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Photo: Acting Against Worms/TheatreScience.

"Science and health often suffer from being taught in a rigid and formulaic way. Drama helps pupils to see a topic in a new light, which may mean more in the context of their daily lives."

Becky McCall, medical journalist and researcher for 'Acting Against Worms'

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Contents

4 What is public engagement in health research?

Siân Aggett

Health research is meaningful to the public and communities when they can understand it and engage with it.

6 Health research in Suriname: where science and indigenous knowledge meet

Daniel Peplow, Sarah Augustine and Leon Eric Wijngaarde

Indigenous communities are suffering from study fatigue. A new approach to scientific research aims to resolve this.

8 Bilharzia: why the drama?

Becky McCall

In Uganda, community members understand the problems of Bilharzia through acting and drama.

10 Casting a finer net: involving fishing communities in HIV research

William Kidega

Fishing communities take part in HIV research activities, improving communication about HIV prevention and treatment.

12 Power in communities: why does analysis matter for health research?

Gerry Mshana and Richard Walker

Engaging communities in research is an interactive process which should take power relations into account.

14 Promoting science in schools: research institutes play their part

Alun Davies, Bibi Mbete, Dickson Ole Keis and Samson Kinyanjui

Bringing health research and scientific knowledge to school children in Kenya.

16 Civil society engagement in health research: from international recognition to local action

Sylvia de Haan, Samuel Anya, Paul Bloch and Ayo Palmer

Increasingly, the public is seen as an active partner in research with more to contribute than data alone.

18 Autism: global challenges and community based solutions

Mayada Elsabbagh, Andy Shih and Eric Fombonne.

People with autism need support and respect from their family and community.

20 Equity Café: health workers in conversations that matter

Maria Elizabeth Gastal Fassa and Anaclaudia Gastal Fassa

What happened when Brazilian health workers came together to talk about their role in fostering equity in health?

22 Resources

Three agencies oversee the production and publication of Health Exchange.

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Photo: Acting Against Worms/Theatrescience



Photo: Alun Davies

Public engagement with health research

The Wellcome Trust is a global charity committed to realising the full potential of biomedical research to improve health. For over 70 years the Trust has supported research of the highest quality, with the aim of improving human and animal health – both in the United Kingdom and internationally. Activities funded internationally have included basic clinical and public health research, technology transfer, the medical humanities, and our public engagement grant schemes.

This edition of Health Exchange presents nine articles from a variety of projects that have been funded through the Trust's International Engagement grant scheme, which funds public engagement projects in low- and middle-income countries. The scheme has supported around 40 projects since its inception in 2008. It aims to build capacity for, and to stimulate dialogue about, health research and its impact on

the public, in a range of community and public contexts in low- and middle-income countries.

The sheer array of articles illustrates the wealth of mechanisms, audiences and motivations behind public engagement initiatives. The articles will take you from fishing communities by Lake Victoria in Uganda to the forests of Suriname, from drama projects with children to meetings with policy makers at the Global Ministerial Forum on Research for Health.

We introduce what we mean by public engagement with health research on the next page.

Siân Aggett, The Wellcome Trust



Photo: Vanessa Vick

What is public engagement with health research?

Biomedical science is embedded in the cultural landscape. By its very nature medical research offers great promise, yet it can challenge cultural norms and personal beliefs and choices. Without engaging with the social, political and cultural fabric in which research is conducted and its results are to be implemented, health research can easily be seen as an endeavour of outsiders, unaccountable to society, misunderstood and mistrusted. Siân Aggett shares the Wellcome Trust's work in this area.

Central to the concept of public engagement is a desire for open dialogue and debate between worlds that might not ordinarily have the channels to understand or speak to one another. Public engagement activities should bridge the research community with the general public, community groups, civil society organisations and any other groups or communities in the outside world where research gains its relevance.

In the UK, 'public engagement' has emerged as a field in its own right very recently. 'Public understanding of science' in the UK has existed since the mid-1980s, when it was felt that good research dissemination, science education and communication were vital to ensure the scientific potential of the country was achieved. It was in 2000 that there was a shift to the term 'public engagement in science', although this is not to say that activities that might fall under this umbrella did not exist before.

The change to this as the preferred term was triggered by specific incidents in the UK that eroded public confidence in health research. The first was the media scare over the measles, mumps and rubella (MMR) childhood vaccination that linked it to autism. The second was the extensively reported bovine spongiform encephalopathy (BSE) 'crisis', where there was public uproar that information had been withheld by both the UK government and the scientific community on potential risk to the health of British citizens from eating contaminated beef.

It became evident that there needed to be more dialogue between the research community, the public and those making and influencing policy. This is a shift from the idea that the public need to be 'educated' about research to a position that recognised that public attitudes towards the social and ethical issues of research and its applications could not be ignored.

Public engagement is not about getting public buy-in for a research programme or technology through lobbying or

campaigning, and it is beyond simple health promotion. It is about really starting a two-way interaction between research and the worlds of public or policy. Good public engagement should nurture a critical awareness of both information arising from research and what research is. Ultimately, it should enable more critically aware insightful decisions for all parties.

True engagement should be more than dissemination of research findings.

Good 'upstream' engagement can ensure that a variety of opinions and perspectives from outside research are articulated and help in prioritising research needs early on in the research process. True engagement should be more than dissemination of research findings. It challenges the traditional academic method of publishing in a peer-reviewed journal as a tool for making information accessible and useful to those that need it. In one article about Maroon forest communities in Suriname, community members are helped to set their own research questions, conduct a process of enquiry and communicate their findings in locally appropriate ways (such as through the stories told by community elders). Participatory work of this kind challenges power differences between scientific and traditional knowledge systems and attempts to marry the two.

Public engagement must be just that: engaging. For this reason you will see a creative assortment of methods employed. In one project to combat bilharzia (schistosomiasis), a team of researchers and drama practitioners join forces and use story and narrative through drama workshops to engage young people in the science behind the parasitic disease and what it is like to live with the illness. This demonstrates how experiential learning, catalysed through the artistic process, can encourage not only the assimilation of scientific information, but also a real emotional understanding of the impact of such public health issues at an individual level. The 'Café' concept is another increasingly

popular way of promoting discussion by creating a safe and inclusive atmosphere, again addressing some of those power dynamics that can pervade conversations through traditional channels.

Public or community engagement is not necessarily a new thing in low- and middle-income countries. One of the main motivations for opening dialogue with various public groups is to ensure the ethical conduct and that the principle of beneficence (ensuring good is done to participants) is upheld within a research programme.

Why else should we push for an increase in engagement projects? Low- and middle-income countries should have the opportunity to capitalise on the economic benefits of an increasingly global industry just as much as any of the industrialised nations. For this reason alone it is important that such countries have the capacity to conduct high-quality research in their own right. Low- and middle-income countries also face specific health challenges linked with poverty and inequity towards which scientific research and innovation could offer insight and part of a solution. In 2001, the United Nations' Millennium Development Goals set out targets for addressing maternal and child health, reducing hunger, and combating the incidence of HIV and AIDS, malaria and other major diseases. These were framed as global issues, but to ensure that health research delivers what it promises to those most in need, mechanisms are needed that embrace

multiple voices and parties including business, universities, government and civil society, not forgetting the voice of the poor and marginalised.

