International Public Engagement Workshop Report

Trust Me I Am a Scientist: Exploring the role of trust within international health research

11–14 November 2013

wellcome trust

Trust Me I Am a Scientist: Exploring the role of trust within international health research

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Executive summary

This report is based on conversations that took place at the Fifth Wellcome Trust International Public Engagement Workshop 'Trust Me I Am a Scientist: Exploring the role of trust within international health research', held in November 2013, which explored the role of trust within the Wellcome Trust's international research programme. The workshop aimed to reach a clearer understanding of what is involved in developing and maintaining trust among relevant actors and groups engaged in international biomedical research, and the implications of this for strengthening community and public engagement strategies.

The Fourth Wellcome Trust International Public Engagement Workshop, 'Engaging with Impact: How do we know if we have made a difference?', identified trust as being important in the ongoing negotiations involved in public and community engagement (**wellcome.ac.uk/stellent/groups/corporatesite/@msh_grants/documents/web_document/wtp052364.pdf**). Subsequent discussions among staff from the Wellcome Trust's Major Overseas Programmes (MOPs) recognised that trust may be both an important ingredient of community engagement *and* an indicator of its quality. In addition, seven small projects investigating different aspects of trust in community engagement are being undertaken respectively by the Trust's five MOPs, the Francis Crick Institute and an associated team in Nepal to inform how they each address trust in their own work. The workshop sought to build on and deepen these conversations about the role of trust in engagement with biomedical research.

Public and community engagement are integral parts of biomedical research for Wellcome Trust-linked projects and MOPs – something that was explored at the Third Wellcome Trust International Public Engagement Workshop in 2011 (**wellcome.ac.uk/stellent/groups/corporatesite/@msh_grants/documents/web_document/wtvm054326.pdf**). *Public engagement* refers to the process of encouraging people in general to become more aware and involved with science, its impacts on society and the ethical questions it brings. *Community engagement* refers to working with specific geographically and identity-based communities who are affected by particular research projects or initiatives. *Community involvement* in research refers to directly involving people in research as participants.

A range of engagement activities aim to build relationships between scientists and the public/communities. These activities may raise the public's awareness and critical understanding of science in general and strengthen the ability of particular communities to hold scientists accountable. They may also inform the agenda and protocols of particular research studies. Engagement with research is about exchanging ideas and opinions on the focus and practice of research between different groups – between researchers and communities, the public and policy makers. Research institutions attempt to engage with people in many different ways, according to different contexts; strategies differ depending on the type of research, the characteristics of the engaging participants and what the different groups want to achieve through engagement processes. Trust plays a role across this range of relationships and engagement practices, though its role may vary.

Conversations at the Fifth Wellcome Trust International Public Engagement Workshop focused primarily on community engagement, and specifically on how fostering trust between communities involved in research and other research stakeholders could strengthen it, drawing on learning from different international contexts. The workshop used participatory methods to gather varied perspectives and insights about the role of trust in engagement with research from the assembled delegates. Participants included community and public engagement practitioners, community representatives, researchers and project managers from the Wellcome Trust MOPs and Centres, as well as staff from the Wellcome Trust in the UK and a range of invited experts and contributors.

Discussions at the workshop explored some key relationships involved in public and community engagement with biomedical research, in which levels of trust are important for success. These included: relationships within a community; relationships within a research institution; intermediaries between researchers and communities; and other relationships that are formed as part of a research study. The discussions also took into consideration how these relationships play out differently in different settings. In addition, across all of these relationships some key ingredients of trust seemed to be important, such as quality of communication, respect, processes of representation, responsiveness and reciprocity; wider factors can also be important, including local history, the legacy of previous research, the relative wealth and reputation of the research institution, the availability and accessibility of healthcare, and the relevance of the research to immediate local concerns.

A clearer understanding of the characteristics of these relationships and aspects of trust, and how to address them in practice, should help to strengthen strategies for community and public engagement with research. A greater clarity and awareness of the various ingredients of trust may also help to enhance the monitoring, the evaluation, and ultimately the impact of research.

One broad conclusion is that, as a goal for public and community engagement, stimulating 'healthy distrust' and critical scrutiny, rather than the extremes of unquestioning trust or automatic mistrust, might be more consistent with a scientific ethos. But equally, it was recognised that trust plays out differently in each context, and that its contours have to be understood and addressed with sensitivity to specific contexts for public and community engagement to be effective.

Looking through the 'lens' of trust also illuminates the broader question of what the motivations are for engaging and involving communities in research. For the Wellcome Trust MOPs, community engagement is increasingly understood to address both 'instrumental' concerns for better research and research data, and 'intrinsic' concerns over showing respect for communities and ensuring that community involvement is ethical. Applying the lens of trust to the relationships and negotiations involved in community and public engagement suggests that these concerns cannot be separated: successful 'instrumental' engagement focusing on improving research outcomes may require an 'intrinsic' ongoing commitment to ethical working, responsiveness and respect for communities, which constitute essential aspects of building trust.

Another issue that emerged from discussions of trust at the workshop is the importance of trust within research institutions themselves, and the need for individual researchers and public engagement practitioners to have the support of their institution in communicating and responding to the concerns of communities. This aspect of trust is one that is less visible in the literature on trust and public engagement with research, and yet participants raised many interesting questions and suggested some practical strategies in this area.

1. Introduction: Why look at trust in public and community engagement with research?

For the Wellcome Trust, interest in the role of trust is driven by a desire to achieve more ethical and effective community and public engagement with science and, in particular, biomedical research.

The stakeholders and activities involved in engagement with biomedical research initiatives vary. Activities might be discrete one-off interventions (such as an art project or a radio show), but they may also constitute more in-depth engagement that happens over a longer period of time through multiple activities or dedicated engagement processes (such as community advisory boards). Understandings of engagement also vary among the different stakeholders involved, and it is important to continue to reflect on what is at stake and consider what it is that engagement activities are really doing. Equally, it is important to consider how the reality of practising engagement matches up to the different expectations of different stakeholders. Focusing on trust at the Fifth Wellcome Trust International Public Engagement Workshop provided a useful lens through which to reflect on engagement practices and the relationships and negotiations they involve.

The importance of trust as an underlying issue of public engagement emerged at the previous Wellcome Trust International Public Engagement Workshop, 'Engaging with Impact: How do we know if we have made a difference?' (**wellcome.ac.uk/stellent/groups/corporatesite/@msh_grants/documents/web_document/wtp052364.pdf**), which focused on evaluation and impact. Could there be a danger of 'too much trust' or unquestioning trust preventing constructive engagement where community consultation mechanisms are well-established? And what happens when broken trust or high levels of mistrust appear to threaten the very possibility of biomedical research being undertaken? Discussions continued after the workshop within a Wellcome Trust-linked community of practice, centring around evaluation of public engagement. Interest sharpened and led to the initiation of a series of small projects to explore how trust plays out in the ongoing work of seven Wellcome Trust Major Overseas Programmes (MOPs) and Centres (the Trust's five MOPs, the Francis Crick Institute and a Trust-associated team in Nepal), as well as in other Trust-supported projects. The Fifth Wellcome Trust International Public Engagement Workshop sought to deepen these discussions.

1.1 Wider debates on trust

Current discussions about the role of trust in public engagement with research take place against a backdrop of wider debates about the importance of trust. In the global context trust has become an increasingly visible issue and challenge in recent decades, as there has been a crisis in confidence in authorities of all kinds: from governments and public bodies, to the banking sector and private corporations, to sources of information and news – such as broadcast media (O'Neill, 2002). This crisis of trust implicates scientists and public authorities responsible for health, as well as the private interests increasingly involved in the provision of healthcare. A Wellcome Trust Monitor survey of UK public attitudes shows that scientists in academia are trusted more than those working for industry or the government (**wellcome.ac.uk/About-us/Publications/Reports/Public-engagement/WTX058859.htm**). Scientists enjoy more trust than the government and the media, who languish at the bottom of the trust league. However, public trust in science is still precarious. Perhaps this is as it should be?

Public trust in health authorities has been undermined. For example, the UK government's handling of an outbreak of bovine spongiform encephalopathy (BSE, also known as 'mad cow disease') in cattle in the mid-1980s saw conflicting information about the risks surrounding eating meat from infected cattle cause public confusion. More recently public disquiet was caused by fraudulent research findings linking the measles, mumps and rubella (MMR) vaccine and autism being widely circulated, unchallenged, in the media. In fact, both 'scandals' contributed to the development of 'public engagement' policies by the UK government and a greater subsequent focus on getting public input into policy advisory processes (Rose and Rose, 2012).

In the international context both the legacy of historically exploitative relationships under colonialism and postcolonial influence continue to haunt people's engagement with contemporary health initiatives. For example, immunisation campaigns to tackle the last remaining pockets of polio have underestimated levels of public distrust, which drives non-cooperation, and testing and treatments for HIV and other infections continue to be affected by rumours about hidden agendas (Kamuya, 2013).

At the workshop Professor Hilary Rose, the keynote speaker, highlighted how science is changing. Long-standing arguments for the neutrality and independence of science, though always contested, look very different in the contemporary context, in which science and technology have merged into the 'technosciences'. In the current neoliberal economy science is increasingly pursued for private profit by scientist-entrepreneurs. The practices of the pharmaceutical industry have long fuelled public distrust, and the infrastructure of scientific research and discourse is becoming permeated by the influence of the private sector – nowhere more so than in the 'big sciences' of genomics, biotechnology and neuroscience (Rose and Rose, 2012). This changing, less 'public' character of contemporary science may also fuel public mistrust (Abelson et al. 2009; Rose and Rose, 2012).

