

Community Engagement – Under the Microscope

12–15 June 2011

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The Wellcome Trust considers it vital to engage individuals and communities with science and health research.

Public engagement activities should create a bridge between the research community and the general public, community groups, civil society organisations and any other groups or communities in the outside world where research gains its relevance.

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 starting a two-way interaction between research and the worlds of public or policy.

This report is based on conversations that took place at a workshop: 'Community Engagement – Under the Microscope' in Thailand in June 2011. It was the third in a series of conferences organised by the Wellcome Trust to examine public engagement with health research. Fifty delegates attended from diverse fields including bioethics research, public health research, anthropology, community engagement practice and the arts.

The views outlined in this report are not necessarily the views of the Wellcome Trust.

The context

Science and health research does not take place in a vacuum. Scientists and scientific processes operate within specific geographical and sociopolitical environments. Scientists, patients, communities and policy makers interact with one another in varied ways and these interactions are of critical concern to anyone wanting to explore community engagement.

Community engagement can be seen as a spectrum of activities and interactions, but as this report shows, it is a slippery concept with which to work. As researchers, activists and artists, how we engage with communities about science and how communities engage with us really matters. This exchange of ideas, opinions and practice is what community engagement is all about.

The 'Under the Microscope' workshop aimed to explore the following: for all our endeavours to engage the public and specific communities with health research, what are the ethical implications of our actions? How do we know when we are doing good community engagement and for the right reasons? How do we learn from what we do and put that learning back into our practice?

Key points about community engagement

This report contains thematic sections. At the end of each section are some key points about community engagement. Here is a selection:

We use a variety of terms to describe engagement, sometimes referring to public engagement, sometimes to community engagement, and even public education.

Engagement is about 'exchange'. It is not just about providing information or disseminating ideas or results. Engagement challenges the notion of communities as 'recipients' and has the potential for community members to become politically and critically aware of scientific processes.

Communities can also drive the engagement process, holding scientists and science accountable for their ethics.

Engagement is about finding formal and informal ways to bridge the divide between two or more knowledge systems and cultures; for example, between scientists, policy makers and community members.

Power and how it operates is central to how scientists and communities engage with one another. A scientist's priority is to do the science but scientists need to assess how power and politics affect the quality of their science, and whether engagement might improve research excellence.

Executive summary

Scientists and community members engage with each other, and with policy makers, for a variety of reasons. Understanding these reasons both from your own perspective and that of other communities is important for the process.

Answering the question, ‘who is the community?’ is not always straightforward. Communities are not homogeneous and power plays out between different groups and individuals. Who represents who in communities is critical for scientists to understand to reduce bias.

Whether to engage with communities or not is an ethical question. Engagement is not a benchmark for ethics. Ethics does not stop when community engagement takes place. Engagement itself has ethical implications.

Engaging with communities in creative ways, collaborating with artists and using participatory methodologies are real options for scientists. Creative methodologies can be particularly helpful to nurture genuine expression, subvert power and catalyse discussion.

Community engagement practices need to be evidence-based. Evaluating and monitoring community engagement processes and outcomes are important. Anyone planning an evaluation should be aware of whose agenda is being promoted, and on whose terms the evaluations take place.

Three poets attended the workshop and provided daily reflections. Delegates were also inspired to write some of their own work. A selection of these poems can be read throughout this document.

In the Hotel Garden

In the hotel garden
At the back
Behind the bougainvillea
Almost hidden
There’s a box on the wall
Four by three
In the old money
Nine lights
Two dials
No switches
Low medium high
Alarm
Pump two overload

In the small hours
In the animal static
Something huge
from something tiny
An electric shriek
Does it matter how
Do we need to know
If a cricket a lizard an owl
The thing is that it’s trying
It’s electricity trying to get the
Lights to change on the box in the wall

Sometimes
nobody is there to see it
The sounds
of the shrieking
meet the voices of the kitchen hands
the monsoon rain
and the rumbling of the delegates
Attain some kind of harmony

A small brown bulb
In the corner of the box in the wall
Lights up

© David Osrin

This report is based on conversations that took place at a workshop: ‘Community Engagement – Under the Microscope’ in Thailand in June 2011.

At the opening of the ‘Under the Microscope’ event, Clare Matterson, Director of Medical Humanities and Engagement at the Wellcome Trust said: “In medicine, sociology, history, anthropology, we are looking at what makes us human. We are interested in forging new relationships, finding common language and situating it within a bigger picture. In relation to community engagement, the Wellcome Trust is a funder, participant, advocate and champion.”

The aims of the workshop were to understand and articulate the variety of motivations for community engagement and the forms that it can take. For all our endeavours to engage the public and communities with science, what are the ethical implications of our actions? How do we know when we are doing good community engagement and for the right reasons? How do we learn from what we do, and put that learning back into our practice? A multisite participatory video project fed directly into the workshop and helped frame discussions by exploring perspectives and bringing voices from different research contexts.

Delegates explored community engagement from a variety of perspectives and entered into some challenging debates about approaches, roles and responsibilities and ethics. Artists, dramatists, film makers, writers and poets shared creative methodologies to inspire new approaches to community engagement. This report documents the discussions held and creative methods used throughout the conference.

Each day, three poet delegates wrote poetry inspired by the discussions that took place. Lucinda Jarrett, Cameron Conaway and Priya Kulasagaran shared their creative expression of the previous day’s work and read their poems aloud. Three other delegates who participated in the poetry session also wrote poetry and read aloud to the other participants. Some of these poems can be found in this document.



We believe that engaging is part of scientific life. We do not believe that scientists should be all things, but research as a process needs to have things built in like art, creativity, engagement and communication. It is part of the modern interconnected world in which we live.”

Daniel Glaser, Head of Special Projects, Public Engagement at the Wellcome Trust

What is community engagement with health research?

What do we mean by community engagement with health research? What do we intend it to be? What does it look like in practice?

During the conference, it became clear that community and public engagement are difficult concepts to fix in place, in theory and practice, and the way in which various parties understand and talk about them.

Sometimes it is unclear as to what we are asking the community to engage with. Is it with the scientific industry, such as study design, policies governing science practice, buildings and people? Or is it with scientific knowledge and understanding that circulates in general? Does this affect the depth and degree of engagement necessary?

Engagement is not a new concept. David Osrin from the Institute of Child Health, London, presented a brief history of modern public health, with examples of how citizens participate to improve public health. This related to both engaging with citizens to change their behaviour, and when citizens hold governments and institutions accountable for their actions that lead to ill health.

Throughout the workshop, community and public engagement were seen to encompass a range of activities including public health, policy making, ethics, community mobilisation and advocacy.



Community engagement is versatile, mutable and adaptable. It plays a slippery role, it plays a lot of useful roles for us, but it is difficult to grasp. Like a bar of soap it slips out of our hands.”

Daniel Glaser, Head of Special Projects, Public Engagement at the Wellcome Trust

What is community engagement with health research?

Although community engagement is fluid and mutable, people have tried to represent the diversity of engagement through different frameworks. At the workshop, we discussed, for example, the Wellcome Trust's 'onion' model, where there is a core of engagement with further layers, Arnstein's 'ladder' of participation, and the 'triangle' of engagement with different levels of activities represented (see Appendix 2 for more information about these frameworks).

Dorcas Kamuya from the Kenya Medical Research Institute (KEMRI) spoke about a far-reaching approach to community engagement, which to her means putting engagement at the core and getting institutional buy-in from everyone who engages with the programme. "Some scientists say that they do not want to do community engagement because they have too much to do. But if you collect samples you have to talk to people, you have to engage with them, and if you do this, it is some form of community engagement," she said.

But can anything be considered engagement if there is contact with the public? In the UK, the 2000 House of Lords Select Committee report on engagement in science (see appendix 2) is important. It was arrived at following crises of trust in scientific authority, with concerns among the public about bovine spongiform encephalopathy (BSE) and genetically modified food. But it emphasises the deficit model, which assumes that if we inject more scientific information into the public, they will understand science better. This model is not proven to work.

Providing information to the public is not the same as engagement. Another demonstration of this might be what happens during consultations with a community advisory board (CAB). Does consultation count as community engagement? It depends on the level of engagement that takes place. A genuine exchange of ideas and opinions is different to information merely passed on by scientists to CAB members.

So what is engagement? At its core, engagement challenges the notion of communities as 'recipients' and has the potential for community members to be 'agents' of change in relation to science through processes of 'conscientisation'.