The future of public engagement in low- and middle-income countries

Supporting public engagement outside the UK is a new endeavour for the Wellcome Trust and it is important that we take stock and reflect on the impact of what we fund. We might also ask ourselves who is best positioned to engage with the public or policy makers in given situations. Is it the researchers themselves or could it be an intermediary, perhaps someone working on a daily basis within the community? It is hoped that public engagement work will proliferate, but it is important not to do engagement for engagement's sake. We ought to ensure that engagement does not become a token activity that is an add-on to the research process but that it infuses and informs the process of scientific endeavour, that it builds capacity for high-quality research, and that it empowers people and is conducted in the most ethical manner. Ultimately, public engagement needs to know how best to inspire people about the wonders of scientific research and its application.

Siân Aggett, Public Engagement Adviser for the International Engagement Awards.
The Wellcome Trust

www.wellcome.ac.uk/Funding/Public-engagement/index.htm

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Health research in Suriname

where science and indigenous knowledge meet

Increasingly, indigenous communities are suffering from study fatigue. They are calling for an end to the traditional scientific approach to health research and management. So how can science and indigenous knowledge meet to improve health and the environment? Daniel Peplow, Sarah Augustine, and Leon Eric Wijngaarde share a new approach in Suriname which aims to resolve these differences.

Indigenous communities are pointing to the frequency with which they are over-studied in their settings. While scientists collect samples and study risk, indigenous individuals and communities are frustrated because they are not benefiting adequately from the results. They recommend that researchers recognise the effects of 'research pollution': that is reticence, despair, mistrust and non-disclosure.

In Suriname, risk assessment studies estimated the potential impacts of mercury pollution from gold mining on public and environmental health. However, few studies have actually been published and are available for use by indigenous and tribal communities to advocate for change. After decades of research, participating individuals and communities are frustrated. The results are not available for them to use, nor do they have any long-term relationships with individuals or agencies conducting the research. "People come often. They say big things, make promises, then leave. I say if you want to help, then talk to us, listen and help. Otherwise, just go away," one indigenous leader said.

Findings from public health research on the impacts of gold mining are being suppressed. This further obscures public health risks and leads to insufficient and misguided regulation. Foreign researchers and in-country collaborators are warned by politically and financially

motivated officials of 'dire consequences' if they communicate the effects from mercury contamination from gold mining.

Defenders of scientific censorship claim that a government has the right to set policy and deliver its own message in its own words. Under this system, research is highly institutionalised and is an integral part of political structures: funding agencies, universities, development programmes and policies. Research is regarded as the domain of governmentally sanctioned experts who have advanced educational qualifications and have access to highly specialised language, skills and resources.

Where can science and indigenous beliefs meet?

Various scientific research institutions have adopted ethical research guidelines that encourage indigenous and tribal communities to participate. Typically, new guidelines include checklists, emphasise full disclosure, and require written documentation of consent and support from community leaders and participants. The research follows ethical guidelines developed from mainstream 'Western' perspectives and approved by institutional review boards, yet it is generally conducted in a cross-cultural environment, and is influenced by a relationship between researchers and subjects where there is often an imbalance of power. Because of this inequity, indigenous peoples are increasingly resisting research studies that ignore their community needs and priorities.

In general, scientific communities argue against the involvement of indigenous people in research because the complexity of the issues is 'not discernible by villagers'. Indigenous communities argue that the unique cosmology of forest people, who do not see a clear-cut distinction between the sphere of nature and the sphere of

society, is not discernable to Western scientists. Scientists face a huge credibility problem with indigenous people because of this position.

Indigenous people's self-diagnosis through research

To avoid indigenous people being marginalised by the research process, a new proposal is for community-based or community participatory research to be taken to a new level; a level which mainstream researchers may consider extreme or untenable.

Indigenous communities are calling for support for research projects that are culturally appropriate, community-owned and directed. This means research that combines both scientific and traditional knowledge systems. Western science focuses on hypothesis testing through data collection and statistical analysis. Indigenous traditional knowledge is based on cumulative experience, close observation and oral knowledge communicated by elders and handed down over generations. How do you combine the two effectively?

Some communities in Suriname are experimenting with the approach. Maroon communities (tribal communities descended from African slaves that escaped from plantations in the 15th and 16th Centuries) and indigenous Wayana communities are acting as leaders to create a collaborative environmental health research project. In May 2009, Suriname Indigenous Health Fund (UW non-profit) and Stichting Wasjibon Wadeken Maria (Suriname Indigenous non-profit) assisted communities of Apetina and Anapayke to assess the risk from exposure to mercury.

These community-owned studies have one over-arching objective: to support indigenous and tribal communities who want to self-diagnose the effects of



Collecting hair samples to perform mercury analyses and determine risk from exposure to mercury from gold mining Photo: Daniel Peplow

development programmes and resource extraction projects on their community and environment. The communities universally identify four objectives:

1. To determine whether they are at risk from contamination of their food and water by waste from mining and siltation;
2. To assess the potential health impacts from mercury exposure;
3. To address the effects of neo-liberal economic development programmes and land privatisation policies on the health and well-being of their communities, and
4. To publish their findings, participate in discussion forums and be acknowledged as legitimate stakeholders by national and international government agencies.

Opponents of the approach say that a broader perspective of the issues affecting these villages is necessary. They argue that the complexity of the issues is insufficiently discernible by villagers. They claim that instead of

raising concern for environmental issues we could inadvertently cause alarm towards 'structural adjustment' (poverty reduction) programmes. When scientists argue that wise decisions can only be made by scientific experts, they are promoting one type of 'specialised knowledge'. We argue that scientific knowledge can only guide, not dictate societal decisions.

Research conducted on behalf of indigenous peoples should avoid the biases caused by Western systems for organising, classifying and storing new information, and for creating theories about the meanings of discoveries. Often, scientific opinions themselves are conflicting, and it takes time to find a consensus. It is our opinion that environmental and public health controversies in Suriname have little to do with science and everything to do with an ethical and political debate over the allocation of resources, their extraction and the effects on indigenous communities.

The community-owned and community-driven approach being applied in Suriname reframes research,

development and the solution to problems. It affirms scientists as experts and indigenous people as equals. Anyone that contributes to the over-study of indigenous communities - including funders, research institutions, researchers and community partners, corporations, military and others - can take an important first step in addressing this long-standing problem by considering this new approach.

This article was translated into the local language, Wayana, and shown to indigenous community members to get their feedback. Aptuk Noewahé, Wayana Granman (leader) from Apetina said, "We support the article and the research because you made us partners in the project and we are involved. Usually people don't discuss their work with us, not even the results of their work. We fully support the [Health Exchange] article because it is important that our problem be known by others . . ."

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Bilharzia: why the drama?



Children on the AAW drama workshop in Busia, Uganda. Photo: Acting Against Worms/Theatrescience

Bilharzia, or schistosomiasis, is a waterborne disease that causes ill-health and can kill, if left untreated. Lakeside communities, especially children, are most at risk, as they fish and play in the waters. But many community members do not take treatment. What is the best way to raise awareness? Becky McCall sheds some light on 'Acting Against Worms' in Uganda.