1.2 About the report

This report primarily documents some of the key issues that emerged during the workshop. It also outlines the workshop process used to bring different stakeholders together and to explore the role of trust in engagement with research. The workshop was designed to be primarily exploratory – to surface and consider the many facets of trust while recognising that they will likely need to be addressed differently in the different settings where participants work. During the final session we returned to some of the key issues that had emerged throughout the three days of discussions and aimed to focus on potential practical strategies to address them within the public and community engagement work of those assembled. This session consolidated some important emerging themes, but also provided an organising thread for drawing together those diverse discussions into this report. The report attempts to highlight some of the main issues emerging and to link them to existing debates and practical strategies to address trust in ways that are useful in public and community engagement with research, rather than to be a record of proceedings.

1.3 Report structure

- In this first section we outline the workshop rationale and the key elements of the workshop process that supported the sharing of experiences and the promotion of reflection among participants.

- In section 2 we look at the various ways that trust affects public engagement. This includes looking at the ingredients of trust and how they can affect engagement efforts. In addition we consider how trust plays out in some of the relationships involved in public and community engagement. We also briefly review a range of wider social and historical factors that can affect current public engagement efforts, drawing on some of the concerns highlighted by Professor Hilary Rose in her keynote presentation.

- In section 3 we look at how these key aspects of trust might be assessed and practically addressed. This includes looking at trust and trustworthiness within communities and within research institutions as well as at a range of cross-cutting characteristics of trust that may help build and maintain trusting relationships.

1.4 Workshop overview

The workshop was deliberately designed to bring together stakeholders with different roles in public and community engagement and with different perspectives on where trust is at stake or has an influence. Most delegates came from the seven Wellcome Trust MOPs and Centres detailed above, with each providing delegates representing the range of roles involved in community engagement, including community representatives. A series of participatory exercises enabled delegates to share their experiences and reflect together on where and in what ways trust plays out across their work. In addition, a variety of guest delegates brought expertise on particular topics relating to trust, including the role of the media, the wider political economy of biomedical research, the influence of the pharmaceutical industry, and the Wellcome Trust Monitor survey on public attitudes towards scientific research in the UK.

The participatory exercises explored substantive issues linked to trust and enabled people to try out participatory techniques that could be useful in their community engagement work. The techniques employed at the workshop included:

- action learning sets – a tool for individual and organisational learning that supports reflecting upon and learning from practical experience
- rich pictures – a participatory drawing method that makes use of people's ability to capture situations and relationships in pictures to surface and elucidate understandings and perspectives
- Theatre of the Oppressed – a set of participatory theatre approaches that can support people to tackle problems and consider possibilities for change
- digital storytelling – a personal storytelling method that supports people in communicating and making sense of their experience through first-person narrative and images
- World Café – a simple, flexible method for facilitating structured dialogue with large groups of people.

See Annex A for more on each technique and further resources.

Image 1. Workshop participants develop a rich picture to explore how trust plays out in community engagement in research in Kenya

1.4.1 Projects exploring trust

In the summer of 2013, in the run-up to the Fifth Wellcome Trust International Public Engagement Workshop, the seven aforementioned Wellcome Trust MOPs and Centres were supported to develop small projects investigating trust in engagement with research. These projects aimed to link to and strengthen aspects of the MOPs' and Centres' existing work on public and community engagement, and also to provide insight on the topics for discussion at the workshop. At the time of the workshop (November 2013) most of the projects were in the inception phase, with a couple still in the design phase.

Each project was presented at the workshop. Presentations highlighted the key relationships, stakeholders and aspects of trust to be explored. Together these different relationships or aspects of trust began to build a picture of some of the key parts of the overall 'map' of trust, showing how it plays out in public and community engagement with research. Once completed, learning from across these projects will be shared to build a comprehensive picture of the influence of trust, which will inform the work of all programmes. Short descriptions of these projects are distributed in boxes throughout the report to highlight and illustrate the different aspects of trust being discussed.

1.4.2 Literature review on trust and health research in developing countries

A literature review, commissioned for the workshop and written by Dorcas Kamuya (Kamuya, 2013; available via the Fifth International Public Engagement page on the Wellcome Trust website), was shared with participants and presented at the workshop to provide relevant background for its discussions. The review focused on trust in the context of health research in developing countries and highlighted a range of challenges affecting levels of trust, including: the disproportionately low investment in health problems primarily affecting developing countries; debates about standards of care during research and benefits provided to participants; the perception that some organisations ‘outsource’ clinical trials to developing countries where regulation may be more lax; and the extent to which the communities who bear the risks of research feel any of its social benefits. We draw on this literature review throughout the report to highlight how some of the issues raised during the workshop link to the existing literature.

2. How does trust affect public involvement in and engagement with research?

In this section we consider how different aspects of building and maintaining trust might shape public involvement in and engagement with biomedical research. We explore different ingredients of trust, including: features of trustworthiness; the showing of respect; how trust relates to mutual interest; and how wider factors beyond the immediate community can impact on trust. We then explore how trust plays out in the relationships between researchers, research institutions and other actors and groups affected by biomedical research.

There has been little exploration of the role of trust in health research in developing countries, but research into healthcare systems has shown the centrality of trust in patient–provider relationships and in health systems. Trust can influence adherence to treatment, patients' perceptions of provider motivations, therapeutic effects, and cooperation with a healthcare system. Given the importance of health, experience of health systems can also affect public trust in wider authorities and government (Kamuya, 2013).

Building mutual understanding and trust with stakeholders from outside of biomedical research involves constructing and maintaining relationships that encourage consistent, effective, ethical and appropriate interaction with biomedical research. Trust is part of the forming and maintaining of any relationship, and is an indication of its quality. A focus on trust raises questions about the relationships, processes and wider contexts that shape biomedical research. Reflecting upon and evaluating practices in the light of these questions will contribute to a more consistent and effective approach to community engagement.

Box 1. KEMRI–Wellcome Trust Research Programme, Kenya – Trust and responsiveness

The Kenya Medical Research Institute (KEMRI) was established in 1979 (under the Science and Technology (Amendment) Act of that year) to be the national body responsible for carrying out health science research in Kenya. The KEMRI–Wellcome Trust Research Programme was formally established in 1989 as a partnership between KEMRI, the University of Oxford and the Wellcome Trust. It conducts basic, epidemiological and clinical research in parallel, with results feeding directly into local and international health policy, and aims to expand the country's capacity to conduct multidisciplinary research that is strong, sustainable and internationally competitive. The KEMRI logo consists of a staff with a red snake around it. There are strong cultural associations of snakes with death in some communities in Kenya. Furthermore, because the snake is red there have been rumours that when KEMRI researchers draw blood it is to 'feed the snake'. These associations, along with poor understanding of what research is and concerns about the reasons why blood samples are taken, have sometimes led to KEMRI's work being associated with devil worship. KEMRI staff have requested that the logo be changed, and for a few years they had permission from the KEMRI board to remove the logo from everything except official paperwork. However, in 2013 a new KEMRI board was put in place that reinstated the logo. Now the staff must renegotiate its removal from community settings and face renewed concerns in the community.

2.1 What are the ingredients of trust?

Exploring the ingredients of trust helps to clarify what is needed to build and maintain trust. This is not an attempt to reduce trust to a formula. However, thinking about some of the ingredients can help support public engagement and consequently ensure public scrutiny of, and informed involvement in, medical research.

Some of the ingredients explored during the workshop are to do with being worthy of people's trust, and others to do with establishing the enabling conditions for building and maintaining 'appropriate' trust.

Trust needs to be built but also maintained. Workshop participants knew that they could not assume that they had established trust with their respective communities simply because they had been transparent about their work or had taken the time to meet with community representatives. Some descriptions of building and maintaining trust highlighted the ongoing work needed to maintain appropriate levels of trust to enable collaboration with communities without creating blind trust that leaves no room for scrutiny. Others described how fragile trust can be when unexpected events affect a community.

Image 2. The many different ingredients of building and maintaining trust were explored by participants during a World Café session

2.1.1 Being trustworthy

When trust is defined as the "optimistic acceptance of a vulnerable situation in which the trustor believes the trustee will care for the trustor's interest" (*Hall et al., 2001*)*, attention is drawn to the factors that provide reassurance for the person doing the trusting – the factors that indicate that the person or body being trusted is* *worthy of that trust. Organisations may provide frameworks for the development of trusting relationships, including transparent mechanisms for monitoring and disciplinary procedures for breach of trust. But a range of more general characteristics of 'trustworthiness' are also commonly identified, including fidelity/dependability, competence in technical abilities, communication skills, honesty and confidentiality (Kamuya, 2013).*

The experience of the workshop participants confirmed many of these ingredients of trustworthiness. The participants' ingredients included:

- openness and transparency about aims, protocols and procedures, and findings
- being competent in conducting research
- being competent in dealing with the public and affected communities
- adopting forms of communication that are suited to the audience
- establishing and using mechanisms to enable public and community concerns to be listened to
- establishing and using mechanisms to enable the institution to be held to account and to respond to public and community concerns
- establishing and using mechanisms to build and maintain long-term relationships with communities.

