the people-research-policy cycle include the linkage to researchers. It should not be assumed that researchers are naturally interested in working with communities and their members, or that they see this as an important link for their work. Likewise, researchers need to be motivated to acquire skills of translating

⁵ Cornwall, A. (1996). Towards Participatory Practice: Participatory Rural Appraisal (PRA) and the Participatory Process. In: de Koning K. & Martins M. (Eds)

research for policy makers and using it to convince various audiences. Politics also pose a threat: communities active in authoritarian political situations are at risk, as their action could attract violent reactions from totalitarian authorities.

But there are signs that research actors are taking note of the community perspective. Master of Public Health curricula have an increased community health focus. Likewise, some policy circles chart the potentially high political cost of ignoring communities in specific decision-making processes. Again, this varies from country to country with developing countries usually in need of the most improvement.

3. Case studies

The participants in the consultation brought a rich variety of experiences to the meeting. This section of the report highlights these experiences.

3.1 Community Working Group on Health (CWGH), Zimbabwe⁶

In Zimbabwe, the government sees NGOs as obstacles rather than partners, making daily operation difficult. The CWGH started as an education project in 1998. It conducted education workshops, helped community groups identify issues for action and engaged with policy makers on their concerns. These community groups faced serious problems with the political environment. Often good work was discarded because of the lack of sophistication of the community groups in presenting their information in their attempts of dialogue with policy makers. CWGH started training community groups in basic research skills. This approach proved to be useful in putting accurate figures on the table, some of which caused the government to react, with comment or its own figures. By becoming recognized as a provider of useful and accurate information, one such group, the Zimbabwe Network for Women, has now become very powerful, systematically sharing the information it collects with authorities and the media. In some cases the government has conducted counter-research in response to the information and questions from the community.

One factor that contributes to the success of this approach is the high education level of network members. CWGH now comprises about 25 member organizations, which function as a link between the authorities and the community groups, and train local actors in basic research.

3.2 Environmental health concerns in India leading to demand driven research⁷

The Centre for Science and Environment (CSE) is an independent, public interest organization, which aims to increase awareness on issues relating to science, technology, environment and development. For more than two decades, CSE has been leading the search for solutions to environmental challenges, which communities can implement themselves. It has been pushing the government to create frameworks for communities to act on their own.

⁶ Contribution by Itai Rusike

⁷ Contribution by Vibha Varshney

In an effort to help investigate issues of public health, CSE set up the Pollution Monitoring Laboratory in the year 2000. One of the first studies carried out was from the state of Kerala in south India. A doctor in Padre village in Kasaragod district of Kerala observed that children in the area were suffering from several disorders of the central nervous system. The incidence of these diseases (mental retardation, cerebral palsy and hormonal disorders to name some) had been increasing in the last few years. After discussions with the community, he linked the diseases to the use of pesticides in the cashew nut plantations. The major pesticide in use was endosulfan. As this was sprayed aerially, the air, water and food was getting contaminated and the community living around the plantation showed signs of endosulfan poisoning. Another key player in this story is a journalist who helped summarize what was happening in simple terms in the local press and for the project.

To fight the use of the pesticide, the people formed an Endosulfan Spray Protest Action Committee. Among other activities, the committee disseminated information about possible linkage in the villages of the affected region. The group managed to get a stay order on spraying of endosulfan from the court but they lacked hard scientific evidence to get it banned. CSE laboratory stepped in here. Tests were carried out and results showed that each resident of Padre whose blood sample was tested has endosulfan residues several hundred times the residue limit for water (the limit for the acceptable levels of the pesticide in the blood are not set). This strengthened the case for the community, that organized itself to present its case in court. Following the court case, the pesticide has been banned in the state.

In another case, an NGO from Punjab in north of India approached CSE to find out the reason for the high incidence of cancer in the cotton growing regions of the state. The farmers in this area use a variety of pesticides to protect the crop from bollworm. An analysis of blood samples showed a presence of a cocktail of pesticides. This points to a need for a system for regular monitoring of pesticides in human bodies for the whole country and a policy to protect the people from this kind of trespass. These cases provide an impetus for even bigger change: a revamp of the pesticide regulations in the country.