A young girl, Auma, lived with her family on the shores of Lake Victoria, Uganda. Auma fished, washed and played in its waters. One day, the Ministry of Health visited the village and gave the local children drug treatment for bilharzia, a debilitating worm disease common among lakeside communities. Fearing the medicine was harmful, Auma's school friend told her to refuse it. Auma became ill with bilharzia and eventually died. This sad story is being acted out by children, just like Auma, from Busiabala primary school, Uganda as part of a local health education project called Acting Against Worms (AAW).

Worm parasites, which cause bilharzia, or schistosomiasis, live part of their life-cycle in snails found in freshwater and part in humans. Lake Victoria, a 68,800 km² stretch of freshwater, supports a thriving fishing community around its shore and due to regular contact with the water, the local community has the highest prevalence of bilharzia in Uganda.

A lakeside district called Busia has one of the lowest uptake rates for annual drug treatment of bilharzia. Prevalence rates dropped by just 75 per cent compared to other parts of Uganda where it reduced by up to 90 per cent. AAW chose Busia as the Ugandan

district most likely to benefit from activities aimed at changing behaviour related to bilharzia infection and transmission.

The Schistosomiasis Control Initiative (SCI) aims to control levels of the disease through drug administration and supports the AAW project. AAW aims to provide appropriate information, education and communication to widen the knowledge and ultimately change behaviour of individuals at high risk.

The project primarily connects with school-age children, who are most at risk and are more likely than any other

group in a community to be infected. As well as swimming in the lake, many follow family tradition and fish for a living, in addition to attending school. Similarly, school children are also most prone to other parasitic and bacterial diseases such as giardiasis, cholera, typhoid and trachoma, so efforts to improve hygiene could help reduce these diseases too.

Drama workshops with schools

AAW began work in Uganda with a series of drama workshops in October 2009. Nine schools were chosen to participate in developing short plays or 'skits' based on bilharzia transmission and prevention. These were then performed at a Busia drama festival in April 2010. School children, parents and other people from the local community were invited to watch, discuss and judge the plays. Nine further schools participated as controls. They completed questionnaires and collaborated in focus group discussions, but did not receive any drama training. AAW will conduct an evaluation exercise to both learn, and hopefully expand, the project.

AAW is working with a drama production company called 'Theatrescience', which is based in the UK. Aimed at engaging new audiences with medicine and science, drama practitioners, Rebecca Gould and Jeff Teare aim to spread relevant health messages outside the immediate scientific and medical communities. Gould and Teare are helping school children in Busia to structure their stories for performance.

"Unlike a list of facts, a story leads us somewhere; it takes us on a journey and in this case the journey is incredibly important. The stories are also about their own lives and tell us about their feelings, preoccupations and hopes for the future. Sharing their stories with their communities is very important. Their mums and dads, brothers, sisters and neighbours will be able to see what they have learnt about bilharzia but also what their concerns and views are about improving the situation," said Gould.

Science and health often suffer from being taught in a rigid and formulaic way. Drama helps pupils to see a topic in a new light, which may mean more in the context of their daily lives. During a week of drama workshops in Uganda, Theatrescience encouraged the children to become less inhibited and express concepts and behaviour relating to bilharzia through mime, song, and dance. Gould explained what was happening while the children imitated people suffering from the disease by rubbing their swollen bellies, and walking with exaggerated pain. "This makes them think about how the disease might affect their bodies and make them move, so they can use this in the play. It helps them understand how to see a character in a play," she said.

Robert Mulimba leads the Ministry of Health community health work for Busia district. Whilst assisting with the drama workshops, he explained the issue of disease control in the area. "Getting treatment is one thing, but instantly stopping the way people use water [infected with bilharzia] is another. We need to keep giving information to schools and the community because we know that behaviour takes time to change. We need to discuss how people can get bilharzia and the activities that transmit the disease: so, humans defecate in the water, transferring the worms to snails, which then release more worms into the water, to infect other humans and repeat the cycle."

In Uganda, effective worm control is led by local district and sub-county leaders, health institutions and community based organisations working at the grassroots. It is a combination of all their efforts that will make the reduction of bilharzia a success.

Becky McCall

Medical journalist and researcher for Acting Against Worms. For more information about bilharzia as a disease and control please visit: <http://www.imperial.ac.uk/schisto>

Information on Theatrescience in Uganda is available at: http://www.theatrescience.org.uk/ee/index.php/projects/view/theatrescience_in/

Please also listen to the Uganda podcast http://www.theatrescience.org.uk/ee/files/podcasts/Theatrescience_Podcast_Episode_1_Uganda_Oct_09.mp3



Children on the AAW drama workshop in Busia, Uganda. Photo: Acting Against Worms/Theatrescience

The project primarily connects with school-age children, who are most at risk and are more likely than any other group in a community to be infected.

Casting a finer net

involving fishing communities in HIV research

Fishing communities in Uganda are taking part in HIV research activities that help strengthen communication about HIV prevention and treatment, and provide important lessons to researchers. William Kidega, of UVRI-IAVI HIV Vaccine Program, tells the story.

More than one million people live in the fishing communities scattered along the shores and islands of Lake Victoria. Due to their geographic isolation, low literacy levels, high mobility, general attitudes towards risk, and the near absence of a wide range of basic health services, these people are vulnerable to a variety of infectious diseases. As might be expected, they have been hit especially hard by the HIV epidemic. Early data emerging from an ongoing study conducted by the Uganda Virus Research Institute (UVRI) and funded by the European and Developing Countries Clinical Trials Partnership (EDCTP) reveal that 27.5 per cent of the population is living with HIV, compared to a national average of 6.4 per cent. Even more disturbing, incidence data which reflect on whether prevention strategies are successful in reducing the number of new infections, reveal that the fishing communities are becoming infected at a much higher rate than the general population.

UVRI has been actively engaged in research on HIV and HIV prevention for the past two decades. Its experience has underscored the importance of engaging those at highest risk of HIV infection in

prevention research and treatment programmes. The people of Uganda's Great Lakes region certainly fit that bill.

So, with funding from the Wellcome Trust UK, a UVRI team is working with the International AIDS Vaccine Initiative (IAVI), and in conjunction with the EDCTP-funded research, to field test a number of novel community engagement approaches to distribute information on HIV and sustain the interest of Lake Victoria fishing communities in HIV prevention research. This work is of particular importance to long-term HIV prevention research, especially the large scale clinical trials necessary for AIDS vaccine development.

Effective communication is obviously critical to community engagement. To help devise a successful communication strategy, the team first systematically analysed the social and behavioural patterns of the fishing communities and prevailing awareness about HIV. These studies revealed, among other things, that most people in the communities surveyed are unaware of existing HIV prevention options and, in any case, have very limited access to them. The

research also suggested a handful of potentially effective communication strategies. In particular, the team concluded that it should harness sporting events (football, pool/billiard games and boat races) and other entertainment—such as music, dance and drama—to communicate HIV information and introduce communities to prevention research. In addition, the team decided to use community dialogues and information seminars to help spread the word about prevention research and ensure the accuracy of the message.

These strategies are all now being used to reach boat builders, fishermen, sex workers, community leaders, beach management units, and restaurant and lodge workers across the area. The turnout at such events has generally been overwhelming, with most people staying from start to finish, providing many opportunities to share information on HIV prevention and related research.