Additional ingredients included less tangible factors, like credibility and honesty.

Sensitivity to context

Social, cultural and economic contexts influence how credibility is established and what constitutes competence or dependability. An understanding of local history and the current context is needed to help ensure that sensitive and practical processes are established for listening and responding to community feedback.

Responsiveness

Research institutions need to be reliable and consistent in their practices, and they need to keep their promises and be responsive to community concerns and needs. They should also have mechanisms for managing conflict when it arises. For example, changes to protocols and practices that move away from what has been communicated to or agreed with communities can undermine trust, since they challenge trustworthiness.

Listening to community concerns alone is not sufficient to maintain trust (nor it is ethical and respectful practice). Concerns need to be addressed. They may relate to practices that are seen to be in conflict with cultural or religious values, to misunderstandings about activities that need to be clarified, or be drawn from wider perceptions of the role of international research organisations in local communities. Some will be easier to address than others; addressing some may require time and the involvement of other authorities.

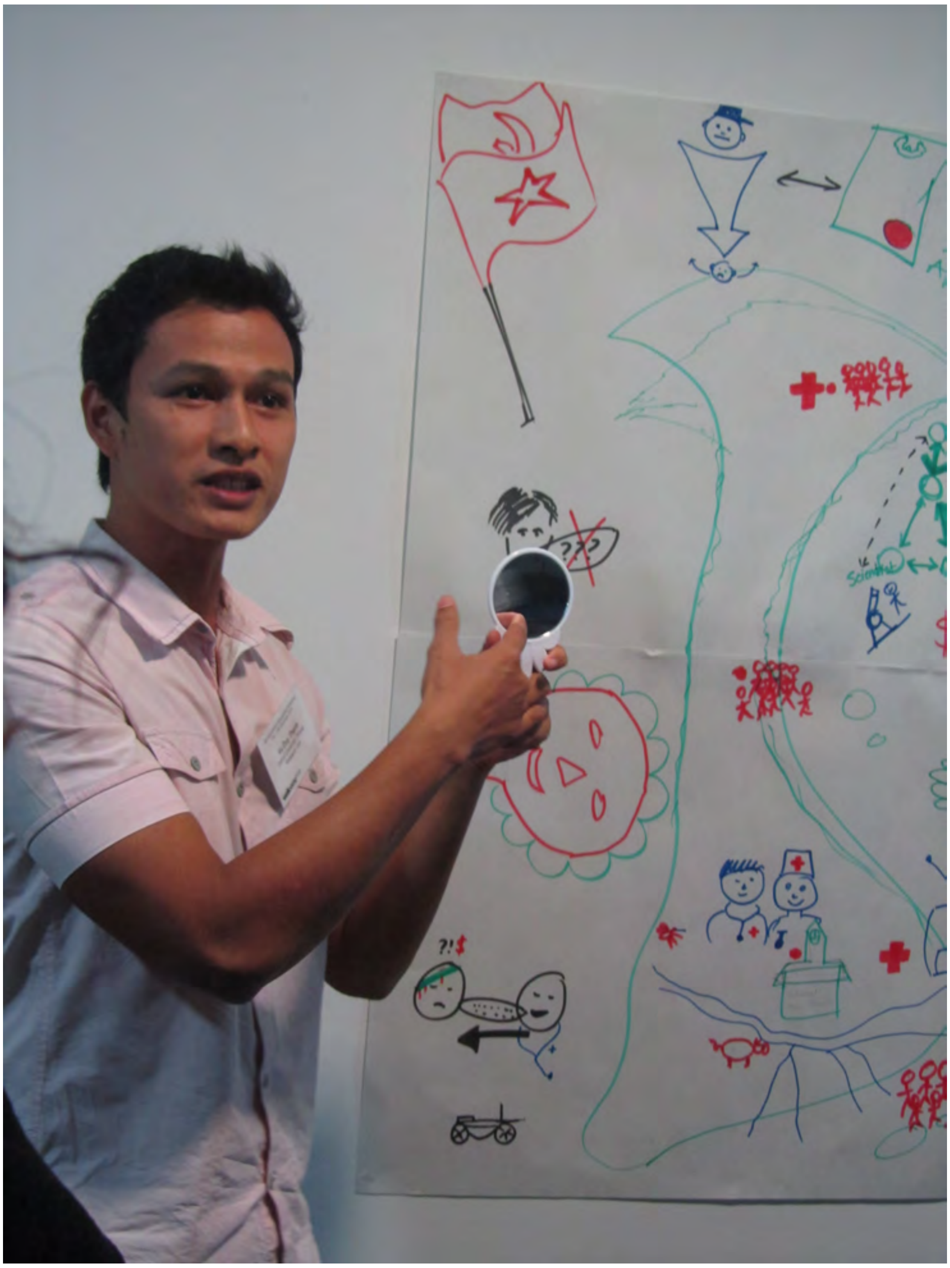
Community concerns cannot be fully predicted, and the capacity to respond to those concerns needs to be built into and costed for in research planning. Agility is needed, rather than what one workshop participant described as "a slow review through various ethics committees". If a response takes too long and people do not see change, then their trust is lost.

If trust is to be maintained then it is important to be clear about the limits of responsiveness and to make these clear to community representatives. It may not be possible to respond to some community concerns promptly or at all. This can be a particularly acute problem when research is undertaken into life-threatening conditions. Perceptions of researchers collecting data or running trials in communities where lives are being lost can lead to severe mistrust, especially if the benefits of such research are not, or are not seen to be, of value to the community.

Trust within research institutions

Public engagement staff need to have confidence in their institution and be respected and well-informed by it in order to recognise if their institution is being transparent and responsive in its dealings with communities. Researchers need to be confident in the quality and consistency of their institution's work.

Image 3. A workshop participant emphasises the importance of trusting oneself and one's institution by holding up a mirror



"We need to trust in ourselves first. So this is a mirror. Looking in a mirror you can see exactly who you are and what you are doing. So you need to trust yourself before expecting the others to trust you."

2.1.2 Showing respect

Showing respect was also considered to be the bedrock of building and maintaining trust. Respect has different forms and can be shown in different ways.

Respect for culture

Showing respect for social and cultural structures, beliefs and practices is important in itself and for developing trust. It is also important to try to understand the relationship between culture and tradition and people's understandings of, and trust in, biomedical research. Respect for beliefs is important for fostering trust. Understanding beliefs and traditions helps identify where community members' concerns might be misplaced and why it is important for research institutions to be open about practices, for example the collection, storage and use of blood samples. The concerns about the KEMRI logo (see Box 1) demonstrate how different interpretations of cultural symbols can contribute to concerns and misunderstandings over research practices.

The starting points for learning about cultural traditions may differ. In Nepal research into acute mountain sickness (AMS) encountered difficulties when trying to carry out research with pilgrims. This highlighted a need to engage with cultural and religious traditions (see Box 2). In South Africa the establishment of the Africa Centre for Health and Population Studies depended upon an agreement with the traditional authorities. The Centre needed to demonstrate respect for cultural traditions literally in order to lay its foundations (see Box 3).

Box 2. Mountain Medicine Society of Nepal (MMSN) – Treatment and prevention of AMS among Nepalese pilgrims: a matter of trust?

The MMSN is an association of health professionals, clinicians and researchers that works to raise awareness of AMS among trekkers, pilgrims and porters, and which conducts research into altitude-related illnesses. Many religious pilgrims to high-altitude sites in Nepal get AMS due to lack of awareness of the dangers of high altitude, poor preparation and a tendency to ascend rapidly. In addition, beliefs surrounding what makes a worthy pilgrim may support an informed disregard for some of the dangers of AMS. A trial with AMS medication in 2011 experienced high levels of non-compliance and dropout as well as unexpectedly low levels of reported AMS incidence. The MMSN project aims to explore a range of potential trust issues in the conducting of the trial along with the ways that AMS and its treatment are understood differently by researchers, health agencies, communities and pilgrims. The project aims to interview field investigators involved in the administration of the trial to gather further information on perceptions of the trial's difficulties. It will seek the views of pilgrims themselves at a pilgrimage site and the perceptions of the community and public agencies from a key catchment area from which pilgrims are drawn.

Box 3. The Africa Centre for Health and Population Studies, South Africa – Respecting tradition

The Africa Centre for Health and Population Studies was established in Mtubatuba, KwaZulu-Natal, South Africa in 1998. It gained initial local acceptance through the building of trust between the researchers and the traditional authority, which is the main authority in this community. The researchers approached the traditional authority to seek land and to seek to work in the area. Trust was built through a number of meetings, out of which a document was prepared that stipulated what the Centre would do in the community and how it was going to do it. Furthermore, the Centre was asked to employ local people. The authority was able to welcome the researchers because "the Zulu tradition is that when a stranger comes you will welcome them". The authority gave the researchers time and space to discuss what they had to offer or wanted. Once this was established and enough trust had been built, the municipal structures of government were also consulted.

Respect for contributions

Respect should be shown for the contributions that people make to the research process by giving their time, making themselves vulnerable by sharing private information, allowing interventions such as providing samples, or participating in drug trials. This includes the voluntary time given by people to consultation processes, advising, attending meetings or receiving research staff in their homes. Respect can be shown through consideration for and attention to the daily challenges and duties of communities, for example by not expecting contributions during particular periods of the agricultural calendar.