Graeme Hoddinott from the Africa Centre for Health and Population Studies, University of KwaZulu-Natal, South Africa presented ideas and evidence from the field of psychology arguing that some approaches in contemporary psychology see critical consciousness as an outcome of community engagement. He suggested that community engagement should be seen, not just as just a step in research, but as a distinct set of human interactions to be studied and intervened upon.

During a small group discussion, delegates discussed the role of conscientisation in community engagement. Critical consciousness is reached when you understand your place in the political and economic context. To be critically conscious you start asking hard questions, and in the context of science, this would mean that the community asks hard questions and engages with scientists about their beliefs, knowledge and practice. Through critical awareness, community members become agents and make decisions about their own participation in scientific processes: what they agree with and what they want to change. The group also discussed the moral imperative to do community engagement, whether it is harmful to raise critical consciousness if people are powerless to do anything about it. One delegate suggested that not everyone has to buy into engagement, but that there should be a process towards developing critical consciousness that takes place.

Is critical awareness only for communities? It is not just community members who should experience conscientisation, but rather scientists and researchers should also become more critically aware. "It is not just a matter of conscientisation of other people. It is about us being more critically aware ourselves. It is not a 'them' and 'us' position," said Tracy Chantler, from the London School of Hygiene and Tropical Medicine.

Conscientisation

Conscientisation is a theory that emerged from Brazilian Paulo Freire, who had radical ideas about the role of education to liberate people and to help them transform their language and interaction with society so that they are more critically aware of the powers around them. They are able to turn this into action, transform and no longer be oppressed.

What is community engagement with health research?

Stories of community engagement

Dorcas Kamuya told the story of her experience of community engagement in Kenya. A baby in the village sadly died of jaundice, but the death followed an intervention from a researcher who had taken blood. The family of the baby drew their own conclusions and rumours began to circulate about why the researcher had drawn blood and the harm that it caused to the baby. These rumours were potentially very damaging for the community and the research. The researchers had to liaise with health staff and the CAB, and spend time talking to the family to prevent further damage. “We realised that individual interactions can have implications and wider impact on community engagement processes,” said Dorcas.

Khin Maung Lwin and Phaik-Yeong Cheah told their story. The Shoklo Malaria Research Unit, Thailand, works with CABs on the Thai–Myanmar border. The people on the border are vulnerable. They are from Myanmar, come to Thailand for work and healthcare, use clinical facilities and participate in research. Researchers wanted to engage with them to find out what their needs are. The team immediately faced huge challenges with CAB members living in different places and 70 per cent of them unable to travel in Thailand. They send five different vehicles to different places to pick up members. The members speak different languages and have different interests so communication is really difficult. But the research team have training activities to help develop skills and capacities of board members.

Katie Matthews from the Francis Crick Institute told her story of community engagement at a new medical research institute in the UK. Somers Town in London is a deprived area, with a very low male life expectancy. It is diverse, with Bengali and Somali communities, but it is quite insular, hard to reach and hard to engage with. The team at the Institute has been talking to the local community for 18 months. They want to engage with them around a range of initiatives to improve local health and wellbeing.

Community engagement activities include meetings, events, exhibitions, school activities to name a few. There is also extensive engagement with the science programme and children as young as five get to work with scientists and researchers in a teaching laboratory. But Katie warned of the dangers of poorly executed community engagement and the need to analyse what you do. “If it is not done well, we could perpetuate an unequal, hugely paternalistic relationship. How do we ensure that the community are not passive recipients? That they are not having something done to them of which they have no control? How can we empower rather than dis-empower? How can we shift the balance of power?”

Key points

- We use a variety of terms to describe engagement: sometimes referring to public engagement, sometimes to community engagement, and even public education. Sometimes we mean these terms to be distinct from one another, and sometimes they overlap in objective and approach.
- Engagement is not new. The history of modern public health demonstrates that citizens and scientists engaging with each other is an important part of improving public health.
- Engagement is versatile and adaptable. It can play a lot of useful roles both for researchers and the participating community.
- Engagement does not mean merely providing information about science to the public or communities, but implies a two-way exchange of ideas and action.
- Engagement challenges the notion of communities as ‘recipients’ and has the potential for community members to be ‘agents’ of change in relation to science through processes of ‘conscientisation’.
- Scientists should also become more critically aware of their own position in the political and economic system and therefore in relation to communities.

**Community, Policymakers and Stakeholders or
A Midsummer Night's Infomercial**

Dictionaries state:

Policy is a definite course, expediency, a contract, an action plan, a forming of a union in an enclosed space on high grounds.

Stakeholder holds the post and the prize to which others are tied and bound.

Community has a long-lasting, massive membership.

A Superstar Cast!!!

Constant (played by Community) is the endless top-giver and moaner.

Policy (played by Policymaker) is the bound foreplay-skipper with a secret fetish.

Stake (played by Stakeholder) is the wealthy, mustached videographer.

Order Now!!!

The action heats up as Policy frees one hand from the post and uses it to embrace the sweat-slick neck of Constant. Policy melts into Constant's collective rhythm and briefly, ever so briefly, listens.

Behind the Scenes Bonus Feature!!!

See Constant finally hold the camera while Policy, in never-before-seen raw footage, speaks the unrestrained dirty talk truth to Stake. A dirty talk learned from Constant....

This film was inspired by Community, written and produced by Policymaker, financed, edited and adapted by Stake Inc.

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Politics and power are key issues for scientists who want to do high-quality science and engage with communities.

Public and community engagement are inherently political processes but this can sometimes put researchers in a difficult position. The first priority for scientists is to 'do the science'. Some, who run laboratories, want to keep under the radar of politics in order to do their work properly. But some delegates questioned whether it is possible to separate science and politics.

"Science can be very political. Many investigators are focused on the science and do not think about what they are doing in a broad manner," said Professor Nick Day, Director of the Wellcome Trust–Mahidol University–Oxford Tropical Medicine Research Programme, Thailand.

Even the presence of a scientific institution in a community has a political effect. Alun Davies, working at KEMRI, in Kilifi, Kenya, said that the research institution is a large centre in the middle of a poor district and employs a few hundred people. This has a dramatic effect on the population of Kilifi and their presence precipitates political feeling.

Delegates discussed how politics means the distribution of power. If you replace the word politics with power, then you see the issues differently. By ignoring who holds the balance of power, scientists risk the research they do. If you do community engagement and you do not acknowledge power – who is included and excluded in the community – you will end up with biased community engagement.

Scientists are often seen as being knowledgeable, authoritative and powerful, so is it possible to create conditions where interactions between communities and scientists are less laden with power dynamics? Science cafés are often cited as places where you can have scientific knowledge circulating with different power dynamics. Ordinary people can have a conversation about science that is not controlled by the experts. It inspires people who have less power to engage, and power is subverted. This is the kind of empowerment we need in community engagement.

If scientists try to address issues of power, then a critical question must be to ask who is framing the community engagement process? If scientists are ultimately controlling the engagement environment, does this disable citizens' rights to protest and hold powerful institutions (such as research institutes) accountable? Are there spaces in community engagement models and frameworks for protest? Would scientists view any protest or advocacy from communities as a positive engagement with the research?

Politics and power

These are difficult questions for scientists to grapple with in their everyday reality of doing scientific research. But they are vital if engagement is to be taken seriously as part of scientific endeavour.

Key points

- Power and how it operates are central to how scientists and communities engage with each other.
- Politics and power should therefore be key issues for scientists to consider.
- A scientist's priority is to do the science but scientists need to assess how power and politics affect the quality of their science, and whether engagement might improve research excellence.
- The way that scientists frame and control the engagement intervention is related to power and will affect the outcomes of engagement.
- Interventions that try to address and subvert power dynamics between scientists and communities should lead to more effective and genuine engagement.
- When scientists are confronted with protest and advocacy from communities, they should see it as a sign of engagement.



If you do not do community engagement and you do not think about people who are powerful who make a difference, you will not do the best science you can.”

Sarah Hawkes, Institute of Global Health, University College London

Scientists engage with communities for many reasons and discussions at the workshop revealed the extent of them.

Engagement can have a variety of goals such as influencing public health, policy making, ethics, advocacy, accountability, research excellence, participation and community mobilisation. When we try to put community engagement into practice, these ideas are sometimes in tension with one another.

Binh Cam, from the Oxford University Clinical Research Unit in Ho Chi Minh City, spoke about the emergence of rapid infections and asked whether we should include public education in community engagement. “Is the purpose of engagement only to educate the population about risk of clinical trials or to share the purpose of the whole research? Or are we seeking the community’s opinion about how we do research and understand their values?” she questioned.