The team has also worked to develop communication processes that are relevant and responsive to community needs, and deployed them to educate people about available methods of HIV prevention:



Using boat races to engage fishing communities Photo: Vanessa Vick

abstinence, effective condom use, monogamy or faithfulness, and medical male circumcision. It has, for instance, conveyed the importance of voluntary HIV counselling and testing as an entry point to prevention through the performance of songs and poems composed by artists within the community. These messages are also integrated into commentaries during sponsored soccer matches and during interludes at other sporting events.

Benefits to researchers

Team members have also learned that the information seminars and community dialogues benefit not just the community, but the researchers as well. These events give researchers a better understanding of the prevailing myths and misconceptions about HIV and HIV research, and a clearer sense of the factors that affect the health of people living in fishing communities. This understanding is critical to their ability to address community expectations and needs in the conduct of their research.

The team has learned, for example, that most fishing communities perceive themselves to be at higher risk of death from accidents

such as drowning, than from HIV. This perception contributes directly to high-risk behaviour. Conversely, given the prevalence of HIV infection, some community members simply assume that they are living with HIV—and may dispute the accuracy of test results that turn out HIV negative. For the study team, this enhanced understanding of factors influencing behaviour, attitudes and practices has been critical to the successful conduct of HIV education, the substance of HIV prevention messages and the design of HIV research.

The team has also found that its understanding of the social and behavioural characteristics of fishing communities has played a vital role in developing effective strategies for sustaining public interest in HIV prevention and research activities. It has found, for example, that conventional modes of information delivery—such as posters, brochures or flyers—tend to be ignored. HIV prevention messages, it turns out, are best delivered in relaxed settings and in entertaining ways.

The initiative has also shed light on the expectations and needs that are likely to feed into any HIV research

conducted in fishing communities. Such work cannot be efficiently conducted without ensuring access to basic health and HIV services for the community: marginalised communities asked to participate in such research often ask, “What is in it for us?” By establishing strategic partnerships with health care service providers, the team has supported the provision of such basic services and that has widened the reach of HIV prevention messages and the acceptance of HIV prevention research.

Finally, understanding the leadership hierarchy within communities is critical to the success of both public health education and HIV research efforts. Outreach teams working in such communities must recognise the importance of engaging local leaders and resource persons as entry points for outreach activities. They can play a vital role in community mobilisation and do much to ensure sustained community support. We credit the positive outcomes of our initiative in large part to the active support and ready cooperation of such people.

William Kidega, UVRI-IAVI HIV Vaccine Program
Website: www.iavi.or.ug

Power in communities

why does analysis matter for health research?

When researchers work in a community, one of the most important things they can do is to communicate with community members. Health research is most effective when community members understand and benefit from the research process. It also reduces confusion, unrealistic expectations and even resistance. Gerry Mshana and Richard Walker explain more about their approach.

What do we mean by community?

The term 'community' means different things to different people. It may refer to individuals living within a particular geographical area, or to individuals with common social, economic and political interests. When talking about community engagement, it is important to be clear about what it means. For example, does it only refer to 'ordinary', and in many cases non-literate, residents in research localities, or does it include the resident elites and professionals as well?

What do we mean by power?

Engaging communities in health research is essentially an interactive process. First, there are interactions between researchers and community members. Secondly, there are interactions between individuals, or groups of people, within communities. In all these interactions, power relations are inherent. Broadly defined, power is the production of causal effect¹. From a social perspective, it is 'a form of causation that has its effects in and through social relations'². Michel Foucault (a famous social theorist) argued that power relations are present in every aspect of social interaction³. He and other social theorists, such as Pierre Bourdieu⁴, highlighted the influential aspects of power and studied its strategies and techniques.

Research and community engagement

We researched people's attitude to stroke in urban (Dar-es-Salaam) and rural Tanzania (Hai district). Through this, and previous research and community engagement activities, we realised the importance of analysing power relations in order to come up with a meaningful community engagement strategy. The social dynamics taking place in the areas where we work made us reflect critically on the concept of community. It was evident that the community was fragmented and had different groups of people with different viewpoints of stroke. Such groups of people had 'symbolic power', such as traditional and faith healers, or real power,

such as religious and village officials. These groups had great influence on the way stroke was imagined and dealt with by other community members. They had influence through their interactions with others in the context of treatment, or social and economic support. Other residents, who had advanced education and exposure to outside life (such as retired workers) had the same kind of influence.

When talking about community engagement, it is important to be clear about what it means. For example, does it only refer to 'ordinary', and in many cases non-literate, residents in research localities, or does it include the resident elites and professionals as well?

Some residents of Hai district (not belonging to the groups described above) had relatives who were professionals (medical experts and researchers), who lived in distant towns, but visited these areas frequently during vacation. These were 'proxy' community members, because though they were not long term residents, they participated in village life through their periodic visits. Their opinion influenced the participation of their relatives in our research activities. During their visits, the 'proxy' community members demanded to see the information sheets and other study materials their relatives had received from us. Through such power dynamics, the 'proxy' community members shaped how we (as researchers) interacted with community members and also how residents participated in our activities. In other words, they were an important part of the engagement process. This is a critical point for researchers. If certain categories of community members, or the dynamics they introduce in study areas, are viewed as either 'not being part'

of the community or 'time wasters', and as such overlooked, such a move could lead to serious counter-productive consequences.

Engaging communities in health research is essentially an interactive process. First, there are interactions between researchers and community members. Secondly, there are interactions between individuals, or groups of people, within communities.

The third group of residents were those who did not possess the characteristics of the two groups described above, but they were probably the most important group, as they form the majority. These are the 'ordinary' community members and are mainly youth and women, who are often under-represented in research processes.

These complex power dynamics made us realise how central power relations are to the whole research and engagement enterprise. It made our team devise better and more appropriate strategies to make certain that the research process was not only participatory, but more democratic, by actively seeking the representation of all groups of people and their interests.

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1. Scott, J., Power. 2001, Cambridge: Polity Press.
2. Isaac, J.C., Beyond the free faces of power: A realist critique in Rethinking Power, T. Wartenberg, Editor. 1992, State University of New York Press: Albany.
3. Foucault, M., The Archaeology of Knowledge and the Discourse on Language. 1972, New York: Pantheon.
4. Bourdieu, P., Social Space and Symbolic Power. Sociological Theory, 1989. 7: p. 14-25.



Stroke patient with extended family. Photo: Gerry Mshana



Women participating in a mapping exercise about stroke services in Hai district, Tanzania. Photo: Gerry Mshana

Promoting science in schools

research institutes play their part

Research institutes, with their community of health and research professionals, hold a largely untapped potential to enrich school-science, demystify health research in the communities in which they work, and encourage future generations of scientists and health workers. Alun Davies, Bibi Mbet, Dickson Ole Keis, and Samson Kinyanjui report on a new project in Kenya to bring health research to pupils.

The KEMRI-Wellcome Trust programme (KEMRI-WTP) in Kilifi, Kenya hosts a large number of multidisciplinary researchers from Kenya, East Africa, and other countries worldwide, and is internationally renowned for its contribution to global health research. Despite this, knowledge of science and research in Kilifi district itself is limited, in part due to poor access to educational and health resources.

To address this deficiency, in September 2008 we piloted a schools engagement programme in collaboration with the District Education Office, head-teachers and science teachers of three secondary schools in Kilifi. The aim of the pilot was to determine, through experience, the best approaches for engagement between the research centre and schools, and secondly to see if the interventions would affect attitudes toward science education, KEMRI-WTP activities and health research in general, in the target schools. The interventions included:

1. Visits to KEMRI-WTP research facilities by students and teachers who engaged in interactive learning activities with scientists and health workers.