Respect for social and political views

People's concerns about and critiques of the social, political or economic role of research need to be heard and respected. These might include, for example, concerns over the role of pharmaceutical or other private sector interests, government agendas, or decision making on how money is spent in their community.

'Showing that you care'

Respect also extends to 'showing that you care'. As one community engagement practitioner expressed it, "Whenever something bad or like a risk happens the researchers need to show the participants that they care. They can even lift their protocol and adopt the cultural values which are adopted by these communities, like at a funeral, so that trust is maintained."

Respect and ambiguity

There are challenges and ambiguities surrounding respect. While it is important to be respectful of beliefs, this should not be at the expense of transparency. Care should be taken to explain and clarify research aims and practices when misunderstandings are linked to beliefs. Likewise, care should be taken to listen and to try to understand community perspectives, which might be multiple and in tension. A further issue of sensitivity for a research institution or staff member is how to deal with cultural or other traditions that run counter to the values espoused by the research institution.

2.1.3 Acknowledging shared interest and reciprocity

Trust can be built on shared experiences but also shared interests and responsibilities. It can be shaped by the kinds of benefits that communities perceive, value or want – not just what research institutions see as values or benefits, whether for the research or the community.

Box 4. The Francis Crick Institute, UK – Measuring trust in a community

The Francis Crick Institute is a new interdisciplinary medical research institute that will focus on research into cancer, heart disease and stroke, infection, and neurodegenerative diseases. The Institute is currently being built and will launch its biomedical research work in 2015. It sees a two-way relationship with the local community as really important; it wants to establish a 'genuine partnership', which will include the development of a 'living centre'. This is envisaged as a community-managed and -determined space within the Institute, aimed at improving the health and wellbeing of the local population.

The Francis Crick Institute project will develop and pilot a simple and accessible evaluation tool to monitor levels of trust in the Institute within the local community in North London, among whom there was some initial controversy about its location. It wants to develop an evaluation tool to assess levels of trust at the start of its work and over time, to help gauge the success of its engagement of the local community. The Institute will explore how best to measure trust, and will look at methods to gather local opinions and to quantify and score them in useful ways.

Reciprocal vulnerability
It is often community participants in research who are vulnerable when accepting to trust researchers and research processes. However, researchers can also be vulnerable and demonstrate trust. For example, KEMRI researchers and field staff in Kenya are required to hand over their identification cards when visiting villages, with them only being returned when they leave.

Benefits in exchange for participation
Healthcare provision and its relationship to research can be important in building and maintaining trust and encouraging engagement in research. While this can be helpful in communities where healthcare is scarce or expensive, it can also unduly influence people to participate in research studies. Reliance on healthcare provision can lead to silenced concerns or reluctant participation for fear of losing that provision. Trust in healthcare providers can influence trust in research processes, and this can mean that too much or blind trust is created, rather than healthy mistrust or scrutiny.

Engagement processes can be mutually beneficial in their own right
Interviews with community advisory group members established by the Shoklo Malaria Research Unit (SMRU) on the Thai–Myanmar border emphasised the benefits of being involved in an advisory board. Advisory group members said that they had benefited from opportunities for learning that could acts as stepping-stones to more important things. In turn the researchers saw benefits because they could ask the advisory group members about the suitability of studies, whether studies were meeting needs, and the logistical aspects of studies: "Things like – is this much blood acceptable to the community? How much compensation should you give?" (Staff member, Shoklo Malaria Research Unit).

2.1.4 Avoiding blind trust

KEMRI held focus groups with community advisory group members during the preliminary phase of their inquiry into the role of trust in community engagement. It was clear from these discussions that blind or unquestioning trust is established through long-term connections, such as clan connections, and is not something given easily to strangers or external institutions.

"Almost all of them say you cannot just trust someone by looking at them. There has got to be something you are trusting about. It's got to be that you know them historically or you know their clan historically or you know the institution they come from. And they were basing their trust on that. And that was very powerful for us in trying to think that a community can naively just trust you because you are researchers. This is a good point for us because it means we aren't just taking communities for granted. They are scrutinising us. They are aware of where you are coming from. They have issues that you need to address and therefore we are building trust over time."
(Community liaison staff member, KEMRI)

However, blind or unquestioning trust can develop when a good relationship with an institution has been established over time. This can prevent scrutiny because research participants and community representatives no longer listen to, nor feel the need to hear information about, new studies or activities. In other cases questioning may be limited because information about research is delivered by trusted intermediaries like government officials, local leaders or doctors providing health services.

This can mean that no meaningful information is shared when new research begins or other things change, and this undermines scrutiny. Some would argue that it verges on an abuse of trust. It can mean that there is poor understanding of what has or is about to happen, and this can lead to problems and broken trust.

Trust can also be built on mistaken expectations and assumptions or misconceptions. When this is the case trust can be eroded if these assumptions and misconceptions are surfaced, even though the participants have come to a better understanding of what is happening.

Ongoing assessment of trust can help establish where relationships are too trusting or where there is little or no trust and in turn can inform changes to redress the balance.

2.1.5 Trust is shaped by wider factors

Trust at the local level is affected by wider events and influences, including the economic, political and social context that surrounds any research programme. The history of previous engagements with research institutions and initiatives is also very important. Furthermore, the media and journalism play a role in shaping wider perceptions and understandings of biomedical research. Much of this may be beyond the control of either the researchers or the community.

History, legacy and reputation
Trust in institutions is important, and in each case is influenced by the status and reputation of the institution in question. Research institutions may be perceived as relatively wealthy and powerful, which may provoke ambivalence in the local community.

"It's not just about [the Malawi–Liverpool–Wellcome Trust Clinical Research Programme]. It's about these differences in wealth. When they see us, a government-affiliated body, with cars, with good food, going all over, paying. The government does not have that. And they question what is it that the Wellcome Trust is doing and how is it contributing." (Community liaison officer, Malawi–Liverpool–Wellcome Trust Clinical Research Programme)

History, legacy and reputation have an impact on the building and maintaining of trust. The immediate experiences of the community with other external researchers and organisations will affect people's willingness to trust any new research initiative. There may also be a longer-term community memory of past disappointments, direct community or individual experiences, or a historical legacy of abused trust and mistreatment. Some workshop participants questioned how North–South collaboration can be promoted when mistrust and injustice continue to permeate this relationship.

However, systems and institutions *are* trusted to a greater or lesser degree. Relationships with different influential authorities and those holding cultural, economic or legislative power can influence perceptions and hence trust in research institutions. Generally, though, there are tensions in relation to public trust in the pharmaceutical industry and its funding of research. At the workshop Dr Ian Harper, a medical anthropologist, presented a number of issues regarding the involvement of the pharmaceutical industry in biomedical research. He highlighted how both media representations of scandals and fictional representations, as in the book (and film) *The Constant Gardener* (Le Carré, 2001), which tells the story of a corporate scandal involving medical experimentation in Kenya, can give the impression that untrustworthy research behaviour is normal and widespread. Alongside this, thanks to widely selling books like Ben Goldacre's *Bad Pharma* (2013), there is growing public awareness of the bias and lack of openness that surrounds the profit-making concerns involved in research. *Bad Pharma* describes the selective presentation of research data by pharmaceutical companies and the tendency for positive research to be much more heavily circulated than negative research. It also points to a lack of openness that prevents other researchers from having access to raw research data. These issues raise questions about the different interests at play. Does research have public interest at heart, or is it about generating profit?

Systems

Dr Harper also highlighted how trust issues are embedded in systems. Can systems be trusted? That is, can it be trusted that the information on drug packaging is correct, or that a recommended dosage is safe? Trust in systems differs from the interpersonal experience of trust, which is central to public and community engagement where trust between individuals can be crucial. There are broader issues concerning trust in systems, including degrees of confidence in regulation – that is, in the production, distribution and prescription of drugs. There is some evidence that private sector interests are having an increasing influence on national regulatory institutions. As a result public concerns may be raised as to who sits on these bodies, whose interests are being served and where there might be a risk of corruption. Furthermore, political contexts and systems shape both these regulatory systems and how and whether research is conducted. Additionally, ideologies impact on what research is conducted and trusted; for example, US-funded research encounters distrust in Nepal as it conflicts with the Maoist ideology within the country, leading to communities protesting and refusing to consent to studies.

Box 5. Science and trust: the bigger picture of economic and historical influences
Excerpts and observations from the keynote presentation by Professor Hilary Rose

Debates about the ideology of science have rumbled on since the 16th century. Francis Bacon presented science as neutral, 'objective' and standing above culture. While they have always been controversial, such claims are harder to sustain in a contemporary world where science and technology are increasingly merged as 'technosciences' and exist as part of everyday life for many people. At the same time, the neoliberal global economy has seen the rise of the influence of the profit motive. Today's scientist-entrepreneurs have the potential to make fortunes out of new discoveries and patented technologies, as neuroscience, biotechnology and genomics have become big business.

The growth of computing has contributed to the merging of science and technology, allowing the handling of immense quantities of data and a broad digitisation of knowledge. The work of scientists has also been transformed, from busy laboratory work and lively discussions and debates to desk- and computer-based work undertaken by silent and often solitary technicians.