Mike Parker, from the Ethox Centre, University of Oxford, showed a participatory video (vimeo.com/34894726) made during a workshop on consent and community engagement at KEMRI, Kenya, in March 2011. Participants on film gave a range of explanations as to why they engage with communities.

People saw community engagement as:

- a means to undertake high-quality research in a conducive environment
- a means to improve health and healthcare provision
- a way to build partnership and trust between researchers and communities
- a way to build social capital
- a way to address and agree on ethical issues and policies
- a requirement of funding
- having intrinsic value as a mark of respect towards communities.

Social capital

Social capital is a sociological term. Its meaning is contested but it generally refers to the nature of reciprocal relationships between networks of people with similar or diverse interests. Links and connections between different people are used to acquire and exchange resources. Informal shared values allow people to gain trust and cooperate with one another for varying degrees of mutual benefit.

Delegates gave further reasons for engaging.

Engagement:

- stimulates interest in science in the general public
- ensures that scientists are accountable for their actions
- builds partnership and trust between researchers and communities
- strengthens the research process
- helps you think about what needs to be done in terms of research
- makes community activists more visible and outspoken in the public sphere
- has potential for communities to make their own enquiries and demands, and advocate for change.

David Osrin presented his work from urban slums in Mumbai highlighting some of the parameters of community engagement, including method, time, space, group dynamics, trust, actors and power. He questioned why we do community engagement. He found that scientists gave these additional reasons for engaging:

- “We are sure that changing practice would be good”
- “We found something out that might change practice”
- “We found out something interesting”
- “We think this issue should be discussed”.

Why do we engage with communities?

David asked the delegates present if there were other reasons why they did public engagement.

Answers included:

- “I think it is going to improve the science that I am doing”
- “I will get more recruitment for a trial”
- “It will raise critical consciousness”
- “I want to conduct ethical research that protects citizens’ rights”
- “I want to engage with policy makers”.

Influencing policy was a motivation to engage with policy makers. Sarah Hawkes from University College London (UCL) described her work to influence sexual health policy in Pakistan. This led to a discussion about the importance of doing policy analysis before starting the research. What are the policy blocks to changing the problem that I am trying to deal with? What are the questions in my research that I can add that will help address policy issues? One delegate said that if you are trying to influence policy in a country you need to take standards of care into account in your research. There is no point in doing a trial with drugs that are never going to be available or affordable.

Sunita Bandewar sees engagement to be about political change which will ultimately improve human health. Sunita is from the University of Toronto and is Research Coordinator for an International Collaborative Initiative in Community Engagement in Global Health. She suggested that research is about putting together evidence to make political change. “I find it difficult to distinguish between myself as a scientist and activist. I am both at the same time,” she said.

Key points

- Drivers and motivations for scientists to engage with communities are many and varied.
- Reasons for researchers needing to engage can be instrumental, including to obtain consent for trials, to fulfil funding requirements or to get public approval for a research project.
- Some scientists engage because they think it is ethical, as it protects citizens’ rights, shows respect to the community and makes scientists and institutions more accountable.
- Some engage because they want to see the community empowered, with increased critical consciousness and ability to protest.
- Some engage because they think it will lead to ‘better science’ and improve health and healthcare provision.
- Some engage because they want to influence and change policy and practice.
- Scientist and community members engage with each other and with policy makers for a variety of reasons. Understanding these reasons both from your own perspective and that of other communities is important for the process.

Plantains in high winds

The swaying plantain leaves
In the silent whisper
Full of knowledge and creativity
Through the caressing wind
They nod in agreement
Satisfied with the budding fruit.

The waving plantain leaves
In a joyful dance in the wind
Celebrate the maturing fruits
A reward for persevering toils
Through earth shattering storms
Carried in their engagement with the wind.

© Daniel Msiska



My primary aim is research excellence. I am more convinced that public engagement is central to that excellence. I think there is a paucity of principal investigators in this subject area.”

Rob Heyderman, Professor of Tropical Medicine and Director of the Malawi–Liverpool–Wellcome Trust Clinical Research Programme

We often use public engagement and community engagement interchangeably and this can get confusing.

If we ask, ‘who is the public?’, the question is easier to answer, as the general public can be understood to be the heterogeneous population at large, although different sections of the ‘public’ can still be identified. Mass media would be an example of how to reach the ‘public’. If we ask, ‘who is the community?’ it is more complicated. Finding ways to engage the community requires understanding *who* exactly the community is, but scientists do not always know this.

Delegates discussed the problematic notion of the ‘community’. If you want to engage with patients who visit a clinic, it can be difficult to identify who these people will be in advance. If you want to engage a community more broadly, you might work with community members represented on a CAB but it is important to understand who these people are and what power they hold in the community. It is naive to think that everyone’s interest will be equally represented. Any community can be seen not as a collective and homogeneous entity, but a group of individuals with power dynamics existing everywhere. “Who represents who in each of the communities is an issue we need to think about,” said Nicola Desmond, Research Fellow at the Malawi–Liverpool–Wellcome Trust Clinical Research Programme.

Lori Miller, of Global Advocacy for HIV Prevention, said that how we use terminology is important. “The Good Participatory Practice Initiative guidelines initially talked about community engagement and in the second edition we took away the word community because it is ambiguous, it is used in different ways, it means different things at different times. Stakeholder engagement is a clearer term that can be understood. Not everyone you want to engage may be considered community – government and media may have greater positions of authority. All stakeholders need to be engaged, you need to work out who they are.”

“Community engagement is a new thing for Nepal. Regarding the research we follow every step from government to local leaders. We try to involve and include

all the community groups if they are happy to participate” said Kirtiman Tambahangphe, Programme Manager of Mother and Infant Research Activities, Nepal.

Another delegate argued that the traditional understanding of community is in a geographical sense. If you are doing work with groups outside the mainstream, such as lesbians at risk of violence or sex workers with disabilities, they are not geographical communities but most people would understand them as communities.

In this sense, policy makers can be understood as a community with their own cultures, processes and pressures. Sarah Hawkes made this point concerning her work to engage policy makers in Pakistan. In coming up with evidence-based recommendations about sexual health in South Asia, she had become increasingly frustrated with never seeing any of her recommendations taken up in policy and put into practice. Providing information was not enough. Sarah described approaches to engaging with policy makers and the way that policy is “the interplay between institutions, interests and ideas”. The policy process is not a single discrete output or event. It is a cycle, and scientists have to think about where on the cycle they are trying to act. Researchers have bright ideas and provide evidence, and have to compete against interests and powerful institutions.

Key points

- Answering the question, ‘who is the community?’ is not always straightforward.
- Communities are not homogeneous and power plays out between different groups and individuals.
- Who represents whom in communities is critical for scientists to understand, to reduce bias.
- Communities are not necessarily geographically based, but can be social or identity-based groupings.
- Policy makers can be thought of as a community.
- Not everyone you want to engage is considered ‘community’, but they should still be included in your engagement efforts.

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Green

Or What is thank you on your tongue?

A tourist in Thailand I wait outside
the green muddy green mountains of Chang Mai,
To awake a Thai resident, To seduce with a smile
and what is thank you on your tongue?

Green Emerald green lime green forest green
Turquoise green Dark green light green Moss
Plural but still a neutral passive colour
Dead green. If only I could find an active other.

No sound from the hills. No human voice speaks.
A bright yellow butterfly flitflats a landing
On a fern. Suddenly there is yellow
In a lighter shade of green; in the pallor

of the plantain leaves is a fair haired shade
And on the centre of the daisies A muddied gold
Nothing I did or needed to do
Just needed to notice The butterfly in flight

Diamond yellow a universal
Warning sign A car sits on top of a triangle
Well balanced it holds its poise
Others might say it is driving precariously

A hotel employee walks out
Quietly unobtrusively he has watered the gardens
In quiet respect Without revving an engine
Already he is on his bike freewheeling

Down That dangerous hill I saw.
As if puzzled by something he half turns back
I wanted to walk to him to provoke his words
Be polite ask what is thank you on your tongue?

Now embarrassed by his courtesy that should be mine
I wave him on and I still do not know
how to say hello. Return to canopied
Corridors where two women are synchronized sweeping

With straw yellow brooms spread like fans.

Good morning she says hands paired in greeting
And I am silenced green with envy.

© **Lucinda Jarrett**

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Whose responsibility is community engagement? Is it primarily the responsibility of the donors or researchers or the community themselves? Where is the overlap and how do you navigate that?

If communities and individuals experience processes of conscientisation through engaging with science and scientists, they may themselves become the main drivers of engagement.