2. A student's competition, where students presented songs, dramas and presentations about health, research and science topics.

3. Scientist/health worker visits to schools to give short talks about careers and health.

4. Provision of science teaching aids, including textbooks, subscription to 'Scientific American' (www.scientificamerican.com), a laptop computer and a projector.

5. Making of a virtual tour of KEMRI-WTP centre film by students and KEMRI staff for use with broader audiences.

Initially some teachers and parents expressed concerns that students would be used as 'guinea pigs for experiments' or that the activities would not be of educational value. However, through a series of meetings in which the teachers contributed to the development of the interventions, we were able to achieve their buy-in.

Following the intervention, both students and teachers expressed a better understanding of KEMRI-WTP activities and of health research in general. Some students described challenging the rumours and misconceptions concerning research they encountered in the community.

"[Friends] said that [KEMRI's] a devil worshipping organisation. I said 'No, I have never heard of that. What I know is KEMRI does research.' Some accepted what I told them and others didn't." (Male, form 3 student)

The students' attitudes towards science also improved. They felt that seeing science being applied in day-to-day lives made them understand it better and hence they enjoyed learning it more.

"We saw carbon dioxide...in solid form which we only read in the books. It also broke the monotony of sitting in the class just reading. We saw it in real life situation whereas in class you just cram the things, not knowing what they really look like." (Female, form 2 student)

The teachers reported that learning about potential careers in research, motivated the students to work harder in science, to respond to questions more confidently and to achieve better test grades. In two schools the students became more likely to pursue biology as a subject option.

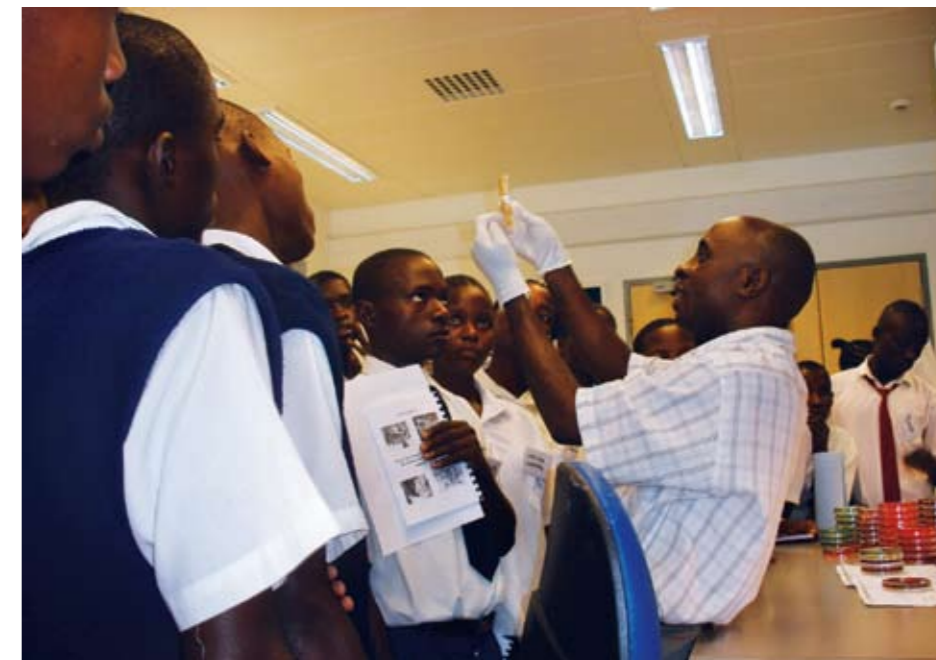
"When they came out of there, ... [students] would say 'I want to work at KEMRI and if you work at KEMRI, you will not work there if you get a D +.' ... They have now gotten the urge to work hard in sciences." (Male biology teacher)

The value of young local scientists as role models for students, and in motivating the students to believe that despite difficult circumstances it is possible to succeed in pursuing science-related careers was highlighted.

The pilot indicates that it is possible to exploit the resources available at

The students' attitudes towards science also improved. They felt that seeing science being applied in day-to-day lives made them understand it better and hence they enjoyed learning it more.

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Salim Mwarumba (microbiologist) shows students bacterial cultures Photo: Alun Davies

KEMRI-WTP to improve science education in schools in Kilifi district. As such, we plan to scale up this programme to all schools in the district over the next five years, and subsequently beyond Kilifi district. We also plan to conduct operational research during the scale-up in order to document best practice.

Although the participating scientists and teachers were very enthusiastic about continuing the collaboration, maintaining their interest, and that of future participant researchers in the long term, will be a challenge. The pilot was funded by the Wellcome Trust (UK), and further funds are being sought for implementation at district level. Support from the government through the district's education office was essential for the success of the pilot phase. We hope and anticipate that it will continue throughout the scale-up.

"I felt it was a very noble cause for the situation ... at least something is happening

that may be help the larger community, rather than our focus on participants in research." (Male participating scientist)

Taking health research and scientific knowledge and practice into schools has clear motivational and educational benefits. It also helps raise awareness about health issues and promotes positive healthy behaviour, both directly and indirectly.

Alun Davies
KEMRI-Wellcome Trust Programme, Kilifi, Kenya

Bibi Mbet
KEMRI-Wellcome Trust Programme, Kilifi, Kenya

Dickson Ole Keis
Ministry of Education, Science and Technology, Kenya

Samson Kinyanjui
KEMRI-Wellcome Trust Programme, Kilifi, Kenya

Civil society engagement in health research

from international recognition to local action: a workforce planning tool with unexpected motivational benefits

In the past the general public was seen as a subject of research. Researchers would ask people to provide information needed for their study. This attitude is changing. Increasingly, the public is seen as an active partner in the study of societal issues. They are seen to have more to contribute to research than data alone. Here's more from Sylvia de Haan (COHRED), Samuel Anya (CIAM), Paul Bloch (DBL) and Ayo Palmer (CIAM).

In recent years, the public's role in research is receiving increasing political attention and recognition. In 2008, the Final Declaration of the Global Ministerial Forum on Research for Health, called upon all partners and stakeholders: "To ensure civil society and community participation in the entire research process, from priority setting to the implementation and evaluation of policies, programmes, and interventions; and to support civil society in advocacy to key decision-makers, including politicians, for increased investment in and commitment to research for health"¹. In support of this statement, the Forum adopted a Call for Civil Society Engagement in Research for Health². This was tabled by 20 civil society representatives.

This international political support is based on evidence that the public makes valuable contributions to health research. Often these contributions happen through civil society organisations. Their involvement varies from influencing specific health programmes and health policies to attempting to influence national policies for research. Examples from India, Bolivia and the United States illustrate this.

In the state of Kerala (India), a local health professional noticed increased health problems in his community that he related to exposure to endosulfan, a pesticide sprayed aerially on cashew nut plantations. The Centre for Science and Environment (CSE), an Indian civil society organisation, collected the

evidence that endosulfan levels in the blood of the population in a village in Kerala were far above acceptable limits. Armed with this information, the affected community went to court and secured a ban on the use of the pesticide in the state³.