The history of the uses of science and medicine is all too easily ignored among narratives of 'progress' and 'discovery', and yet it underpins ambivalence about scientific research for some people. Many African Americans remember the infamous Tuskegee syphilis research carried out between 1932 and 1972 on African-American men, who were neither informed about their syphilis nor treated for the condition.

The disproportionate investment in global health research that addresses the health priorities of the North rather than South – the so-called 10–90 gap – is a reminder that science and medicine may not serve everyone's interests in equal measure.

When members of the public do have concerns about scientific projects, dismissing them rather than taking them seriously can have consequences. In the early 2000s the UK Biobank undertook a public consultation in which serious reservations about the biobank project were voiced. In a resulting report on the consultation (Wellcome Trust and MRC, 2000) these were characterised as negative attitudes instead of being probed to understand more. They were not respected as legitimate concerns. Subsequently, when the UK Biobank started to try to recruit people to donate, they found that nine out of ten people refused. This was a much higher refusal rate than the biobank had envisaged (see also Rose and Rose, 2012, p. 201).

There is also a tradition of seeking to hold science to account and working towards a science that is more democratic and accountable to 'the people'. Professor Rose was involved in the radical science movement, which emerged out of the anti-war movement in the USA during the 1960s, initially to resist how research, such as that into toxic agents, was being used in the Vietnam War.

Scientists are more open to public engagement these days. Public engagement can be a dialogue about the aims and priorities of science and not just about recruiting people to take part in studies. However, it is also important to remain critical. Contemporary efforts to build community and public engagement may be double-edged – they may be an attempt to manage public misgivings about science and equally play a role in holding science to account.

The influence of the media on perceptions of research

Media scandals can have a significant impact on all aspects of health research and healthcare. While thorough and responsible investigative journalism can play an important role in maintaining scrutiny and keeping the public informed, unwarranted concerns can be raised by poorly researched and unsubstantiated journalism. This can be compounded when journalists have poor access to scientists and research institutions and must rely on other sources.

At the workshop Rachel Jones, an international media consultant, presented her Wellcome Trust-supported work with journalists in East Africa. Mutual trustworthiness is a key principle of this work. Journalists need to be able to trust that they will have access to researchers who will help them and help illuminate their research topics. Researchers have to trust that journalists will get it right. Rachel works to support journalists who want to cover health issues, and is trying to create a brand for health reporting for African journalists who want to establish themselves as health specialists.

In many cases information about health, health policies and new research is released by a ministry of health press release or a ministerial speech. These lack opportunities to establish a dialogue and an understanding of context. Short timescales, particularly for daily news reporting, mean that stories are poorly researched and sourced and can cause harm. A newspaper headline about, for example, an alleged link between vaccines and autism can have a major impact on the uptake of vaccination and cause significant long-term damage. Journalists' research and due diligence are insufficient if they lack the skills, time or opportunities to thoroughly research and explain the contexts of their stories.

This can be addressed through better relationships with research institutions, in which journalists have access to researchers and time to understand, observe and ask questions. Not only does this help explain the research being undertaken and its findings, it also enables media specialisms to develop. The journalists learn how to properly research health issues, work on context and scrutinise. Importantly, they also develop the confidence to ask questions.

2.2 Relationships and trust

In this section we look at a range of relationships that were identified as important for building effective public and community engagement efforts. These include relationships between researchers and communities, the role of intermediaries such as public engagement practitioners, relationships with community representatives on community advisory boards, and relationships with a range of local authorities. What makes community members trustworthy to researchers was also deemed important. The relationships and their associated challenges described here are not exhaustive, but reflect many of the issues, benefits and challenges relating to trust that emerged at the workshop.

Trust is founded and maintained to a large degree through the forming and maintaining of relationships between different stakeholders involved in research and public engagement about research and science.

Developing trusting relationships is an iterative process, and research into health systems has shown how people can dynamically make distinctions – alliances or cleavages with trusted or distrusted others – depending on whether they are seen to act for or against their individual interests (Kamuya, 2013).

Images 4 and 5. Using forum theatre to explore relationships and trust

Key to building and maintaining trust, or a healthy mistrust, is understanding and managing the range of relationships at play in involvement in and engagement with research, including temporary or contingent alliances. Discussions at the workshop identified a wide range of different relationships that may be important to public engagement in biomedical research in any setting. The seven trust projects linked to the workshop also illustrate the diversity of these relationships, with each attempting to focus in on the relationships most relevant in its context to explore where trust plays a role (see Box 6).

Box 6. Understanding the range of relationships – examples from Kenya and Nepal

Each of the projects investigating trust is considering the different relationships that are integral to its engagement with the public and/or specific communities. KEMRI, in considering trust in relation to its overall public engagement structures, has identified primary stakeholders that include:

- community members often involved in research
- community leaders
- research participants
- Ministry of Health staff
- researchers and fieldworkers at the research centre.

It has also identified secondary stakeholders that include:

- the national mass media
- other policy makers
- funders and donors
- ethics review committee/board members
- consortia involved in collaborative research.

Representatives from the MMSN in Nepal mapped out the different stakeholders invested in the issue of pilgrims suffering from AMS. Despite focusing on one constituency and one disease in one study, the stakeholders are also wide-ranging, and include:

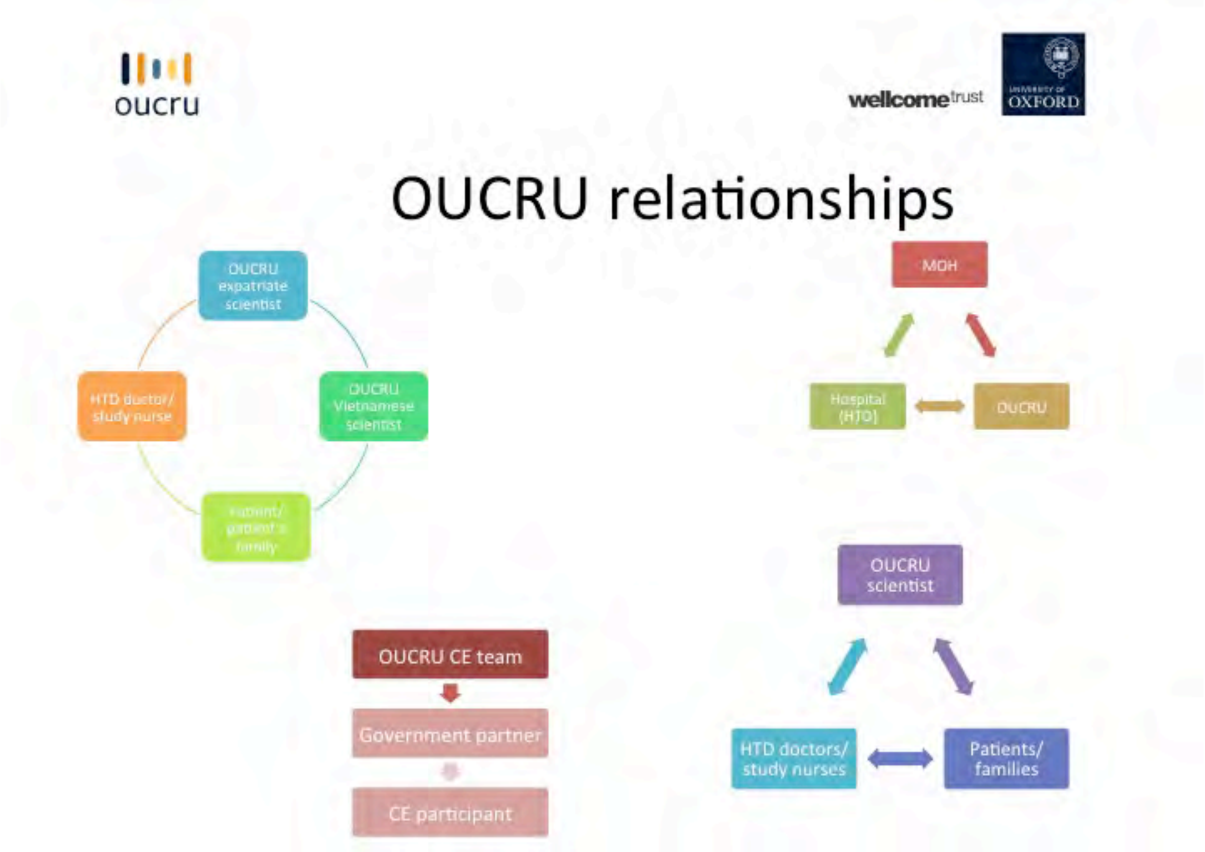
- rapid trial investigators
- key stakeholders like the MMSN and the Himalayan Rescue Association
- the Nepal Tourism Board
- journalists
- the pilgrims' communities, including community leaders and community groups
- religious leaders
- the pilgrims themselves.

The relative importance of relationships differs between settings. Social, cultural, economic and political structures will affect how different relationships are maintained and how trust is established. In Vietnam all research relationships are mediated by government officials, and in the case of expatriate researchers, by translators. The mediated nature of these relationships means that trust is in some way deferred or mediated (see Box 7 and Figure 1).