Who drives the engagement and who controls resources and power are of critical concern to both researchers and communities. Engagement by its very nature should be a two-way process and it is important to analyse what scientists are contributing to the community and vice versa. Are scientists putting something positive into the community, such as improved healthcare provision? Is the community putting something positive into the scientific process by, for example, demanding more attention to ethics? What are the benefits to whom?

Susan Bull, Senior Researcher in the Ethics of Genomics and Global Health at the Ethox Centre, Oxford, presented evidence of how sporadic public engagement with unethical research studies led to national and international guidelines on research ethics. In addition, communities responded both positively and negatively to the revisions of the Helsinki Declaration – a set of principles regarding human experimentation. She said that requirements for engagement on a study-by-study basis are becoming more common.

This raises an important question: Should researchers always have to engage with communities when they want to do research in communities? Who should be the judge of this? If we hold up an ideal that the community knows best, might the community reject an intervention that provides no immediate benefits, but may be positive over the long term? If there is always a precondition that engagement takes place, would some important studies potentially not occur? One delegate suggested it is patronising to communities that researchers decide whether community engagement happens or not.

If a community is not engaged, where does the responsibility lie? Is it the researchers' fault? Or the community liaison officer's fault? Or is the community at fault for not demanding it? If limited access to resources is the reason why scientists and communities are not engaging, should the funder provide opportunities for engagement through their funding mechanisms? One delegate said that any research done in a community goes through an ethics committee and community members sit on that committee. At that point, there should be responsibility within the committee to question it or discuss it further.

Delegates discussed the danger of turning the responsibility of community engagement into a burden. For scientists, the notion of having to do community engagement alongside every project is sometimes challenging. One delegate suggested that although engagement is very important, there are examples of clinical research that are time-sensitive and in these circumstances you would not want to get public engagement. For example, having to respond quickly to large-scale emergency epidemics can conflict with community engagement principles due to time pressures.

Yet, conversely, as one delegate pointed out, if scientists engage with communities meaningfully over the long term, they are highly likely to save time later should there be a public health crisis. Another delegate agreed and said that if you have a good relationship with the community and you are already engaged with them, when you require a fast piece of research, the relationship is already built and the scientific process will benefit as a result. Others argued that community engagement is the platform from which we are able to do better scientific research.

Community engagement: a scientist's responsibility?

One delegate said: "Some form of community engagement is important in any research. The depths of engagement vary in different contexts such as urban or rural."

Yet another important question is how do we decide about the appropriate degree of engagement for both researchers and the community? Again, who decides what is appropriate?

With public and community engagement increasingly recognised as a vital part of scientific life, the delegates discussed the skills you need to be a scientist today. In the field of climate change for example, a combination of scientists and activists are prominent. If science and activism is closely linked, then in some cases, it should be encouraged and rewarded. Upcoming generations of researchers appear more comfortable with community engagement. The difficulty is that younger researchers have to publish a lot to gain their credibility. They are the ones who could do community engagement but they do not necessarily have the time to do it.

Delegates raised concerns about the lack of reward for scientists doing community engagement. There are few incentives for researchers apart from a box-ticking exercise.

"The real challenge is bringing researchers from a laboratory background to talk to communities and start conversing with them. People have generated interest around this from the social science end, not from a laboratory end," said Professor Rob Heyderman.

Key points

- Navigating who is responsible for community engagement, and the appropriate extent of engagement is difficult.
- Engagement is about 'exchange'. It is not about providing information or disseminating ideas or results. Communities can also drive the engagement process, holding scientists and science accountable for their ethics.
- If a good relationship is already established between scientists and communities, it is possible to do a fast piece of research that also engages the community as a matter of principle.
- Scientists should be rewarded for engaging with communities well.



Community engagement is the platform from which we are able to do better scientific research."

Delegate



If we really believe that community engagement is an important part of scientific process we should reward scientists."

Elizabeth Pisani

Ethical questions are raised either in deciding to do community engagement in the first place, or in choosing the way that it is done.

Community engagement is sometimes seen as ethics itself. We have heard of community engagement as a benchmark of ethics: once you have done engagement you can tick the ethics box. But does community engagement constitute ethical practice? Do ethical questions stop there? Is engagement as an activity or process in itself ethically neutral?

Ethical considerations are continuous in community engagement processes. What happens in situations where what constitutes a local understanding of community engagement is not something you are happy with? For example, the group is made up of men only. What happens if you are in a process but a decision is made that you are unhappy with? For example, if the group decides to exclude other people. What do you do when the community comes to a view that is factually incorrect?

So what determines whether community engagement is ethical or not? Tracey Chantler suggested that “having a moral dilemma as a scientist and sharing that with communities is really important. We are assuming that community engagement equals ethical practice. What difference does it really make? What is it going to do to help me unpack the ethical issues of this trial?”

There is also a link between community engagement and ethics through understanding and consent. If communities are engaged and understand the scientific project, what does this actually mean and how do you measure it? Also, how realistic is this to expect? MalariaGEN, for example, is a technologically driven project. The programme covers 21 countries, involving specialists from many disciplines. If you ask any one scientist to explain the whole project, they would struggle. What is it appropriate to ask a community to understand? It is clearly not reasonable or realistic for anyone to understand the full complexity and implications of a project.

Susan Bull asked what happens, for example, when communities do not understand a long-term biodatabase. So how do you set up systems for long-term input and engagement with communities? It is difficult for ethical bodies to appreciate this. How do you create communities with links to broader communities to speak to and curate long-term projects?

A further ethical consideration therefore might be in relation to who is driving the engagement and where the power lies. If the engagement is always driven by scientists in relation to specific projects, where is the room for communities to engage on their own terms and at moments of their own choosing? How open are scientists to responding to community-driven engagement?

Is non-engagement with communities unethical? This was a critical question for delegates. One scientist argued that it depends on the size of the clinical trial. Engagement should be done if the study is large enough to have an impact on the broader community or it is a topic sensitive enough for the community to want to be involved. Others felt that non-engagement was clearly unethical as scientists cannot decide who the community is. They may end up excluding people who want to participate.

A researcher who participated in clinical trials in the UK suggested that non-engagement was not unethical, particularly in an urban environment where the notion of community is less clear. It is just different people participating in a trial. Another agreed that not all research requires community engagement, it depends on the context. Sometimes it is difficult to get people to understand about the research. Some researchers are more concerned about getting approval from the authorities, than the community.

Ethical considerations

“It is the responsibility of all of us to discuss community engagement, the pros and cons, and the costs. When you do a research study, there are ethics but it is the responsibility of the principal investigator to make sure that the research they do is ethically sound,” said Professor Nick Day, Director of the Wellcome Trust–Mahidol University–Oxford Tropical Medicine Research Programme, Thailand.

Key points

- Whether to engage communities or not is an ethical question.
- Engagement is not a benchmark for ethics. Ethics does not stop when community engagement takes place.
- Engagement itself has ethical implications.
- Ethical considerations occur, for example, when community groups exclude people, when individuals or groups hold factually incorrect understandings, or their decisions conflict with those of the scientists.
- Asking communities to understand long-term, complex scientific projects may be unfair, and innovative ways to link groups and communities over the long term should be sought.
- Scientists sharing a moral dilemma with communities can be a positive form of engagement.



Before the conference, I saw a separation between the work that I do and ethics. Now I see a fabric of ethics that weaves through all the disciplines.”

Mdududzi Mahlinza, Community Engagement Manager, Africa Centre for Health and Population Studies, South Africa

Scientists must first decide whether and why they want to engage with communities about health research.

They must identify which community they want to engage with and then who in particular in that community. The depth, duration and method of engagement are then critical.

Engaging with communities requires a variety of approaches that are appropriate to the context. The best methods are those that can be owned by the community themselves. Engaging with communities in creative ways, collaborating with artists and using participatory methodologies are real options for scientists. In order for delegates to experience some creative and artistic processes during the workshop, they chose one of four creative sessions to attend: participatory video, theatre, creative writing and poetry.

Participatory video, Michael Brown, Development Media Workshop

During the participatory video session, participants agreed that they would explore the issue of respect between scientists and the community. They each filmed their initial thoughts about respect, and then watched together what they had filmed. They then used the film as a way to discuss the topic. The film was shown to the rest of the delegates, but for those who took part, the process was more important.

“The film making was part of the process and it was much more about self-reflection and finding common ground in the group, and reflecting that back to the wider community and assessing what action or change would come from that.”

Delegate

Theatre, Kris Reardon, Thirdway Theatre, GABFAI

Participants worked through interactive physical exercises. They talked about how the exercises made them feel and then they used this as a metaphor and discussed how it relates to the issues we face in public engagement. This drama-based way of working helps develop intimacy and helps participants to get to know one another.