These incidents highlight that communities have a very important role in monitoring the health status of a region and help researchers identify possible research areas. The data generated from studies must be used for informing people of risks. Public pressure then helps translate protest into policy.

3.3 An academic approach to community engagement from Pakistan⁸

An example from Pakistan, illustrates how academia have examined ways of how to work with community in a meaningful way. Researchers of the Community Health Sciences Department of the Aga Khan University (Karachi) looked at how the poor describe poverty, in order to identify priorities for action. The purpose of the study was to try to develop benchmarks of fairness in health care and to try to develop this together with the district health care teams and the village people.

The mechanism used to develop partnerships was to find out first which disparities the community wanted to reduce. Some communities have been living with a problem for years, and may not identify it as a problem. It was felt to be important to create the opportunity for the community to start identifying such issues as health related problems.

Researchers need to be given the space for engaging the community. Often this process is not seen as part of the research per se. In the Pakistan case, space was created by the university, emphasizing the need for focusing on primary health care and system development. Research methodology is also a key issue - especially the building of capacity to analyze and report on qualitative data. The research-community partnership enhances

⁸ Contribution by Kausar Khan

the capacity to take health issues forward, and gives opportunity to build up the social capital of people.

3.4 Tajikistan - the need to take a long-term historical perspective⁹

Tajikistan used to have health services 'for all'. The end of the USSR era and the establishment of new independent States, had a negative impact on these health services, their accessibility and quality. Health sector reforms were needed, but these have also impacted on the 'services for all' concept. Tajikistan had a top-down administrative system, with no history of community involvement, but rather acceptance by the community of authority.

The definitions used in the health sector reforms were being imposed on the people from outside. Change is difficult to implement because of the existing vertical system. Decentralisation projects are implemented, but the local administrative levels find it hard to relate to central government level. Many international organizations working in Tajikistan do this through work with the communities. Research capacity in the country is very weak though, and mostly biomedical, the question then comes up that even if the community is involved in setting the research agenda - what would actually happen with this?

This example raises the question of the role of the state. How does a state fulfill its responsibility of providing health care and ensuring the health of the population? Probably only few states implement their health reforms using active community participation. But this does not mean that states should not be challenged in this. The Tajik example illustrates the need to take a long term, historical, perspective, as this can help understand the community perspectives and attitudes and may help identify ways of ensuring involvement in a useful way.

3.5 The People's Science Movement, Kerala: an example of changing values and approaches to community engagement¹⁰

The people's Science Movement, Kerala Sastra Sahitya Parishad (KSSP), was started in the Indian State of Kerala in the 1960s. It was founded by scientists who wanted to popularize science and create a scientific temper among the people. They believed that the unscientific practices existing in communities' should be changed, and that this could be done by creating a scientific attitude in the population, by translating scientific literature into local language and distributing them to the people.

The movement started street theatre in 1980, which became very popular resulting in an increase of membership to over 70,000. There was one unit (10-15 people from a cross section of the population) in almost all the villages of the State. The Movement objected a hydroelectric power project in order to protect the Silent Valley rain forest. Left and right wing policy makers opposed the Movement on this issue, as it was seen as blocking the development of the state. The Movement was able to influence the research agenda particularly in the field of health as much of the health research in Kerala was done by members of the movement (an active member became vice chancellor of the Kerala University). Many school teachers became members, and the Movement was awarded the prestigious King Sejong Literacy award by the UNESCO for making one of the districts of Kerala fully literate.

⁹ Contribution by Mouazamma Djamalova and Zarina Iskhakova

¹⁰ Contribution by KR Thankappan

The People's Science Movement started with providing information to the community from outside. This needs to be done very carefully so as not to destroy the cultural values of the community by imposing outside views. A way must be found to bring scientific views and cultural values together. This also relates to the concept of participation. Outsiders must respect communities' values, be ready to share their views and possibly disagree, and treat them as equals.