Box 7. The Oxford University Clinical Research Unit (OUCRU), Vietnam – Deferred or borrowed trust

The OUCRU conducts research on tropical diseases, including dengue fever, malaria and influenza, informing national and international health policy. It works closely with Vietnam government ministries and aims to ensure that there is a critical mass of trained Vietnamese clinicians and scientists. The OUCRU 'trust' project will look at where research participants place their trust when scientific research is always to an extent conducted through government intermediaries. It will explore levels of trust in the relationships between the OUCRU, the broader scientific community, national government partners and the public in a health research setting in Vietnam. Research always has to go through a third party to reach patients or participants in research trials, and it is the same for involving the public in engagement activities. Given this indirect relationship, the project will explore where trust is placed by patients/participants recruited into research trials and engagement activities.

Figure 1. OUCRU relationships



In Vietnam all research relationships are mediated by the government. This diagram illustrates the different actors involved at the institutional level, the community engagement (CE) team level and the individual research scientist level.

At the institutional level the Ministry of Health (MOH) approves and mediates the work of the Oxford University Clinical Research Unit (OUCRU) with the Hospital for Tropical Diseases (HTD).

The OUCRU community engagement team engages with different communities through a government partner who recruits participants.

At the HTD, OUCRU expatriate scientists and Vietnamese scientists work with patients and their families in collaboration with hospital study nurses and doctors.

Understanding different groups and needs within communities

Understanding and managing the relationships and aspects of trust important to public and community engagement requires looking beyond a generalised idea of community relationships and focusing on different groups or practices within those communities. For example, the Africa Centre for Health and Population Studies is interested in investigating the trust, or lack of trust, placed by adolescent girls in authorities of different kinds (see Box 8). Adolescence is a temporary state so there will always be new members of this constituency, and hence relationships and trust building have to be continuously renewed and adapted. This is the case for all work with people at a particular stage of life, including childhood, old age and pregnancy.

Box 8. The Africa Centre for Health and Population Studies, South Africa – Health-related challenges for adolescent girls in rural South Africa: cultural nostalgia or a lack of trust in government policies and services?

The Africa Centre for Health and Population Studies carries out research on population and health issues affecting a rural population with one of highest burdens of HIV in the world. It runs a large rural primary-care-level antiretroviral treatment programme, which is linked with clinical research, HIV surveillance and household demographic surveys to monitor HIV trends. Its research includes exploring the role of social support in HIV prevention, treatment and care, as well as exploring the strengthening of health systems. The Centre has a strong partnership with the community, drawing on input from local leaders in the traditional authority, supporting a Centre-specific community advisory board (CAB) and routinely sharing research outcomes with the community.

There is currently interest in seeking to redress the lack of research on adolescent girls and the range of issues that affect their health. In a context of multiple challenges – poverty, violence against women, sexual abuse, lack of information and stigma – girls continue to lack knowledge of and access to healthcare services. Transactional sex, involving girls and women in risky sexual relationships and concurrent sexual relationships, is also a feature of their context. Traditional practices are often assumed to perpetuate gender inequality and gender violence – and yet what is 'traditional' and what is considered 'right according to policy and healthcare services' is unclear. Girls are caught between both sets of ideas and practices and there is a lack of clarity in both spheres. The project aims to explore where girls place their trust and whether (and how) trust might be an issue in their healthcare decisions. Learning from this research will inform the Centre's engagement strategy.

Messages can spread quickly through small communities and get reproduced in different ways that can be hard to manage. An example from South Africa serves to illustrate how this can happen, but also how solid relationships built on trust and good communication can help to repair any damage.

"In a TB study in the community a nurse gave a child an injection. Through that injection the mother was going to know if the child was infected or not infected. If the child is not infected some kind of reaction will happen, like maybe a little rash or something. The mother had not understood, and when the child got a little rash the mother thought the nurse had infected the child with TB... The news went to the traditional authority and the community didn't want anything to do with the Africa Centre any more, so the matter was taken back to the traditional authority, CAB [community advisory board] members were called and then everything was explained. The CAB

members had to go back to the community to explain." (Community liaison officer, Africa Centre for Health and Population Studies)

Researchers and public engagement professionals bring with them their individual backgrounds and characteristics, which will influence relationships of trust. One of the questions asked by the Nepalese researchers in regard to the disappointing participation in their study compared to those conducted by Western researchers was whether people trust Western researchers more. In other contexts importance is placed on recruiting local fieldworkers and public engagement staff to ensure a greater understanding of context and a higher chance of developing trust.

2.2.1 The role of intermediaries

There are a range of different intermediaries between research institutions and study communities. They are crucial to building and maintaining trust. Common types of intermediary include public engagement professionals, members of community advisory boards, the media, and different regulatory and governmental authorities; field administrators and investigators can be regarded as intermediaries too.

Public engagement professionals

Public engagement professionals (PEPs) play a crucial intermediary role between communities and research institutions. They foster trust in both directions. For PEPs to confidently undertake the role of fostering trust in a community they need to be confident in the trustworthiness of their institution. This means being both equipped and allowed to scrutinise research protocols and other institutional frameworks.

Some PEPs at the workshop stressed the need to spend more time sharing the outcomes of engagement work with researchers so that they can understand better what patient engagement achieves, as well as what community members think, how they engage, the kind of scrutiny they offer and the implications of blind trust.

PEPs are at the forefront of dealing with community mistrust and concerns. They take concerns back to institutions, where the response may be slow if a concern is of low priority or if it is complex (which may make it difficult to handle within institutional structures). An intermediary may be blamed by a community when unanticipated events occur, or when changes that a community wants to see do not happen. This is the case even when an intermediary puts forward concerns to their institution but the institution does not respond.

"Sometimes you allow yourself to be blamed, but within that blaming you try to form a relationship where you tell people what's happening – only that kind of explaining on the spot may not always work because already the trust is broken." (Community liaison staff member, KEMRI)

Community advisory boards/groups

Community advisory boards/groups are another key set of intermediaries. They are made up of members of the public and are usually voluntary. As semi-formal bodies, they often only have advisory authority. A community advisory board/group shares information from a research institution with a community. It also then gathers feedback from the community and shares it with the research institution. The informality of this role places a heavy burden of trust on it, requiring researchers and PEPs to trust that the voluntary representatives are true to their responsibilities and really communicate, represent and scrutinise.

Most of the examples discussed at the workshop included the use of community advisory groups to maintain channels of communication. These channels provide a space for communicating what is happening with an institution and its research, as well as soliciting feedback on research practices and listening to community concerns. Relationships of trust between advisors and institutions develop over time. These channels help to communicate institutional goals, communicate practices and frameworks for ensuring ethical and good practice, and also help institutions learn how to communicate effectively and clearly and to listen to community concerns.

An advisory group is made up of individuals. The role these individuals play in their relationships with researchers differs from the role they play with groups within the wider community. The T-CAB, a community advisory board (CAB) on the Thai–Myanmar border that advises the Shoklo Malaria Research Unit, is made up of people from a range of backgrounds (including, for example, a teacher, a 'housewife who became a cook', and a pastor) and different ethnicities. This means that the T-CAB's reach extends into different communities and groups and that it represents a complex mix of concerns and needs.

Relationships are particularly fragile in areas where populations are less stable, such as the Thai–Myanmar border.

"The clinics along the border serve migrant workers. People are poor. The Burmese refugees are fleeing Burma because they are persecuted. There's a lack of education and high rates of illiteracy, poor healthcare. And the border is porous because it is divided by a little river and you can cross the river all the time. The population is unstable. There are landmines, especially on the Burmese side; there's a lot of armed groups; there's a lot of fighting, and in the [last] year or two there has been a lot of movement along that area and a lot of increased economic activity." (Staff member, Shoklo Malaria Research Unit)

An evaluation of the T-CAB after four years of operation revealed some aspects of trust that, with care, have developed over time.

"The CAB does not give approvals. It is a formal board but it wasn't constructed under any institution because there simply isn't any institution. So this is a voluntary thing and researchers seek and value the CAB's blessing, and I think trust emerges there." (Staff member, Shoklo Malaria Research Unit)

"CAB members trust researchers. Trusting that they will do their best. Trusting that they will take their comments seriously." (Staff member, Shoklo Malaria Research Unit)

"CAB members have the confidence to question researchers, and this was not present when we first started because there was [only a] very basic knowledge of science, [and] of the human body for that matter." (Staff member, Shoklo Malaria Research Unit)

"The CAB members are drawn from different villages. They started trusting each other discussing amongst themselves and through many heated discussions. And remember that this is an area where people feel vulnerable about saying something for fear of being persecuted. So they are from a very hierarchical society, so they come from different religious backgrounds, different political affiliations, different social status but they trust each other. In the interviews they don't say they trust each other but it is very obvious from the way they talk and question each other that they do." (Staff member, Shoklo Malaria Research Unit)

Authorities
Relationships with authorities shape relationships with communities. In Vietnam, for example, this is highly formalised, with all contact with patients and the public being mediated via government officials (see Box 7 and Figure 1). At the Africa Centre for Health and Population Studies, overall decision making about research undertaken in the area is mediated via traditional and then elected authorities, but contact with the community is direct once these authorities have been consulted (see Box 3).

Relationships between communities and different authorities, and communities' trust in those authorities, can damage trust in research institutions as well as help build it. One workshop participant highlighted a situation in which a community took the word of government authorities as the absolute truth. If a researcher thus contradicted a government official this would seriously undermine the researcher's relationship with the community.