Creative Writing, Alison Dunn, In the Write Space

Participants used free-writing exercises and metaphor to explore their experiences of community engagement in their own settings. They discussed group dynamics, describing what they would bring to the group and what they would get from the group. They also wrote about a ‘turning point’ in an ethical dilemma they faced in their work to engage communities.

Poetry, Lucinda Jarrett, Rosetta Life

Three delegates chose the poetry session, none of them having written poetry before. They were led through some fundamentals about poetry, and allowed to wander around the physical environment in which the workshop was taking place, looking for inspiration. They all wrote poems about their relationship with community engagement and read them to the other delegates.

Delegates shared their experiences of using creative methodologies. They said creative methodologies are interesting because they:

- allow you to express opinions and ideas that would be hard to say in a discussion
- mean there is less prescription and more innovation
- allow you to work with diverse communities
- encourage new ways of learning, reflection and evaluation
- can subvert power and build empowerment
- tell stories that cannot usually be told
- can be helpful as a social science research tool informing and strengthening the scientific research process
- open people up to new possibilities
- teach new skills
- catalyse discussion and action since outputs can be used with external audiences.

How do we engage with communities?

But delegates warned of the need to choose the most appropriate methods for the desired depth of engagement. If poorly chosen, the outcome might not be what you hoped for. “We tried to be creative, using television adverts to promote immunisation awareness. It did not work well, especially because we were not tapping into the layers within the community that we wanted. We had to be creative, take in cultural sensitivity, and figure out ways to engage the community in our message. We had much better results when we were able to talk with community, find the leader and from there talk about the ways we could engage with them,” said one delegate.

David Osrin presented his work in urban slums in Mumbai, describing it as a blend of art and health. There are three strands of artistic work in the project: photography, textile and ceramics. These creative outputs are used to express ideas and concepts about health. Much of the creative expression was concerned with dirt and water. He talked about the importance of the quality of the artistic products, suggesting that high-quality art is a positive outcome and that external audiences will not engage with a product of poor quality.

But there are also issues of the responsiveness of research. David’s research is community-driven and the actual intervention is decided and done by communities. But the focus of the research is always perinatal health. If the community wants better water supplies, they would not and could not intervene. What is the responsibility of the researchers here? There are multiple agendas operating at the same time and the agendas of all the participants are contextual. Some are asking themselves, can we get money out of it? Can we get a better water supply if we work with these people? Others are wondering, do you think we can get good works of art out of this people? How long is going to take? Where are we going with this? The key issues to consider are space, time, participants, priority, agendas and trust.

Key points

- Choosing the most appropriate form of engagement, at the right time and with the right people, can be difficult. Engaging with communities requires a variety of approaches that are appropriate to the context.
- The best methods of engagement are those which can be owned by the community themselves.
- Engaging with communities in creative ways, collaborating with artists and using participatory methodologies are real options for scientists.
- Creative methodologies can be particularly helpful to nurture genuine expression, subvert power and catalyse discussion.
- If scientists are required to engage with communities using suitable methods, they will need to develop new skills, and learn to identify and work with intermediaries such as media professionals and the not-for-profit sector.

I. Ethox Centre at the University of Oxford, MalariaGEN

Test tubes to trail shoes sometimes
we know we need to leave these
clean white walls and enter the hallways
of mind, leave the dry peer-reviewed behind
and enter HELA not under lid and light
but through Skloot's *The Immortal Life*
forget functional fixedness find comfort
in discomfort
remember
that numbers and bars in a chart
can't speak like a forehead crease
nor can a bar chart chart a scar's story
that *analysis for analysis sake is not*
very gratifying in the end when we end
we'll be remembered
by our blend of elite science with real life
our blend of *Skype* and strife
not just that we served those deserving
but that we first knocked gently on their door
introduced ourselves
listened with our ears opened like eyes
and took our shoes off before we entered.

II. KEMRI

Mud huts to lab coats sometimes
the collective foot-tapping used
to break ice to bridge gaps to engage
fills more than consent forms.
The vibrations can change elder expressions from
Man, you don't know where I've been to
Yeah, I've been there. I've been human.
Snake symbols can shape-shift from hell
to health. Still you can't
force hindsight on self or others.
A taste from the River of Mistake
leaves residue on our lips.
Two sips can crush.
Too few sips and ego-algae metastasizes.
To sip and savor empowers
Explain it to me. Tell me who you are. Tell me why you're here.
The river will run toward you
or away
depending on where you choose
to stand.

III. 203 Women's Groups, Makwanpur District, Nepal

Children use their fingers to write their names in the dust
on the top of unused X-Ray machines.
Mothers use their hands to pry placentas
to tie umbilical cords to shush the mouth
of a woman who mentioned undergoing gestation's
finality in a hospital. Then a nod trumps a shush
and through image a tear-smile trumps a nod
results in trust
of iron, dewormer, folate and electrolyte pills
and in the distributing hand the trust
to sing the song of silent numbers
to dance in dirt road drama
to promise life with a handshake.

© Cameron Conaway
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There was a strong focus on film at the workshop. A multisite community film project was conducted in the lead-up to the event.

Participatory films were made with researchers and communities linked to Wellcome Trust research in Kenya, Nepal and the UK. The aim of the films was to explore the attitudes, beliefs and behaviours at the interface between research and the researched community or the community in which the research centre is situated physically. This could potentially break down barriers, and transform relationships between researchers and communities, forging greater trust, respect and understanding.

Michael Brown, who managed this multisite film project, discussed participatory video (PV) as a tool for community engagement and participatory communication.

“When we talk about communication typically, lots of people think of sender, audience, channels etc. Try and forget this and think about the process of people making their own films and drama. Self-reflection for me is the key to all participatory communication initiatives, the media outcomes are a by-product of the process of self reflection. Sometimes the media that people produce does have a purpose. Sometimes it doesn't. Sometimes it is enough to make a film for the process itself and it never has an audience,” said Michael.

Participatory video

Participatory video (PV) is a process where a group of participants are supported by a facilitator (rather than a director or film maker) to create their own film. Participatory film making is fundamentally different from film making for social activism or documentary film making. A well-conducted, participatory film-making process is led by the participants. The facilitator helps a group to identify and analyse issues important to them and equips them with the technical skills to explore these issues through film. The emphasis is on finding a voice rather than communicating a message although a finished film can also be a useful tool for advocacy and stimulating action.

PV is a versatile tool. It is applied in social research, public consultation processes and decision making, advocacy and knowledge sharing both within and between communities. It can also play a role in an intrinsic, therapeutic sense with participants expressing feelings and demonstrating agency, empowerment and self-worth. Often a full participatory video process requires time and participants are free to follow their chosen themes. In the 'motivations project', time was limited and there was an externally identified objective for the films, in that they would bring unrepresented voices into the 'Under the Microscope' workshop. Each project team navigated external requests as well as those of the project participants and for this reason the films are participatory to varying degrees, and each has its own approach and character. All projects were invited to reflect on the ethical and practical challenges that came with the methodology.

Using film making to engage

We watched the participatory films that came out of the multisite project and discussed processes and outputs:

The Shoklo Malaria Research Unit, Thailand

The Shoklo Malaria Research Unit (SMRU) has been working on the Thai–Myanmar border for many years and has been informally engaging with the community for its healthcare and research initiatives, especially in the area of ethics and consent. Staff here facilitated the set-up of the Tak Province Border Community Ethics Advisory Board (T-CAB) with the aim of ensuring that research activities on the border respond to the needs of the community, while adhering to community standards and sensitivities.

The project team chose to explore the personal motivations and experiences of the members of the T-CAB through film, with the aim of improving the effectiveness of the T-CAB. This supplemented an earlier project involving in-depth interviews with each of the members. The T-CAB members now plan to use participatory video to capture the conversations they have in their communities in order to bring community voices to their meetings.

vimeo.com/34903287

KEMRI–Wellcome Trust Research Programme, Kilifi, Kenya

The KEMRI–Wellcome Trust Research Programme conducted a participatory video project in Kilifi during April and May 2011. Participants in the project were six teenage attachment students who did work experience with the Programme between November 2010 and February 2011. The film project allowed these students and KEMRI staff to explore views about research and community engagement, and student attachment as a community engagement activity. This was done through the use of interviews where the students set the questions.

vimeo.com/34894726

vimeo.com/34892572

Oxford University Clinical Research Unit (OUCRU), Vietnam

Due to political sensitivities in Vietnam at the time, the Vietnam team had to postpone their participatory film process. The plan for the future, however, is to bring together patients and families who have been involved in dengue research studies undertaken by OUCRU. The project will adopt a similar focus to OUCRU's research activities, centred on the clinical questions relevant to a broad patient population from across Ho Chi Minh City and southern Vietnam. The project will use participatory film methods to explore interactions between medical researchers and the individuals/communities they work with, and produce film material that will contribute to the wider discussion of community engagement in medical research.