3.6 Kenya - Community engagement for better health information¹¹

The Kenyan organization, AfriAfya, works with NGOs to increase communities' access to health information, using information and communications technology. It has helped set up a system that provides NGOs at district level, and community groups with the opportunity to access health data. Using this information they can also identify specific problems and initiate corrective action. The system builds on the provision of morbidity and mortality data, on a monthly basis, by the community. The advantage of involving the community in data collection is that non-health service data - such as home deliveries - are also recorded. In providing this information to the district, health management team creates opportunities for discussion on key health problems and priority areas. The dissemination of local information also helps sensitize people on HIV/AIDS. The main incentive for the community to get involved is that they can see that the data collection can actually help identify health problems and contribute to addressing them.

The big challenge of this approach is the development of partnerships with the health care workers. There is competition between health care workers and NGOs. The provision of data on the real health situation in a community or district (which is often worse than recorded in official statistics) may also be perceived as a threat by the health care workers, as their responsibility is to enhance population health in their community. Attention, time, and outside support, is needed to develop the relationship and partnership. Conflicts should not be ignored, and researchers have a big responsibility to ensure that they do not fragment a society. With some NGO partners, with whom long-term working relations exist, there is trust on both sides. With others it is more difficult, as some groups can be excluded, most often women.

3.7 The Science Shop - a forum for increasing people's demand for research¹²

A number of concepts, models and examples can be a starting point for communities to become involved in the health research cycle. These activities may serve the purpose of engaging policy makers, health authorities and civil society, or of using different services and techniques to *increase the demand for community-level information and participation in the research and policy process* from the community level on specific topics.

The Science Shop is one such approach. This concept was developed in the 1980s at several European and US universities, to link research with communities and their needs (and vice versa). These small resource centers do scientific research on a wide range of disciplines - usually free of charge - on behalf of citizens and local civil society. They are different from other knowledge transfer mechanisms as they respond to civil society's needs for expertise and knowledge, and are directly linked with civil society groups and partners and customers. They are often, but not always linked to universities, where students conduct the research as part of their studies.

¹¹ Contribution by Caroline Nyamai-Kisia

¹² Contribution by Sylvia de Haan

While practical, this approach to research-society cooperation has some drawbacks from a scientific perspective. As it is informal, there is a risk that lower quality or un-validated information becomes common currency. Proper supervision and peer review mechanisms by senior researchers are needed. Maintaining adequate funding and the potential that specific donors might have on community agendas is also a concern.

These drawbacks considered, the science shop approach offers a number of significant and long term benefits that support a new health research for development process. It creates links between researchers and communities. It is a mentoring pathway between junior and senior researchers and between the research and community groups, creating a partnership between the community and the next generation of researchers. And the science shop is a unique way to bring academia in closer touch with the needs, language and interests of communities and how these link to the world of science.

As a tool for communities, the science shop concept is a practical example of how people can analyze their situations and problems and interface with researchers.

3.8 Sensitizing researchers to the real needs of community - the example of sex workers¹³

Researchers have often been lured towards investigating sex worker and intravenous drug user populations. Very little of the resultant research has been responsive to the main issues of concern to these communities. Consequently it has been of negligible benefit to them and has often produced predictable harmful consequences. So much so that such communities are now withdrawing from certain projects.

Contrary to what most outside observers think, the priority issues for sex worker and intravenous drug user communities are not HIV or Hepatitis. The primary concerns are safe working and living environments, being accorded respect by service providers, not being hounded by police and others who may exert control over their lives, and the well-being of their families. Research priorities on subjects that concern them are not established by these communities. They are created by others physically and intellectually a great distance away, from a different class and often race.

Taking a rights-based approach suggests that improvements in health status cannot be achieved unless other fundamentals are also addressed. These fundamentals, such as reasonable wages and safe living and working environments are often taken for granted - as is to be expected in the lives of researchers and research funders. But a street based sex worker might be pulled off the street by a police officer at any time, working or not, waiting at a bus stop, shopping at the market or just going for a walk. She may be charged, expected to pay money to the police and to others, go to court, and pay a fine or go to prison. If she is beaten or raped, no one will come to her assistance and there is nowhere for her to turn. She will not go to a health service, opting instead to self-treat for illnesses and injuries. There will be no recourse to a system of justice.