Representativeness
It is important that an individual involved in an advisory role or as a representative of the community within which they live has both the trust of their community and the research institution working with them. Issues of representativeness come into play when it comes to community members, existing community authorities and influencers serving as intermediaries. In the case of community advisory boards it is also important to ensure that they are made up of a range of people – not just those commonly seen as having authority, but also people from a mix of backgrounds and with a variety of experiences who are typical of that community and of those who might be participating in research.

Where populations are more stable, efforts can be made to ensure that the board goes some way to being representative of the make-up of the community. This remains a challenge in more volatile contexts, such as the Thai–Myanmar border.

"We call it a community advisory board, but members are from a hundred kilometres along the border so they're not a real community and it's an unstable population. Representativeness is probably non-existent here. The average community member is displaced, vulnerable, illiterate, poor and all the rest of it. But people who sit on the community board have to be able to read and write in their own language, [and] have to be able to stay in that area for a few years and not be under threat. So it's quite difficult." (Staff member, Shoklo Malaria Research Unit)

In addition, the format and conduct of meetings may require levels of literacy and familiarity with meeting procedures that may automatically exclude some people.

2.2.2 What makes community members trustworthy to researchers?

Trust is a two-way thing. Researchers and public engagement professionals also need to trust communities. There was some frankness during the workshop about how difficult it can be to trust community members. One participant described the following situation:

"We've got a radio programme that is aimed at conveying science or research to the general public. And with that programme we had established what we call radio listening clubs. And we're using them to pass on information to the communities. So the question that we're asking ourselves is: can we trust [the people at the radio listening clubs] to pass on accurate health information to other community members?" (Community liaison officer, Malawi–Liverpool–Wellcome Trust Clinical Research Programme)

Others questioned whether they can trust feedback from community advisory groups, that is, whether they can be sure that the feedback represents the views of other community members.

Beyond the issues of trusting community members to share or collect information, there are also the issues of trusting research participants to give accurate information to fieldworkers and to adhere to trials.

Trust involves accepting that it is legitimate for communities to scrutinise, as well as accepting the legitimacy of what emerges from that scrutiny. However, this is not to say that researchers should have blind trust in the feedback received from communities. When questioning strangers or authority is not a cultural norm, relationships and opportunities for people to meet, talk and develop confidence need to be fostered to enable scrutiny. Silence should not be interpreted as consent or trust. When there is not much familiarity with research, communities need to be supported to help develop a culture of critical scrutiny. This requires informing and educating people about biomedical research as well as the protocols and objectives of the research that an institution is undertaking. It means working through issues with care and usually on more than one occasion. In addition to accepting and recognising that community views need to be heard and taken into account, institutions need to trust that communities are being honest and open, for example in contexts where benefits like access to healthcare are provided in exchange for, or are closely linked to, participation.

3. Assessing and addressing trust

Trust holds a central role in involvement in and public and community engagement with biomedical research. Therefore, it can be valuable to periodically reflect on and assess trust. This in turn helps when planning how to build trust where it is weak or create opportunities for scrutiny where it is too strong. In the previous section we explored many of the ingredients of trust. We now turn to thinking about how to assess and address trust on an ongoing basis, to maintain strong relationships between the public and research institutions.

In this section we consider how some of the ingredients of trust described in the previous section might be assessed. We draw out some questions from the workshop discussions that may help with such assessment and outline some practical steps to help address trust in engagement with research. Each of the following subsections presents a different way of considering trust in relation to good-quality public engagement. First we look at how trust works within a community and within a research institution. Then we consider a set of cross-cutting issues that are relevant to trust in most relationships, including communication, representativeness, respect, responsiveness and reciprocity. Considering trust from these different viewpoints also helps address some of the other factors (outlined in section 2) that influence the establishment of trust, including:

- identifying and tackling blind trust
- assessing how wider factors such as legacy, reputation, history, media influence, legislative and regulatory systems, and commercial interests impact on trust
- building and maintaining relationships.

Image 6. Trust needs to be nourished – an image from the World Café session

3.1. Assessing trust and trustworthiness within the community

Understanding the landscape of trust within a community helps both when building and maintaining trust and when assessing the degree and nature of trust between research institutions and the public. Understanding who is or is not trusted in a given community, and why, can help indicate how to build trusting relationships with different individuals, groups and authorities within that community.

The following questions might be useful when mapping the landscape of trust within a community:

- In whom or what do people trust?
    - Do different groups trust different authorities and systems?
    - Is it clear who trusts whom and why?
    - Who has power and influence and what is their attitude to biomedical research and/or external institutions?
- What are the key channels of communication that people use?
- How do different cultures and values operate in the communities or areas where the institution works?

Considering the role of trust within a community should extend to how perceptions shape trust. In Malawi, for example, the Malawi–Liverpool–Wellcome Trust Clinical Research Programme is investigating how community advisory group members are perceived by communities, how communities perceive the researchers and vice versa (see Box 9).

Box 9. The Malawi–Liverpool–Wellcome Trust Clinical Research Programme, Malawi – Exploring trust in community engagement

The Malawi–Liverpool–Wellcome Trust Clinical Research Programme (MLW) conducts health research and trains laboratory scientists, working with the Malawian Ministry of Health on their malaria, HIV and TB control programmes. MLW's current project seeks to explore whether community advisory groups (CAGs) in health research enhance trust between researchers and communities. Key areas of investigation include how CAGs solicit views from communities and how community members perceive CAGs. Related investigations are concerned with how well CAGs represent community views to researchers and how researchers respond to feedback from CAGs. Learning from the project will help illuminate the role and effectiveness of CAGs in community engagement work.

3.2 Assessing trust and trustworthiness within an institution

Undertaking a health check of the trustworthiness of a research institution can be valuable since researchers and public engagement professionals need to have confidence in their institution before expecting trust from others. The following aspects of institutional practice might be considered:

- *Mechanisms and frameworks intended to demonstrate trustworthiness:*
    - What are these mechanisms and frameworks?
    - How are they used?
    - Are they fit for purpose and if not, how might they be improved?
- *The quality of communication (internally and externally):*

    - Are there examples of gaps in understanding that could have been avoided through better communication?
    - What other, more appropriate forms of communication or different communication channels might be used to address this in future?
    - Are there sufficient opportunities for sharing information about research and about public engagement activities?

The relationship of the individual to the institution

Assessing how trust is faring within an institution can be a basis for establishing greater trust outside. If one feels trusted within one's institution and trusts others within the institution then that can impact on community engagement. Questions to consider include:

- Do researchers and public engagement professionals (PEPs) trust the institution's working practices and protocols?
- If there isn't trust within the institution then why should the public trust it?

This can operate on a personal level:

- What does it mean to be a trustworthy individual?
- What does or should the institution do to incentivise trustworthy behaviour by researchers?

A number of *practical suggestions* for addressing trust and trustworthiness within an institution emerged during the workshop.

PEPs need to be able to trust their institution and be able to question and scrutinise internally if they are to work effectively to build trust in communities and foster critical scrutiny externally. This needs to be considered as legitimate within the institution. PEPs also need to be equipped with information and training to ensure that they have competency in their institution's area of science, so that they can critically scrutinise, question and hold researchers to account before asking the community to trust them, and to ensure that they can answer questions from the public. The following questions may be useful when considering the role of PEPs:

- Are there opportunities available within the institution to build the capacity of PEPs?
- What opportunities are there for researchers to hear from PEPs about the public's experience, understanding of, attitudes to and willingness to engage with biomedical research in general and their work in particular?
- What opportunities are there to hear the concerns of the public?
- Do researchers and PEPs enjoy different levels of trust among the communities and constituencies with whom they engage?

A weakness in providing feedback to communities during the later stages or at the end of studies was identified by workshop participants.

It is common for community engagement to drop off once data collection has been completed. In some cases this can lead to a failure to keep people informed or share what researchers have learned. Sometimes engagement stops due to funding and logistical reasons. The results of a study emerge a long time after its data collection phase has ended. People are no longer employed locally for that study so the mechanisms for providing feedback are lost. Ongoing engagement could be built into the planning and resourcing of every study and donors could make this a requirement. Useful questions to consider include:

- Is there sufficient engagement at the end of research studies?
- Is time and effort given over to feeding back to communities about what has been learned beyond the initiation and data collection phases?

When considering an institution's relationship with the public it is important to take a longitudinal and cross-institutional/cross-study approach. Where there is a broader longitudinal approach to public engagement that is not tied to individual study plans and budgets there might be better ongoing feedback about results. Longitudinal approaches also impact on the legacy or standing of an institution within a community.

3.3 Approaches to building and maintaining trust in key relationships between communities and researchers

In section 2.2 we explored the importance of maintaining good relationships between the public, communities and research institutions, and the role that public engagement might play in this. Relationships are founded on trust. When fostering, maintaining and improving trust it is important to have a good understanding of the nature of the relationships and influences within which you are working. This involves assessing and addressing trust within institutions and within communities as outlined above. It can also be useful to assess and address trust in terms of communication, representativeness, respect, responsiveness and reciprocity.

Communication
"The community may consume or not consume depending on ***how*** *it is communicated to them."* (Workshop participant)

The quality and relevance of communication impact on relationships, as do the choice of channels for communicating and the opportunities provided for dialogue.

Communication needs to happen through a range of channels (such as public meetings, radio broadcasts and one-to-one conversations), in a range of formats and languages, and with sufficient opportunities for dialogue.