Mother and Infant Research Activities (MIRA), Nepal

MIRA's mission is to improve the health of mothers and newborn babies by reducing maternal and neonatal mortality and morbidity through research, training, service, publication and advocacy. MIRA has shown through controlled trial design that working with women's groups can have a significantly positive impact on maternal and infant mortality figures. MIRA used participatory film methods with a women's group with whom they had an established relationship. The group had already experienced using photographic participatory methods to explore their voice and to communicate. In this project the women decided on the theme: they wanted to communicate with other women within and beyond their district about why it is important to have a women's group, their own main achievements, and what it is like to be a woman having a baby in rural Nepal.

vimeo.com/33243824

vimeo.com/32257088

Wellcome Trust Centre for Human Genetics, Oxford

This project used a participatory film method to stimulate reflection and dialogue about community engagement between staff involved in a large multidisciplinary international research programme. Staff from the Wellcome Trust Centre for Human Genetics and the Wellcome Trust Sanger Institute explored how they conceived community engagement. What motivates them to engage with communities? What challenges do they face in doing this? Why would they do it? Their initial reactions were recorded and used as stimulus material for a round-table discussion with web chat.

vimeo.com/33371207

vimeo.com/33268718

Delegates discussed the following questions:

- Where is the emphasis in participatory video? Is it an exploration of issues through the film-making process or a product to show a wider audience?
- As part of ethical consent, how do you ensure that participants understand the potential impact of the films, for themselves, within their community?
- Do we, as facilitators of the films, understand the potential impact of the films? How do we explore with the community what the possibilities are and mitigate any damaging impact?
- How important is it to have high-quality productions?

Using film making to engage

Different uses of PV

Different uses of PV are far-ranging, including: to empower, communicate, reflect, evaluate, strengthen the research process and build identity.

Participation as an end

Delegates discussed the difference between the process and the product. Gaston Schmitz, Manager at The Constellation, Thailand, remarked, “The videos are a spin-off product, the essential part is the making of it. We use a lot of video as well. In the Congo we had 250 facilitation teams. Through the country they all had a video camera to catch their work. I was frustrated as I wanted to capture it all and watch it all, and I didn’t think so much about the process. But this was the spin-off. The spin-off can be powerful to inspire others and other local responses.”

Michael Brown also commented on how important it is to think about how film is used after the process. “I come from a community development background, using media in an individual way to reflect or collectively in communities. A group of boys made a film about domestic violence and alcohol abuse. They brought all their respective community members to watch the film, and they did focus groups. Films can bring out issues and be a catalyst for further discussion or action. They decided they didn’t want the film to be publicly available. It is about the film that we made and if other communities want to address these issues, they should make their own film. This meant they really recognised what they did and were not seduced by a showy film.”

Empowerment

People who used PV suggested that the camera itself has the potential to open up and allow participants to enter new spaces and talk to different people.

“The power of the camera bestows something. People can turn the camera on members of the community and powerful leaders that they would not have talked to before. It opens doors,” said Siân Aggett, International Engagement Project Manager at the Wellcome Trust.

Evaluation

In Kilifi, Kenya, the process of making the film helped the team to assess the effectiveness of their community engagement work. It was an opportunity to hear what the community thought about the scientists. “In terms of the engagement project in Kilifi, our motivation to get involved in the film was that it could be a tool to help us evaluate our community engagement strategy. It has been very helpful” said Alun Davies, researcher at the KEMRI–Wellcome Trust Research Programme.

Communication

Films can also be used by the communities to communicate with external audiences. “The women wanted the film to be objective to show others what they were doing and show other women what they could do too,” said Jo Morrison of UCL, working in Nepal.

In the UK, scientists used film to share experiences, reflect and communicate with one another. “It was a good emotional connection and with more time and space to reflect it would have been a very rich form of communication and expression. It called for something different from me than Facebook does for example,” said Michael Parker, Professor of Bioethics at the Ethox Centre, University of Oxford.

Strengthening engagement

Another outcome of using PV was that the process of engaging with your own community strengthens the research process itself. It solidifies the research team and the quality of the research.

Reflection and building identity

One delegate commented that when you ask a research participant or community member to make a film, it is intoxicating to see how people work out who they are. The camera is about defining identity and community-building. It makes people ask ‘who is the community?’ It becomes self-definition.

“People, in front of a camera, construct themselves when they otherwise might not have done. It is not whether they are honest or not but they are now thinking about the world in a different way just because the camera is there,” said Graeme Hoddinott.

“The strength of the camera is that it provides greater depth and ability to be introspective” said Nick Fernandez, Media Producer/Director at Fact and Fiction Films.

Challenges

Using participatory video with communities and scientists is not without difficulties. Delegates discussed their concerns about representation, sensitive information, choosing the content, editing, timescale, protecting vulnerable people, self-censorship and quality.

Representation

In Nepal, there are 203 women’s groups; the participatory film was about one of these. Jo Morrison said: “We spoke to the women about who they wanted to see the film. They wanted all the women’s groups in the region to view it. I don’t think it was representative of what they were doing. Some people in our organisation did not think it represented what we do and it made us seem like we worked in conflict. There are dilemmas – should some things be taken out? Do we not show the film at all? Do we give the film to the women as it stands to show themselves? It’s a compromise.”

Using film making to engage

Timescale

In Nepal, the women had 13 days to film the footage but they have met every month since 2000. It was difficult to capture all their work and represent it.

Self-censorship

When people are on camera, they are not at their most critical. So, while participatory video can be a tool for reflection, sometimes film is not the best way for people to express a critical opinion. At KEMRI, when asked about their experiences of filming, students said they felt uncomfortable about being critical. One student asked to remove a negative comment he had made.

Another researcher who participated in the film making with other scientists had a similar experience. “I wasn’t completely honest. I asked Michael to remove something I said which I wasn’t comfortable with,” said Phaik-Yeong Cheah, from the Wellcome Trust–Mahidol University–Oxford Tropical Medicine Research Unit.

Power

In PV, the editing process – who decides what gets cut and what stays in – can be difficult. “When we edit the comments out that are not acceptable or desirable, I wonder what we do to the process? Should we be actually doing that kind of editing?” said John Ganle, from the Department of Public Health, University of Oxford.

“I thought that the editing process was similar to qualitative analysis, almost the same. We looked at the whole footage, we had to make decisions on themes and make sure all views were represented in the final cut,” said Alun Davies.

Consent and protecting vulnerable people

A key concern is the need to protect vulnerable people. Films can be powerful and they can have effects that are unpredictable. How do you ensure that people who participate understand the potential impact of that film? Should you try to control it? How do you help people understand that? This is an ethical question. It is important that people fully understand the conditions under which the film is going to be used. Delegates gave examples where people were persecuted because they were identified on film by authorities.

What are the parallels between consenting to participatory video and being on film, and consent in the research process? The issue is how people understand the implications of being in a film. For example, if there is a clinical trial and a journalist wants to interview a participant for a newspaper article, how do you let people know it might have a larger effect than what they might think? One delegate suggested that this understanding should be stated explicitly in informed consents.

Another delegate pointed out the similarities and differences of consent to research and consent to being on film. The origins of protective structures are different but both originate in harms. Consent to research results in us protecting people from the activities of scientific researchers, based on bad experiences of the past. But consent to film-making protects mainly the film maker or photographer from financial litigation.

Delegates acknowledged the power of film and therefore the perceived threat it can bring. Mary Chambers and Nick Fernandez both discussed why they did not make a PV, which involved political sensitivities. Katie Matthews from the Francis Crick Institute also decided not to do any PV as it was not considered to be at the right stage of a sensitive community consultation process to do so.

Quality

Delegates discussed the importance of the quality of the final product. It depends on what you want to use the film for. If it is for external audiences, and you want to communicate or influence or stimulate discussion, then it matters. If you are distracted from the content, it does not do its job. The film should be ‘fit for purpose’. Others agreed that the film should be of high quality because of professionalism and respecting your participants’ expectations.