How might we approach the research enterprise differently? Here is an interesting example involving Cambodian sex workers.¹⁴ The principal researcher having known and worked with this community for some time advised that funds were available for research and advocacy. Sex workers were told they could choose an area to investigate and they would be trained so that they would be the ones doing the research. Sex workers selected the issue of violence. Three ex-policemen in whom they had confidence were also identified by the sex workers and recruited to assist in the conduct of the study.

¹³ Contribution by Bebe Loff

¹⁴ Carol Jenkins Cambodian sex workers conduct their own research: *Research for Sex Work* June 2005 Issue 8 pp3-4

1000 sex workers, 58 police and 2 gangsters were interviewed over a period of two months. The rate of refusal was about 5%. It is thought that most sex workers provided truthful responses. Usually the incidence of violence is under-reported. In this study 97% of sex workers reported they had been raped by someone in the past year, somewhat more often by clients and gangsters than police. Independent data derived from interviews with police supported these results. This information will be used to advocate for better conditions for these workers.

What questions arise from this example? First, there must be changes made in the way decisions are taken about what research is to be funded and the funding process itself. Secondly, it may be that the research community does not have the ability to respond to the issues of greatest concern to the community in question. Finally and most importantly, how are we to develop respectful relationships with those we are trying to assist that are founded upon adequate understanding and confidence?

3.9 Improving housing conditions in rural Bolivia to prevent Chagas disease¹⁵

PROCOSI, a Bolivian umbrella NGO, representing over 30 national and international NGOs in the country, implements with its partners many health projects through active community involvement. One of these projects is dealing with the prevention of Chagas disease, a major health problem in the country, through the improvement of housing conditions (i.e. by moving the animal quarters away from the living areas). The work is building on community organisation and participation and has reduced infections levels considerably.

The example raises interesting issues re ‘who sets the agenda’? Is this the community or the NGOs? In the case of Chagas disease the vector causing the disease was seen as a good luck omen by the community, rather than as a public health risk. It is important to understand the community, its relationships and beliefs, and to work with organisations that are already active and respected in the community. Sessions were held with the community to identify priorities and health needs and what they can do about this. Education took place on how local resources (mud, tile roof) could be used against the vector. The success of the project also raised the interest of the government, and discussion is ongoing on how to scale up the project across the country.

The government plays a role in creating a favourable environment for community involvement. In Bolivia, various health information systems, from central to local, are set up. At local level the ministry of health, health workers and mayors come together to discuss the health situation. The participation of the community in these committees has so far been low, and work is ongoing to increase their involvement and to make health data accessible and understandable. Negotiation with government remains a key issue, especially if the health issues brought forward by the community is not in line with government policies. Sometimes power balances are disrupted (i.e. women are empowered). In Bolivia the government often gives in though, and responds to the demands of the population.

¹⁵ Contribution by Erika Silva and Ricardo Batista

4. Strategies to bring a community perspective to research for health

In discussing the case studies, the expert consultation, identified a number of strategies and ideas that can be applied to strengthen the role of community in research for health.

4.1 Strategies for mainstreaming community engagement for health research

There are many gaps and obstacles to communities' involvement in shaping health research policy. They include:

- Varying levels of awareness in countries about what communities can contribute to the health research policy process.
- Recognition by communities that they have something to contribute.
- The capacity of communities to engage in the process.
- The extent to which processes are in place in countries, government bodies or development and research organizations to include input and debate with different groups and organizations.
- The degree to which research organizations and researchers see input from the local population as an important contact for this.

A key question, then, is how can community perspectives best be 'mainstreamed' in the health research process. Past work in the areas of gender mainstreaming and rights-based development programmes give examples of approaches, frameworks and models that can support communities in this quest. A focus on equity is important in any framework used. Communities have an intuitive feeling for equity, especially where it concerns their own setting or situation. They may be less conscious of their rights (the example was given of women raped by their husbands and not being aware of their rights). However, in working with the community, it is the community that should indicate the framework within which they want to work.