In Bolivia, an NGO named El Programa de Coordinación en Salud Integral (PROCOSI), works to improve housing conditions as a measure to prevent Chagas disease. The bug which transmits the disease-causing parasite was seen as a good luck omen by the community, rather than as a public health risk. Community based research carried out by PROCOSI brought this situation to light. Together with community groups, priorities were set and suggested practices for reducing the impact of Chagas in affected communities were discussed. This was combined with education on the use of local resources (i.e. a tiled roof) in the fight against the vector³.

In the US, the NGO Research!America, works to increase funding for health research and to motivate and empower the public to support and call for research in areas where more attention is needed. Research!America successfully lobbied for an increase in the government's national research budget. Findings from some of Research!America's surveys illustrate the supportive attitude of Americans towards health research. For example: 67 per cent of those surveyed are willing to pay \$1.0 more per week in

taxes for additional medical research, and 95 per cent indicated that it is important to conduct health research to understand and eliminate health differences within the population⁴.

Inspired by these and other practical examples, the Call for Civil Society Engagement in Research for Health identifies strategies and actions that government, academia, funding agencies and civil society organisations can apply to strengthen civil society engagement in health research (see box).

For health workers and other health professionals there are clear benefits to using research in day-to-day practice. Through their exposure to people's health problems on a daily basis, health professionals are well placed to identify knowledge gaps, and shape research questions and agendas. They can also collect and help interpret data so that results improve the quality of health services, facilitate understanding of health behaviour, and can help improve access to health services.

In a situation where health care provision takes priority over health research for many health professionals, civil society organisations are an important partner in obtaining and using the information needed to improve service delivery. A good partnership between civil society organisations and health professionals can provide health workers with better data to manage their day-to-day challenges.

Strategies for civil society engagement in research for health

Governments to:

- Develop legal and policy directions that specify citizen's rights to have a say in research;
- Coordinate the other actors in research, facilitate partnership building, and
- Facilitate inclusive agenda setting for research and encourage civil society participation in this process.

Research institutions to:

- Adjust institutional policies to facilitate civil society engagement within their research programmes;
- Provide training for researchers and civil society partners;
- Develop clear partnership arrangements, and
- Play a key role in developing the research agenda, and work with civil society in this process.

Funding institutions and development agencies to:

- Provide planning grants, training grants, and long term funding to civil society partners, and
- Set funding criteria that ensure a focus on collaboration with civil society for part of their funding schemes.

Civil society organisations to:

- Develop networks of civil society organisations to create a stronger voice to influence policies, strategies and agendas of other actors;
- Engage with media to disseminate information to the public about the benefits of research;
- Highlight priorities and real needs of populations, and use this to contribute and influence the agenda setting process, and
- Identify their own capacity building needs and ensure staff training where needed.



An endosulphan poisoning victim in Padre village, Kerala. Photo: Sopan Joshi/CSE

Sylvia de Haan (COHRED - Council on Health Research for Development, Switzerland)
Samuel Anya (CIAM - Public Health Research and Development Centre, The Gambia)
Paul Bloch (DBL - Centre for Health Research and Development, Denmark)
Ayo Palmer (CIAM - Public Health Research and Development Centre, The Gambia)

¹ The Bamako Call to Action on Research for Health. Strengthening research for health, development, and equity. From the Global Ministerial Forum on Research for Health; Bamako, Mali, 17-19 November 2008 [annex]. Geneva: WHO. (2009) [http://apps.who.int/gb/ebwha/pdf_files/EB124/B124_12Add2-en.pdf]

² A Call for Civil Society Engagement in Research for Health. Towards a Post-Bamako Action Plan. Input to the Global Ministerial Forum on Research for Health, Bamako. (2008) [<http://www.cohred.org/sites/default/files/CSOEngagement/CallForCSOEngagementFinal.pdf>]

³ Council on Health Research for Development [COHRED]. (2006). Can communities influence national health research agendas? (Record Series Paper 3). Geneva: COHRED [<http://www.cohred.ch/sites/default/files/rp3.pdf>]

⁴ Woolley, M., & Propst, S.M. (2005). Public attitudes and perceptions about health-related research. JAMA. 294(11), 1380-1384 [<http://jama.ama-assn.org/cgi/content/abstract/294/11/1380>]

Autism

global challenges and community based solutions

Autism is a life-long condition interfering with a person's ability to communicate and relate to others. From data collected in several countries, a form of autism affects up to one in 100 individuals. Mayada Elsabbagh, Andy Shih, and Eric Fombonne discuss what steps are appropriate at community level.



Baby Violetta and her family are participating in the British Autism Study of Infant Siblings. Their family believes that research discoveries can in the future help others affected by the condition around the world. Photo: Leslie Tucker

What is autism?

Autism is a spectrum of conditions that affect a person's social skills and communication. As early as three years of age, some children with autism have unusual eye contact and are less likely to share attention or interest with others through pointing, smiling, or appropriate language. Some children display stereotyped and repetitive behaviours and may be overly sensitive to sounds or other forms of stimulation. Those who are mildly affected often have no apparent intellectual or verbal difficulties, but still struggle with interpreting others' expressions or understanding their intentions.

Despite being defined on the basis of behavioural symptoms, autism is a biological condition giving rise to changes in brain development and functioning. Raising awareness about this 'hidden' disability is challenging because it is not associated with clear physical symptoms. As a consequence, behavioural symptoms are likely to be missed in primary health care settings. Most families experience a significant delay between the time they become concerned about their children and the time of diagnosis.

The impact varies greatly from one person to another. Some people are able to lead independent and

fulfilling lives, but the impact for others can be disabling. While there is no cure, strategies focused on improving quality of life are necessary. Autism seems to present similarly across cultures and contexts, yet we still know very little about the burden of autism in different communities and countries around the world.

Scientific understanding of autism has dramatically changed in the last decades and continues to change rapidly. Global public awareness of the condition has also increased significantly. However, there is still a wide gap between public awareness and the extent to which

available services are validated scientifically. The gap appears wider in developing countries where research capacity is limited and health professionals and the public have little or no contact with research.

Where significant progress has been made at community level in different countries, three complementary approaches have undoubtedly brought about positive change in improving quality of life for families affected by autism. These are bridging the gap between evidence and practice, community awareness, and partnerships among various stakeholders.

Bridging the wide gap between evidence and practice

Less than 30 years ago, an influential theory posited that so-called 'refrigerator mothers', described as cold, distant and rejecting, were to blame for causing autism in their children. In most of North America and Europe, psychoanalytic therapy for the mothers and placing their children in institutions formed standard clinical practice. Now, advances in research have contributed to a striking shift in acknowledging that autism is a biological condition, and there is consensus that autism is a result of interactions among genetic and environmental factors.

Autism may be difficult to identify for those with limited experience and in some communities relevant information is not always accessible or accurate. Yet, understanding the condition is vital because it enables families and practitioners to provide a supportive environment, helping people with autism to cope and giving them opportunities for interaction and learning. Because autism affects people differently, interventions need to be individually customised, but there are some general principles such

as providing structure and predictability in the environment, fostering independence and new skills, and engaging the family.

People with autism are often able to reach their full potential when they are treated with dignity and respect and supported by their family and community.