Key points

- Different uses of participatory video are far ranging, including to empower, communicate, reflect, evaluate, strengthen the research process and build identity.
- The process of making the film in a participatory manner is as important (and sometimes more important) than producing a film that can be shown to external audiences.
- Using participatory film to engage with your own community can strengthen the research process itself. It solidifies the research team and the quality of the research.
- Films can be powerful and they can have effects that are unpredictable. Ensuring that vulnerable people are protected is a vital part of participatory film approaches.

Some delegates said it is important that we move from implementing to evaluating what we are doing and questioned whether there were adequate models to evaluate community engagement.

“One challenge is how we can go about evaluating our community engagement activities? We believe we have been able to use community engagement in a successful manner but in terms of quantifying community engagement we are not,” said Mbongseni Buthelezi, Head of External Relations at the Africa Centre for Health and Population Studies, South Africa.

Others agreed that community engagement practice needs to be based on evidence. They need to be able to show it has value. But this raises the questions of whose agenda frames the evaluation? Who decides who benefits? If communities protest through a well-conducted and open engagement process, and scientists are held back from conducting some research, would scientists consider this successful engagement?

Alun Davies from KEMRI said that researchers are still learning. At KEMRI, they want to continue to learn how to do community engagement and improve communication within the centre itself.

A small group discussed some of the challenges of trying to monitor and evaluate community engagement. They talked about qualitative versus quantitative data and considered who should conduct the evaluation. Is it appropriate to have self-evaluation or should external evaluation of community engagement be promoted as the norm? The group also explored frameworks for monitoring and evaluating community engagement. Lori Miller described how the Guidelines for Participatory Practice (GPP) can be used to monitor and evaluate stakeholder engagement. There are 16 topic areas detailing good participatory practices, which trial entities are expected to follow. Each of the practices is written in a way that can be monitored to see if it has been accomplished.

Development practice has many examples of participatory evaluation and there is a wealth of experience and resources relating to evaluating at community level. This is something that researchers or community liaison officers responsible for community engagement may wish to learn more about.

Key points

- Community engagement practice needs to be evidence-based.
- Evaluating and monitoring community engagement processes and outcomes is important.
- Anyone planning an evaluation should be aware of whose agenda is being promoted, and on whose terms the evaluations take place.
- Existing evaluation frameworks and participatory approaches may prove useful to researchers wishing to undertake evaluation at community level.

You say you want a revolution

You say you want a revolution
Yeah well, we all wanna change the world
But you can count me out.

You bury our love
In philosophy
Extract my history
Dissect my identity
Baby, all I wanted was
A cup of tea,
And conversation
Not checklist participation

If you can't tell
By the arch of my spine
By the curve of my hip pressed against your palm
By the pace of my breath crashing upon your ear,
If you can't feel
The sandpaper grading
Of our bodies colliding
Then I'm afraid you'll never understand.

And although our first kiss
Is tattooed on my lips
I will not have you pinning down my limbs
For your mausoleum of butterflies

I could say:
It's not you, it's me.
But we have trust issues as it is.
I feel trapped by our potential
I feel trapped in our potential.

You say you want a revolution
Maybe I don't wanna change the world
Maybe all I wanna do
Is hold your hand.

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Are you designing an engagement intervention? Have you thought about the following things?

Who?

Engagement takes place as an exchange between different people. Who do you want to engage with? Who do you want to engage with you? Who is making efforts to engage with you already (community advocacy groups, media etc.)?

If you decide you want to engage with a 'community', what does this mean? Is the 'community' a geographically located community? Or a social or identity-based community? Or perhaps a community of patients?

Importantly, communities by their nature are made up of many individuals. Often, scientists engage with community representatives. But who represents the community? Are they powerful people with particular interests and agendas? How much do you know about them and what they want? Are they a fair representative of the rest of the community? How do you go about achieving this given the communities own demands on time and resource?

When?

At what point and over what duration of time do you want scientists and communities to engage with each other? Engagement can take place as a long-term approach, designed to build continuous relationships between scientists and community members. Some engagement strategies focus on short-term interventions for a particular project.

At what stage within the research programme or project do you engage? Is this upstream at the point of research design and research agenda setting? Or is it more appropriate to start engagement further along in the life of the research project?

Have you considered the implications of the duration of engagement? Would a longer-term engagement strategy support short-term projects more effectively?

How much time are you asking the community to spend on engagement activities? Is this realistic?

Why?

Engagement can have a variety of goals such as benefitting public health, informing and influencing health policies, ensuring ethical conduct, advocacy on behalf of otherwise unheard voices, accountability of the research to government or the public, consultation and empowerment and community mobilisation.

What is the goal of your engagement?

Are you clear about what you are asking from the community when you engage with them?

It is important to be clear about why you want to engage communities and this should inform your strategy and approaches.

How?

What methodologies and approaches are appropriate to encourage genuine engagement between scientists and communities?

There are many participatory and creative methodologies, including film, theatre, poetry and other artistic forms, that can be used to allow communities to express themselves in ways they control and are able to use effectively.

Participatory processes should encourage a process of 'conscientisation' so that communities become critically aware of science and health research. Empowerment is a legitimate outcome of community engagement.

What?

Community engagement should mean a two-way exchange. Scientists need to find ways to understand and engage with communities (see 'How?' section above) about science, and about community knowledge and understanding.

How open are scientists to communities who wish to engage on the community's own terms?

Designing a community engagement strategy

What processes and procedures do scientists and research institutes have in place to be responsive to community-driven demands?

It is important to remember that there are always multiple agendas in relation to health research.

If a community rejects or opposes a scientific health project or programme, what, as a scientist, would you do? While any protest can be interpreted as true engagement by communities, it has the potential to cause difficulties for scientists. Are you prepared for the risks involved?

Can you find ways to reward scientists who engage with communities?

Evaluating engagement?

Understanding how community engagement is proceeding is vital for building strong relationships between scientists and communities. But how do you measure this dynamic and power-laden process? On whose terms are you measuring 'success' or otherwise?

Can you find ways to document the engagement process from the scientists' point of view?

Could you think about ways to find out from the community their experiences of engagement?

Is external evaluation of community engagement the most appropriate course of action? Who will fund this?

Ultimately, how can we collectively provide an evidence base for the value of engagement?

‘Under the Microscope’ was an opportunity for scientists, community engagement specialists and intermediaries using creative methodologies to come together and explore the area of community engagement.

The breadth and depth of discussions that took place at the workshop show that community engagement can indeed be a difficult concept with which to work.

For many scientists – whose priority is to ‘do the science’ – it can be challenging to make decisions about why to engage, how to engage and with whom to engage. Yet as we have seen, engaging with communities is a critical part of scientific life. The benefits to scientists are multiple and ultimately can lead to the highest-quality research possible. When communities develop the potential to hold scientists and scientific institutions to account for their actions, the research process is strengthened.

The benefits to communities are also evident through critical awareness, empowerment and ultimate improvements in healthcare. Such potentially reciprocal relationships should not be underestimated. However, the challenges are multiple too, and ethical considerations do not disappear when the decision to engage is made. Scientists and intermediaries are faced with ethics continuously when engaging with communities.

What next? As researchers, scientists and intermediaries interested in working to engage with diverse communities, what can we do collectively to improve our understanding and practice in the area of community engagement?

Firstly, we need to learn from one another. We need to develop a **community of practice**, so we can exchange ideas and share experiences. We also need to ensure that our engagement approaches are **ethically sound** and well considered. But crucially, we need to provide an **evidence base** for the value of community engagement with science. This means developing and putting into place evaluations of community engagement. It means doing contextual analysis of different engagement interventions and trying to understand what works and under which conditions. How we do this and how it is funded is of great importance and a subject that we hope to explore more fully in the future.

This report was written by Alison Dunn. Alison Dunn is a writer and writing trainer with a background in international development. She specialises in health, participatory approaches and communication. www.inthewritespace.org

Background to International Engagement at the Wellcome Trust.

The Wellcome Trust is a global charitable foundation dedicated to achieving extraordinary improvements in human and animal health. It supports the brightest minds in biomedical research and the medical humanities.

The Trust also funds activities and research to stimulate the public's interest in science, to inform and facilitate public debate on science, and to improve understanding of the social, ethical, historical and cultural context of science. It is independent of both political and commercial interests.

The Trust is in the fourth year of its International Engagement programme of activity. This builds capacity for public engagement with health research in low- and middle-income countries. The programme is a part of the Trust's overall International Strategy, the main components of which include:

- grants for public engagement linked to Wellcome Trust-funded research in low- and middle-income countries
- grants for bioethics research in low- and middle-income countries
- International Engagement Annual Workshop.