The goal of defining a framework is to place interaction and work with communities as a required step in specific parts of the health research process. *Entry points* for community engagement must be clearly defined, as should other *non-negotiable* elements for development and health research actors such as alliance building, documenting of a process to track and measure community engagement and document learning.

A framework will guide project and research managers on why, when and how to engage communities in their organization's activities. It will also help communities voice their needs and interests, and support their influence on research agenda setting. While there are many experiences in community engagement and agenda setting at the research project level, the challenge is how to translate this into research agenda setting at the country level. A related issue is the need to move community engagement from 'tokenism' to something meaningful and recognized (or even required!) as a component of research. How can a community be engaged in choosing research topics, and is it possible to develop a framework that supports this, by linking research to potential health outcomes?

Situating the precise role of a research effort and the level of community engagement needed depends on the context and the problem addressed, and on how one defines what is needed to change a particular situation.

A research project rating system or set of indicators will be useful to track and measure the quality of community engagement in a research activity. The Research Assessment

Exercise¹⁶ used in the UK is a useful example of how the quality of research criteria can be assessed as part of a university review system. This approach is used to make objective decisions on research funding allocations. A similar ranking could be useful to measure community engagement in research.

4.2 Forming alliances - strengthening isolated communities... and researchers

Alliances and partnerships help link communities as a recognized component of the people-health-research-policy chain and part of the agreed agenda for health research. They also help connect researchers with the community perspective.

The perception may be that communities are the *primary isolated group* in this picture. It is also a fact that researchers interested in community matters often find themselves in the vast minority in their professional setting. One colleague voiced the need to link with a peer group of researchers with an interest in community matters, as her direct colleagues generally felt this focus was irrelevant to their work.

Clarifying the outcomes desired from the partnership helps define who are the best partners to achieve the goal and the best way of working - i.e. what are the responsibilities and working relationship between partners. Community players may not be accustomed to these approaches, and may need to build their skills and receive training in the art of creating, negotiating and nurturing strong partnerships. If this is the case, then a framework needs to explicitly include partnership building skills as an organizational capacity to be measured.

Several types of partnerships benefit the healthy interaction of communities with research partners and the policy community. Communities' most common link is with civil society organizations. These NGOs can help communities find their voice and facilitate contact with key partners or the groups they want to inform and influence - such as local or regional government, health care officials, or other communities. But the NGO should act in support of the community and its needs, rather than as a social mobilizer and advocacy body that 'speaks for' or 'represents' the community's interests.

It could benefit communities to formalize or expand existing links between health workers and the community and use this relationship to feed into the research process.

Another approach that offers good potential, is the partnership between the community and a research organization. The view researchers and communities have of each other varies considerably, depending on location, culture, topic and history of the collaboration. Both the agricultural and health sectors have good examples of community engagement in research initiatives. Equally, a variety of reasons can be given that lead to a lack of contact between the two groups - or worse - a mistrust and feeling that the work of the other is not relevant or not understood¹⁷.

There may be a legitimate reason for these negative impressions. A community may have experienced a 'participatory' research activity that consisted primarily of involving the community in responding to questionnaires or collection of data for research teams (household surveys, etc.) with no explanation of the context or relevance of the work to their situation, nor ensuring appropriate communication channels during and after the research project. In the view of some researchers, the business of research is not the business of communities. Not because they see the community as unimportant, but because researchers feel that they first need to do technical and analytical work whose scope lies

¹⁶ <http://www.lums.lancs.ac.uk/Research/RAE/>

¹⁷ Abma, T. A. (2005). "Patient participation in health research: research with and for people with spinal cord injuries." *Qual Health Res* 15(10): 1310-28.

outside the interest and skills of communities. This view does not necessarily reflect top-down thinking. It could simply be the perception that both researchers and communities have a role to play in the research process, but they need not work together in areas where one party is not specialized. On their side, communities may not see the need to be engaged in research, or be aware of the process that researchers follow, and what might be the entry point for their perspective.

Choosing the right research methodology is important. Methodology matters: if it is primarily the community that should use the research results, the way in which such results are obtained is very important. The community must feel a sense of ownership, the choice of methodology can contribute to this. Community engagement in methodological choices does not mean that lower research standards and quality are acceptable. The researchers in the partnership have a role to play in ensuring good standards and quality.