Promoting awareness within the community

Communities who combat stigma and misconceptions against disabled people benefit from their skills and competencies instead of marginalising them as a burden to society. People with autism are often able to reach their full potential when they are treated with dignity and respect and supported by their family and community. In most communities where improvements have taken place, it was the families of those affected who spearheaded changes in policy and practice through tireless activism, fundraising, and lobbying.

Promoting awareness about autism encourages families to seek help from health practitioners if they are concerned about their children, and to access available services or support groups. It also encourages health workers to take parental concerns seriously and help families to distinguish symptoms of autism from general developmental difficulties, some of which may be short-lived. More targeted awareness activities among health and education workers are essential in communities where service development is still under way. This would prevent a situation where concerns are inadvertently raised in peoples' minds without providing them with concrete solutions.

Partnerships

Organised grassroots efforts led by families have provided impetus and drive for change. Family support and advocacy groups in some countries have flourished into large-scale national organisations that continue to effect real and positive change. Similar grassroots efforts are increasingly visible in low- and middle-income countries. The success of the groups rests on their ability to engage a wide range of stakeholders and reach out to the public at large.

Priorities in research, policy, health services, education, vocational training and family support, are all essential components in the process of supporting individuals with autism throughout their lives. Coordination and partnerships guarantee their overall success. Collaboration among government agencies and advocacy and professional organisations enhances feasibility and long-term sustainability of such partnerships.

International partnerships are also growing in the area of autism. These partnerships are essential for translating evidence into practice and allowing different communities to learn from each other. Forming strategic partnerships among countries with different cultures, levels of expertise, and existing service infrastructure is critical for achieving this goal.

Mayada Elsabbagh, Birkbeck, University of London, UK & Montreal Children's Hospital, Canada

Andy Shih, Autism Speaks, United States

Eric Fombonne, Montreal Children's Hospital, Canada

www.worldautismawarenessday.org
www.autismspeaks.org

Equity Café

health workers in conversations that matter

Citizen participation in health is one of the fundamental parts of the Brazilian health system. When Brazilian health workers came together in the Equity Café to talk about ‘What is the role of public health workers in fostering equity in health?’, the conversation required an analysis of the Brazilian health system and its strengths, the difficulties of fostering equity, and why citizen participation matters. Maria Elizabeth Gastal Fassa, and Anaclaudia Gastal Fassa, from the Federal University of Pelotas report on some recent events.

Why public engagement?

The WHO's Commission on Social Determinants of Health calls for the health gap between the poorest and the richest to be closed in one generation. Leadership, community involvement, local focus and good data to inform decisions are important to promote equity in health. To close the health gap we should start action now. The IX Brazilian Congress on Collective Health, in November 2009, gathered 6,000 health professionals. It was a great opportunity to host an Equity Café which aimed to spread public engagement and promote ideas about equity among health professionals. The participants were encouraged to take these ideas to their professional environments and communities, reaching the farthest points of Brazil.

What is the Equity Café?

The Equity Café gathered 167 participants, in a café scenario: tables covered with white paper and coloured pens available for annotating ideas, flowers on the tables, background music, appetizers and coffee. We invited the participants to have a friendly conversation on the question, ‘What

is the role of public health workers in fostering equity in health?’

The presence of just four participants at each table allowed every person, including those more shy, to talk and to be listened to freely. After twenty minutes, one person stayed as a host at each table, while the other three people changed to other tables, as ambassadors, taking the collective ideas built at the previous table's conversation and cross-pollinating ideas. After three rounds, we held a plenary session, gathering all participants to summarise and intertwine the conversations.

Health care is viewed as a political field and a tool to change the reality and promote equity.

Equity and equality

The group identified the difference between equity and equality. Equity in health means providing health care according to each person's needs, respecting the individual's values and choices, respecting singularity and also

viewing healthcare in a holistic way. Most importantly, equity refers to citizenship, rights, duties and responsibility. More than access to health care, it refers to access to knowledge and information.

Health care is viewed as a political field and a tool to change the reality and promote equity.

The Brazilian public health system (SUS)

The Brazilian public health system, ‘Sistema Único de Saúde’ (SUS) is one of the most important Brazilian reforms of the past two decades. It is strong, spread all over the country and involves a great number of professionals. Thus, when talking about the role of collective health in fostering equity, participants talked about the structure, functioning and troubles of this system.

The participants approved the SUS model as a political proposal, but pointed to the distance between the proposal and practice. Some comments health professionals made were; ‘SUS is good written on paper, but in practice there is no equity.’ ‘In theory everything is wonderful, but when it gets to the practice...’ Their dream is to turn



Health workers in conversation at the Equity Café. Photo: Federal University of Pelotas

Undergraduate and graduate health programmes should promote the interchange of ideas about how to foster equity, develop social awareness, leadership and the ability to deal with differences. Professionals should enable the development of citizen participation and awareness about rights, duties and social responsibility.

the proposal into reality, fulfilling fundamental principles of universal and equitable access to health care and information, and at the same time fostering citizen participation.

A really good care for all

In Brazil, complex care such as organ transplants or cancer treatment is of high quality and almost exclusively publicly provided. The extension of primary and secondary health care coverage for everybody, independent of their income, could be a path to surpass the frontier of ‘poor health care for poor people’.

Citizen participation is seen as the path to reach universal and full access to health care, as well as to guarantee resources. However, participation is the weakest part of the system. This is related to problems with education and the population's lack of knowledge about the public health system, which means people are less likely to demand their rights.

Undergraduate and graduate health programmes should promote the interchange of ideas about how to foster equity, develop social awareness, leadership and the

ability to deal with differences. Professionals should enable the development of citizen participation and awareness about rights, duties and social responsibility. Citizenship means engaging with all health, equity and social justice issues.

Evaluation

The Equity Café evaluation by participants showed there was as much enthusiasm about learning about equity and interchange of experiences, as for the opportunity to experience the café dynamic. The event had an impact on the participant's professional activities. It made them re-think the Brazilian health system, bring the subject of equity to the academic environment and change their behaviour when delivering health services, being more careful to welcome and listen to patients. The café dynamic was replicated in eight different situations and six participants are planning more cafés.

Maria Elizabeth Gastal Fassa, Associate Researcher, Post-graduate Program in Epidemiology, Federal University of Pelotas
Anaclaudia Gastal Fassa, Associate Professor, Department of Social Medicine, Post-graduate Program in Epidemiology, Federal University of Pelotas
Report from the Equity Café
<http://www.epidemiologia-fupel.com.br/cafe/>
World Café <http://www.theworldcafe.com>

Resources

For information and websites about subjects discussed in this issue of Health Exchange, please take another look at the articles. You may also find these resources interesting.

Articles, papers, reports

Kemri schools engagement programme science cafe held at Hazz cafe, Kilifi

[Article] 2010, 4 p

This article describes an informal chat between scientists and students, over a cup of coffee and soft drinks, in Kilifi, Kenya where students from two schools had the rare opportunity of meeting face to face with scientists for answers to their questions on HIV and AIDS among the youth.