The International Engagement programme runs an annual international collaborative workshop that brings together practitioners involved in the field of public engagement with health research in low- and middle-income country contexts. So far, there have been three workshops. The first, entitled 'Engage to Empower', was held at the Africa Centre in South Africa in December 2008. The second, 'Telling Stories', explored the power of storytelling for engaging audiences and was based at the National Centre for Biological Sciences in Bangalore, India, in December 2009. The third workshop, 'Under the Microscope', explored some of the ethical dimensions of public engagement with health research and took place in Thailand in June 2011, with the support of the Wellcome Trust–Mahidol University–Oxford Tropical Medicine Research Programme.

Extract from Wellcome Trust Public Engagement Workshop, by Pippa Hyam and Daniel Start.

Rapid review of some popular public engagement (PE) models

The term 'public engagement' has grown to cover a very wide range of fields and practices, and an even wider range of definitions and models. The term 'public dialogue' has also undergone a similar dilution. While this inclusive approach has expanded the field and profession, with market research and consultation experts now working in the same field as science communicators and educators, the lack of clear terminology can create problems in planning and assessing PE work and managing the expectations of those publics involved.

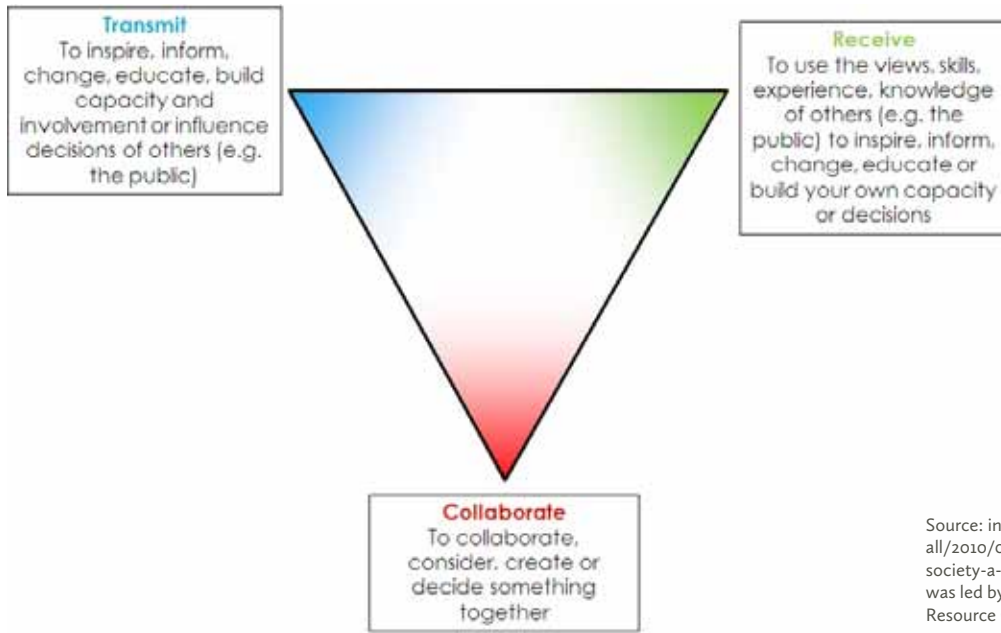
'What' models: The most common type of PE model in use by science organisations today is a usually three part adaptation of Sherry Arnstein's ladder of citizen participation (1969). This was developed while she was studying citizen power and local government in the USA. The 'what' refers to the amount of power, control or decision-making influence the citizen has in comparison to the state/funder/larger organisation. It has become particularly relevant to science engagement since the House of Lords Select Committee report¹ which highlighted the risks of a public understanding of science (PUS) approach (based on a deficit model) and heralded a public engagement (PE) model, which emphasised the opportunities for much greater control by citizens of the science agenda.

Framing and shaping: Arnstein's original framing of the model was as a hierarchical ladder, with partnership/empowerment at the top, and informing or communicating at the bottom. Her agenda was clearly to promote citizen participation, and her model framed non-participative efforts as less valuable, or downright harmful. She hinted at the problems created by mock participation by including the 'darker' side of PE into her model, with loaded terms such as 'placation', 'manipulation' or 'tokenism'.

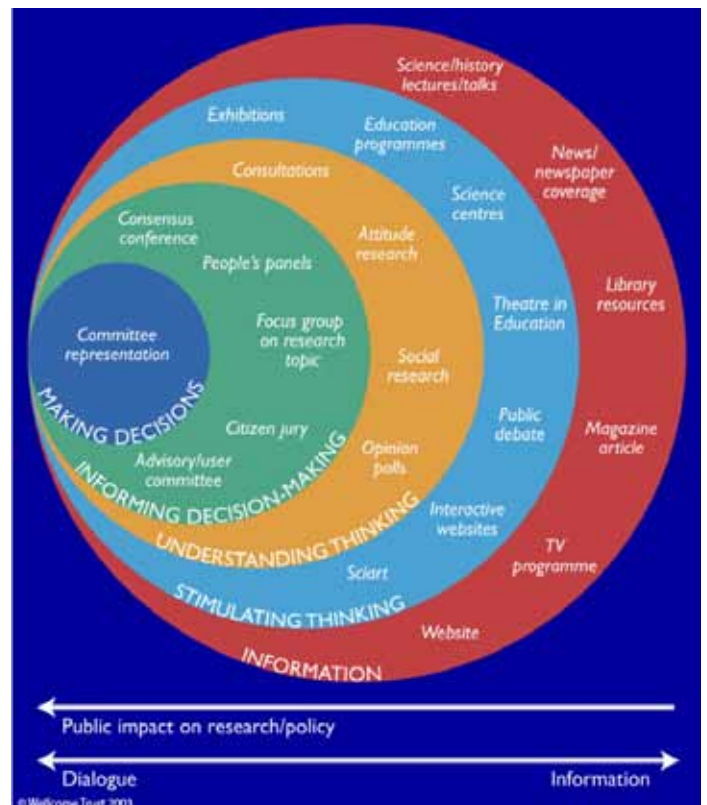
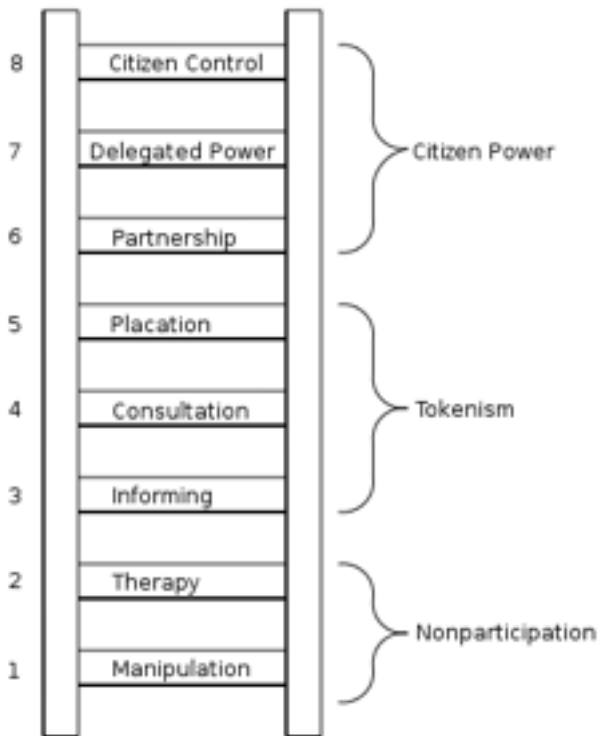
Arnstein's ladder clearly emphasised the risks of over-promising in PE and participation, especially when expectations run high. However, when taken to other contexts, such as science, where education, inspiration and agenda-setting are higher causes in their own right, this framing is less useful. Subsequently the model has been reframed and is now more usually presented as a spectrum, a set of interlocking circles, a triangle and even an onion.

¹ House of Lords Science and Technology Committee. Science and Technology – Third Report. London: HMSO, 2000. www.parliament.the-stationery-office.co.uk/pa/ld199900/ldselect/ldscitech/38/3801.htm [accessed 17 January 2012].

Appendix 2



Source: interactive.bis.gov.uk/scienceandsociety/site/all/2010/09/23/public-engagement-for-science-and-society-a-conversational-tool/. Development of this was led by Lindsey Colbourne (Sciencewise Expert Resource Centre) for the Science for All Group.



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We are a global charitable foundation dedicated to achieving extraordinary improvements in human and animal health. We support the brightest minds in biomedical research and the medical humanities. Our breadth of support includes public engagement, education and the application of research to improve health. We are independent of both political and commercial interests.

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