Government officials are the final link in the people-to-policy chain who can be informed by the issues that communities face. Just as NGOs should not be in a role of 'mobilizing communities' but supporting and advising them, government agencies and officials should ideally be engaged in dialogue and debate with communities and researchers, rather than be the target of information pushed at them.. There are many examples of how lobbying and aggressive advocacy have forced governments to change policy. There is also much scope for building partnerships and alliances that bring government into the discussion at an early stage - with the goal of explaining how communities view a given situation, and soliciting input and opinions.

So, rather than being a linear process leading from communities 'upwards' to legislators, the ideal people-to-policy link should be a process of engaging, consulting and mutual learning between the various stakeholders - people and their community, public health workers, health researchers, and government advisers and officials - at the local, regional and national levels.

4.3 Skills and pathways to create a favorable environment

To effectively inform and influence policy or health, the need to translate knowledge into action is an imperative for both communities and researchers. The traditional view is that 'knowledge' is generated by the science community and its benefits explained to policy makers, who are encouraged to enact guidelines, rules and legislation for the betterment of society - including local communities. Taking a more progressive view, we recognize that both health researchers and communities hold specialist knowledge that can, when shared, contribute to improved health. To achieve this, both health research groups and communities

Key skills to enhance community engagement in health research

Communities and researchers

Objective: to raise awareness of community concerns among researchers at the local university.

Skills and pathways required: Ability to summarize the situation and communicate it in a way that is relevant to the researchers; to engage the researchers face-to-face in an interesting way; to negotiate with them and convince them to work with you; to clearly set out the objectives you have and why they should work with you.

Objective: To involve the local research community or civil society in giving advice and support on a specific issue faced by the community.

Pathways and skills required: Ability to summarize the situation and communicate it in a way that is relevant to them; to interest them in providing assistance, and to negotiate an agreement that is beneficial to all sides.

Community and government

Objective: to increase visibility of the community concerns among local government decision-makers.

Skills and pathways required: Ability to understand the situation of the local legislator and engage them with a message that provides a benefit to them; to negotiate and engage them personally in a way that projects credibility.

Community and civil society

Objective: To engage a civil society organization to provide support or expertise to help address an issue of concern to the community.

Skills and pathways required: Ability to engage the organization and clearly state the problem, objective and support/advice required; to negotiate present a compelling case for why the organization should help; and negotiate an agreement and manage a plan of action with specific outputs.

need to acquire skills and perspectives that can help them mainstream their work into the policy process.

The third partner, governments, are typically viewed as targets for policy shaping activities, but some are leading initiatives to involve all parts of society in decisions in health and health research. For example Bolivia's Ministry of Health has created a three-tier system for the flow of information and consultation, between the national, regional and community levels.

If communities choose to become involved in influencing the health research process, it is to have input and influence on a number of factors that affect their daily lives. To have influence requires that the community has a grasp of the problems it faces, of ideas or pathways to potential solutions, and an idea of the means it will employ to create change. Or who can help bring the skills or provide the services needed to create the change.

Changes can be affected at different levels. Does the community feel that a situation needs to be improved close to home - for example reducing water pollution from a local producer, or increasing involvement in a certain local decision process? Does it see the need to make its case at the regional or national level - for example by changing or modifying legislation that requires people to pay more for certain essential medicines for children?

Common terms used to describe these activities are: social mobilization, lobbying, advocacy, activism, community rights, policy shaping, etc. Behind these lie a set of skills that communities need to acquire, or be aware of, so they can hire or request the help of people with these skills.

On their side, researchers need to have a better grasp of what is needed to translate the results of their work into messages, activities, or products that will interest and inform policy makers as well as relevant communities.

Skills and pathways to translate research operate at different levels. Researchers need to develop skills in summarizing the results of their work for different audiences and the sensitivity to think from different users' perspectives when communicating their findings.

Research managers need to develop the skill to bring to groups of researchers the users' perspective and create mechanisms - such as guidelines, examples and processes - to bring out useful examples and lessons from research and encourage their sharing between researchers and with partners.