<http://www.kemri-wellcome.org/node/515>

WHO's role and responsibilities in health research

[Report]

WORLD HEALTH ORGANIZATION (WHO)

Geneva: WHO, January 2009, 6 p

This is a report on the meeting of the executive board about the 2008 Bamako call to action on health research - strengthening health, equity and research.

http://apps.who.int/gb/ebwha/pdf_files/EB124/B124_12Add2-en.pdf

A call for civil society engagement in research for health: input to the global ministerial forum on research for health

[Paper]

COUNCIL ON HEALTH RESEARCH FOR DEVELOPMENT (COHRED)

(et al) Geneva: COHRED, October 2008, 4 p

This call for action sets out a blueprint for strengthening the role of civil society organisations in research for health following the Bamako global ministerial forum on research for health.

<http://www.cohred.org/sites/default/files/CSOEngagement/CallForCSOEngagementFinal.pdf>

Can communities influence national health research agendas?

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

[Report] BATISTA, Ricardo (et al)

Geneva: Council on Health Research for Development (COHRED), 2006, 23 p. ISBN: 9292260057

This is a record of a consultation on 'Communities matter' which reviewed case studies of successes and failures of community and civil society engagement, participation and action in health research.

<http://www.cohred.ch/sites/default/files/rp3.pdf>

insights [Articles/briefing]

Eldis Brighton: Eldis,

'insights' is a thematic overview of recent policy-relevant research findings on international development which aims to make research accessible to non-academics and non-native English speakers.

<http://www.eldis.org/insights>

Toolkits

Malaria control in schools: a toolkit on effective education sector responses to malaria in Africa

[Toolkit]

BROOKER, Simon

Partnership for Child Development: London School of Hygiene and Tropical Medicine: Kenya Medical Research Institute-Wellcome Trust Research Programme: The World Bank, December 2009, 60 p

This toolkit offers practical up-to-date information and experience on the control of malaria in schools, with technical and policy advice and how to plan and implement school-based malaria interventions.

<http://www.schoolsandhealth.org/Documents/Malaria%20Toolkit%20for%20Schools%202009.pdf>

Websites

Schools & health: health, nutrition and HIV and AIDS

[Website]

Partnership for Child Development. This website contains information about research and resources on topics to ensure that children are healthy and able to learn, as an essential component of an effective education system.

<http://www.schoolsandhealth.org/>

How stuff works

[Website / Multimedia]

This website has articles, graphics and videos of easy-to-understand explanations about how the world actually works. The 15 broad topics include: communication, food, geography, health and science.

<http://www.howstuffworks.com/>

The naked scientists: science radio and naked science podcasts

[Website / Multimedia]

This is a group of physicians and researchers from Cambridge University who use radio, live lectures and the Internet to strip science down to its bare essentials and promote it to the general public and all age groups.

<http://www.thenakedscientists.com/>

Planet science [Website]

London: National Endowment for Science, Technology and the Arts (NESTA)

The aim of this website is to encourage children to learn and become enthused about science. It is organised into eight main sections, each with its own type of visitor in mind and its own content.

<http://www.planet-science.com/home.html>

SciDev.Net : Science and development network

[Website]

This website offers policymakers, researchers, the media and civil society information and a platform to explore how science and technology can reduce poverty, improve health and raise standards of living.

<http://www.scidev.net/en/>

Autism speaks [Website]

This is the website for an autism science and advocacy organisation, which funds research into the causes, prevention, treatments and a cure for autism; increases awareness and undertakes advocacy.

<http://www.autismspeaks.org/>

UVRI/IAVI HIV Vaccine program

[Website] This is the website for a collaborative partnership in Uganda, which is one of the many sites in the development of an HIV vaccine where volunteers can participate in a trial.

<http://www.iavi.or.ug/>

Schistosomiasis control initiative

[Website] London: Imperial College

This website describes the work of the Schistosomiasis control initiative, which aims to control or eliminate the seven most prevalent neglected tropical diseases from sub-Saharan Africa.

<http://www.imperial.ac.uk/schisto>

KC team: speak your world

[Website]

A collection of health and development stories from Key Correspondents (KC), and tips for writing and posting stories. KC Team is a network of more than 250 citizen journalists, from all walks of life, based in over 50 countries.

<http://healthdev.net/site/index-full.php>

Public engagement with science on the internet

[Website]

Wellcome Library

This is... "a gateway to internet resources on public engagement with science and technology and science communication."

http://library.wellcome.ac.uk/doc_WTL038907.html

Welcome to the world cafe

[Website]

This website describes the World Café - a conversational process based on a set of integrated design principles that reveal a living network pattern through which people co-evolve their collective future.

<http://www.theworldcafe.com/>

Future health systems: innovations for equity

[Website]

This is the website of the Future Health Systems consortium, which aims to ensure real health gains for the poor, through research and partnership that informs and influences the health systems of the future.

<http://www.futurehealthsystems.org>

Suriname indigenous health fund

(SIH Fund) [Website]

This is the website for a project which gives indigenous people in Suriname's interior Greenstone Belt region the materials and technical support they need to self-diagnose the effects of mercury pollution from gold-mining on their community's and their environment's health.

<http://www.sihfund.org/>

Multimedia

Uganda: acting against worms

[online audio]

MCCALL, Becky

Crickhowell, UK: The Theatre of Science, November 2009, c.10 mins

This podcast describes the 'Acting Against Worms' initiative, which works with primary schools in the Busia district of East Uganda, using educative drama to raise awareness about bilharzia.

http://www.theatrescience.org.uk/ee/files/podcasts/Theatrescience_Podcast_Episode_1_Uganda_Oct_09.mp3

Theatrescience in Uganda schistosomiasis control initiative festival, Busia 2010

[Online video]

Crickhowell, UK: The Theatre of Science, April 2010, 6 mins 18 seconds

This is a video of clips from the 'Acting Against Worms' (bilharzia) school drama festival in Busia, Eastern Uganda, in April 2010.

http://www.theatrescience.org.uk/ee/index.php/projects/view/theatre-science_in/

The crossing

[Blog]

The Social, Technological and Environmental Pathways to Sustainability (STEPS) Centre

This blog has been created to encourage debate and discussion about pathways to sustainability through research. Its work covers agriculture and food, health and disease, and water and sanitation.

<http://stepscentre-thecrossing.blogspot.com/>

Databases

Health

[Website / Database]

Brighton: Eldis

This part of the Eldis website shares resources on development, policy, practice and research in health. It includes topics covering specific diseases, health and development information resources and newsfeeds.

<http://www.eldis.org/health/>

The science communication unit: resources

[Website / Database]

Bristol: University of the West of England

This list of project materials and evaluation reports is part of the Science

Communication Unit's commitment to the dissemination of learning from best practice to the general public.

<http://www.scu.uwe.ac.uk/index.php?q=node/155>

psci-com

[Website / Database]

London: Wellcome Library and Intute. Psci-com is a gateway to evaluate, high quality Internet resources relating to public communication of science, public engagement with science, and the impact of science on society.

<http://www.intute.ac.uk/psicom/>

Compiled by Deepthi Wickremasinghe, co-ordinator **Source International Information Support Centre** www.asksource.info

Source is designed to meet the information needs of individuals and organisations working in health, disability and development worldwide. These include health workers, researchers and students, non-governmental and governmental organisations, and disabled people's organisations. With both a resource centre, based in London, and electronic databases, this is a unique collection of around 25,000 health and disability information resources. These include books, journals, manuals, reports, posters, CD-ROMs, websites and organisations. Many materials are from developing countries and include both published and unpublished literature not readily available elsewhere in the UK.