Forward-looking research organizations will have a strategy and develop tactics to communicate their results to different users. They will develop pathways and relationships to facilitate this exchange and they will have information and learning products and systems in place to encourage the transfer and exchange of this information. They will also have an institutional style (and perhaps

Within and between communities

Objective: to inform peers in the community and make an action plan to solve a specific problem faced by all - to explain the problem or issue.

Skills and pathways required: The ability to organize information and present it in a convincing manner to peers; to lead a consultation gathering opinions, to document the inputs and prepare them in a manner in which all members feel consulted; to lead a process of decision making and consensus so that all members feel that they own the outcome and final decisions.

Objective: to locate other communities with similar concerns and views.

Skills and pathways required: The ability to summarize the problem or issue clearly and in a way that brings out the concerns that another community will relate to; to locate and engage other communities face-to-face in a constructive and convincing manner; to negotiate and manage a plan of action with specific outputs.

Researchers and community

Objective: To engage a community for input in the preparation or execution of a research activity.

Skills and pathways required: The ability to bring together a group of people with a non-research background and gain their interest in participating; to clearly explain the input that is needed and the unique input they can give to contribute to the research; to know techniques in motivating, informing and gaining the trust of a diverse group of non-researchers. The ability to deal with conflict situations.

Researchers and policy makers

Objective: to communicate the results of a research project to a decision maker in a way that motivates them to act.

Skills and pathways required: The ability to summarize the research from the perspective of the audience; to engage with a professional partner in a convincing and business like way; to write up and draw out messages from the research, or be able to brief a specialist to do produce the right information product with the right message. Political and diplomatic sensitivity to inform and convince this audience with credibility; the ability to present convincing to a group of people.

rules!) that encourage researchers to see their role as taking research beyond the research study or paper - to explain how their research is relevant to those groups. This implies developing skills - or having advisers or other specialist resources - synthesis and messaging, interacting with the media or other groups outside the research sphere (communities, management, NGOs or government officials).

In this scenario, the skills needed for interacting with communities, then, become a part of an organization's 'research communication' skills set. Here, choosing the approach that encourages the most fruitful interactions for all partners, is a key consideration. This could involve training on how to reach consensus, running a focus group, resolving conflict in discussions.

To become credible partners in the health research cycle, both communities and researchers need to acquire skills and gain perspectives in the areas described above, or have access to others who can provide them. The scenarios (*see box examples*) summarize typical situations related to gaining influence and awareness in the health research cycle. These examples give an idea of how this can work.

Typical skills and techniques needed include the ability to engage and communicate with the media and to have some knowledge of the general environment. Key personal skills required of a research or community team are the ability to summarize a situation into key messages and to communicate clearly, through either written or face-to-face interactions.

ANNEX 1 - Briefing note circulated for consultation, including list of participants

Making health research work ... for everyone: Communities matter!

COHRED Satellite meeting, September 16&17, Mumbai, India

Introduction

The ultimate relevance test for research or interventions is the difference it makes to the lives of those whose health was the reason to invoke the research or intervention in the first place. For example, a review of ten years of research in the area of safe motherhood in some provinces in Pakistan revealed that these studies had made no difference to the lives of the vulnerable women studied.¹⁸ The Essential National Health Research (ENHR) strategy, among others, refers to three groups that should be involved in health research to enhance its impact: i) policy-makers, ii) researchers and iii) the community of civil society. Involving decision makers and communities is also essential to increase the accountability of researchers to society. One way in which to achieve meaningful community involvement is to establish 'coalitions' of stakeholders and organised civil society. In the next decade of health research for development, it may be most useful to think of community-researcher relations as coalitions for defining problems and learning how to solve them¹⁹. This applies, of course, as much to research in the 'south' as research in the 'north'.

This COHRED satellite meeting is intended to provide both a conceptual and operational framework to include communities in research as partners and not just as 'beneficiaries'. The meeting will review case studies of successes and failures of community and civil society involvement, participation and action in health research. We will attempt to extract the main issues, and also look at the specific contribution COHRED and our partners can make to respond to concerns, challenges and opportunities.

During the meeting we will address the following issues:

Community involvement, participation and action: some concepts and approaches. Not one community is the same nor is there one generally accepted definition of community involvement, participation or action. Perhaps this is a major reason why it has often been more aspirational than actual. Community involvement in health research for development was the topic of a COHRED working paper published in 2000. Since then the role of and confidence in organised civil society has grown substantially. What are current concepts to community involvement and what are some lessons learnt from the past?

Do communities matter? What is the aim of research? What guarantees the usefulness of research? And *who* guarantees its usefulness? Who judges whether or not research is 'useful'? Should the community be empowered to use research results and demand research, or is this best left to those in power? What happens in states where the politicians and decision-makers do not take up this responsibility?

Community demand for research: Research should address health needs and should be conducted in a methodologically sound manner. The role of communities in the conduct of research can vary from exclusion to active participation or even initiating research. What are good and bad practices? Can general lessons be drawn? Can and should communities demand and initiate research, or is this the responsibility and expertise of

¹⁸ Kauser Khan, Discussion paper for COHRED meeting July, 2005

¹⁹ Susan Reynolds Whyte, Community participation in ENHR, COHRED, 2000

researchers, policy makers and donor agencies? Who speaks for vulnerable groups about research on health inequities? Who will monitor the programs that are implemented to improve health of and health care delivery to the poor?

Community utilisation of research: What ultimately counts is the use of research results to improve population health. The potential for use of research results is closely linked to the sense of 'ownership' of research findings and to the process of involving of target groups in the preparation and conduct of research. Ideally, communities should be empowered to act on research outcomes and, if necessary, act as pressure groups to demand solutions and action if political will or leadership is lacking. Equity remains a key concern: how can the voices of the vulnerable, marginalised and under-represented be heard - especially where health inequity forms the basis for the conditions that are being researched?

The Objectives of the meeting include:

- This meeting aims primarily to provide an operational framework for the inclusion of communities in research as partners and not just as 'beneficiaries';
- We will review and discuss case studies of community involvement, participation and action in health research;
- In addition, we aim to identify key partners, tools, resources and competencies required to effectively enhance community involvement in national health research;
- Finally, we intend to form the nucleus of a group of partners to develop this topic further in future.

Expected outcomes:

- Proceedings, presenting case studies, lessons learnt and discussion of the session.
- A working model of and approach for COHRED on effectively increasing community involvement, participation and action in health research and in national health research systems;

Dates and Venue:

The meeting will be in Mumbai, September 16 & 17, in the Grant Hyatt hotel. The meeting times are on 16th September from 2 - 6 pm (start after the closure of the 9th Global Forum for Health Research meeting) and on 17th September from 9 am - 5 pm.

Workshop participants:

- Kausar Khan (Aga Khan University, Pakistan)
- Susan Reynolds Whyte (Institute of Anthropology, Copenhagen University, Denmark)
- Erika da Silva (PROCOSI, Bolivia)
- Ricardo Batista (Ministry of Health, Bolivia)
- KR Thankappan (Achutha Menon centre for health science studies, Chitra Tirunal institute for medical Sciences and Technology)
- Vibha Varshney (Health and Environment Unit, Centre for Science and Environment, India)
- Itai Rusike (Community Working Group on Health (CWGH), Zimbabwe)
- Bebe Loff (Monash University, Australia)
- Caroline Nyamai-Kisia (AfriAfya, Kenya)
- Mary Manandhar (National University of Ireland, Galway)
- Robin Vincent (Exchange, UK)
- Nalini Visvanathan (Harvard, USA)
- Mouazamma Djamalova (SDC, Tajikistan)
- COHRED: Carel IJsselmuiden; Martine Berger; Sylvia de Haan, Michael Devlin, Zarina Iskhakova

Meeting format:

Friday 16th September will be used to explore and discuss the general concepts and approaches around community and organised civil society engagement in health research, and to put this into the context of COHRED's focus on national health research system development. During the second day we will discuss and share experiences around community demand, utilisation and engagement for and in health research, the lessons learned, challenges faced, opportunities existing.