It is important to assess how well representatives of research institutions communicate with the public. As one community liaison officer from the Malawi–Liverpool–Wellcome Trust Clinical Research Programme asked at the workshop, are we "giving the right information, in the right language, in the right dosage to enable people to make sense of it?"

Kenyan participants shared an example of when the reasons for data collection were poorly communicated, with this having a distressing effect on the families of the research subjects:

"We also find that trust is important when we get findings and how we explain things. For example, we sometimes measure the height of people or of children – for example, to know what is the dosage of drugs. But in the process this person has questions because maybe we don't explain why. In this case they think we are measuring to make their coffin. The children have to lie down there and get the measurement and the mother is thinking – so now the coffin is being made." (Community liaison staff member, KEMRI)

How good are the channels of communication and the dialogue with key influencers and authorities and with other groups in the community?

- Are the right formats and languages being used?
- How well do community intermediaries share information?
- How can this be improved?

If a community advisory group member has not understood the process or has not felt able to ask questions, then the information they share with other community members may be unclear or incorrect. The following questions can be considered to help avoid this:

- How can community intermediaries be better supported to understand scrutiny and to be able to ask a broader range of questions in relation to it?
- What written or other material might be prepared to help community representatives share information and enter into dialogue with others in the community?

Representativeness
Is trust being built with all parts of the communities who are affected by research?

It is important to be aware of the extent of the representativeness of community advisory board members and other community intermediaries. It can be challenging to ensure representativeness in complex and often fluid contexts, but it is important to find ways of engaging with people whose views are seldom heard or who do not have the stability in their lives required to be part of an advisory group. Questions to consider include:

- Do the researchers trust the community representatives?
- If not, what information, training or opportunities for collaboration (on both sides) might address this?
- Even if the existing representatives are trusted, are they adequately representative?
- How effective is their sharing of information with the community?
- Do they seek community views, or is their feedback based on their perspectives alone?

Respect
How is respect shown to a community? This should be considered in relation to culture and tradition, local authority structures, day-to-day challenges and practices, political and economic analysis or critique of international researchers and science, and the time and contribution given to research.

Researchers and engagement professionals need to be aware of community values, norms and beliefs that conflict with their own, or with institutional policies and practices. Such conflict may influence:

- the extent to which researchers accept the legitimacy of different kinds of community concerns
- how a research institution deals with cultural and other traditions that run counter to the values that it espouses
- changes to policies and practices, which might be made to ensure respect for the communities affected by research.

The following questions may help inform the above:

- To what extent do the institution and its staff accept and recognise that community views need to be heard and taken into account?
- Do scientists trust the public enough to share the negative results as well as the positive ones?

These questions also relate to the social, economic or political critiques that may be made by community members.

Research institutions, with the help of their community representatives, can reflect upon their research activities and make practical adjustments to ensure that they are showing respect to people for their time and contributions. Institutions might reconsider the timing of interventions, and work to ensure respectful conduct during research activities, the sharing and appropriate communication of findings, and openness to feedback on the conduct of institutional staff in the field.

Responsiveness
Institutions and the people who work within them need to review how they have (or have not) listened and responded to the views of the different communities and stakeholders involved in their research, in order to assess and address responsiveness to community concerns:

- What are the concerns that have been raised and how have they been addressed?
- Are there examples where protocols or other aspects of the research institution's practices have been altered to reflect community concerns, feedback and scrutiny?
- Has attention been paid to the kinds of benefits that people value or want and not just to what researchers see as value or benefit?
- How is responsiveness managed?
- Is there sufficient agility and resourcing to allow for unforeseen changes within research activities in response to community concerns?
- How are engagement professionals supported by the institution to ensure that they do not bear the brunt of community dissatisfaction?
- If no concerns are being shared is this because there is blind trust?

Reciprocity
How are issues of reciprocity understood and managed? Research institutions need to be aware of what communities and research participants value in terms of the benefits of participating in research. Institutions also need to recognise where this differs from what they perceive to be of benefit. Attention should also be paid to how particular benefits linked to participation in research affect people's willingness to scrutinise or to voice concerns.

Additionally, institutions and public engagement professionals should plan and assess engagement processes to ensure that they are mutually beneficial. Questions to consider include:

- To what extent are there wider benefits of participation for community representatives?
- What opportunities are there to develop wider benefits?

Finally, reciprocity is not just about shared benefits but also shared responsibility and care:

- How do researchers show that they care?
- Do researchers experience vulnerability?
- Is it only research participants and the community who experience vulnerability?

3.4 Key dimensions of trust between the public, communities and research institutions

The table below summarises some of the key relationships and areas that the workshop discussions identified as being of importance to the building and maintaining of trust between the public, communities and research institutions. These findings, together with the questions outlined above in the rest of section 3, may provide a useful starting point for assessing and addressing trust in any community or public interaction with research. These different relationships and ingredients of trust are of greater or lesser significance in different places. This means that it is important to pay attention to the specific mix of such factors in any particular context, rather than expecting the same things to be important everywhere.

Table 1. A summary of the key relationships, ingredients of trust across relationships and wider contextual factors that may be relevant to monitoring and assessing community and public involvement in research

Key relationships	Ingredients of trust across relationships	Wider factors affecting trust
Community relationships • Relationships within the community. • Relationships between research participants and the rest of the community. • Relationships with research intermediaries.	**Processes of representation**: representing the community in structures and advisory boards as they relate to the research process. **Quality of communication**, openness, transparency, use of appropriate channels. **Respect** for culture, contributions, and social and political views and analysis; 'showing that you care'. **Responsiveness**, sensitivity to context.	**Local history** of and perceptions of health and other research. **Previous research efforts'** practices of involvement, including 'benefits' offered in exchange for research participation. **Relative wealth** of the research institution. **Reputation** of the research institution. **Availability of healthcare** and social
Researchers' relationships • Relationships with participants in research. • Relationships with public engagement practitioners. • Relationships with local intermediaries influencing the research process. • Relationships with research institutions.		

Research institution relationships • Internal relationships: trust within the research institution. • Relationships with researchers: providing consistent procedures and support for researchers. • Relations with the public: the reputation of the research institution. • Relationships with intermediaries (e.g. local authorities, the media).	**Reciprocity**: showing reciprocal vulnerability, clarity on both shared and different interests, and clarity on the benefits of involvement in studies.	support where research is being conducted. **Relevance of the health issue** to the local population.
Intermediaries (between researchers and communities) Relations between • public engagement practitioners • community representatives • local authorities • the media and • researchers • communities • research institutions.		

Conclusion: What does the right kind of trust look like?

The wide-ranging exploratory discussions at the Fifth Wellcome Trust International Public Engagement Workshop confirmed that trust is important to many aspects of involvement in and engagement with research. At the same time, the discussions shed light on what makes for effective engagement and how this both builds and indicates trust. The dialogue at the workshop helped build an understanding of where and how trust matters in different engagement efforts and how it might be assessed or nurtured.

A key insight from the workshop was that a balance needs to be struck between there being too little and too much trust. Too much trust can result in a lack of understanding and impede scrutiny; too little might undermine the basis for any kind of collaboration or even actively hinder it.

Some academic literature on trust suggests that its benefits may include stable relationships and cooperation – which may in turn increase efficiency and reduce transaction costs. Equally, however, trust – if it is too unquestioning – may encourage a lack of scrutiny of authorities and leaders, risking exploitation and corruption (Kamuya, 2013).

4.1 A ‘healthy distrust’

Achieving a ‘healthy distrust’ or critical scrutiny might be a sensible aim for engagement, as opposed to having too much trust (‘unquestioning faith’) or too little (immediate mistrust and rumour). In the context of the challenges of conducting biomedical research in developing countries, encouraging such a critical scrutiny and ‘healthy distrust’ may be a realistic middle ground for community and public engagement efforts. Such an emphasis is consistent with an ethical approach to community involvement and helps to ensure that research efforts, however good their intentions, can be held to account by local communities and the wider public. So, for example, some instances where potential subjects decline to participate in research could be an indication of a good balance of trust.

4.2 Trust – implicit or explicit?

Some participants in the workshop questioned whether an explicit focus on trust was helpful or whether trust might be better understood or developed as an implicit aspect of engagement. In some settings surfacing and explicitly referring to trust might risk shifting and damaging relationships. It may be that trust exists because of good practices and mechanisms and because sufficient time is given to building relationships. This in turn may be part and parcel of practising open, ethical and respectful research and engagement, rather than being due to working with the explicit aim of gaining trust.

An implicit focus on trust would imply observing and being aware of trust, or monitoring trust, rather than directly asking about it. In this way trust may be useful as a ‘sensitising’ idea or concept, alerting practitioners to important aspects of relationships and acting as a barometer or indicator of the quality of engagement in any setting, rather than being a predetermined goal.

4.3 An ongoing commitment to engagement

Our exploration of trust during the workshop highlights the importance of maintaining healthy mistrust (appropriate levels of trust) and investing in the necessary processes to keep ongoing questioning and negotiation alive. Even where there are strong relationships that have been built up over time, it is important to avoid relying on unquestioned trust. At the same time, a healthy scepticism need not lead to the questioning of every detail and to paralysis. Rather, agreed processes can ensure and facilitate critical reviewal and independent scrutiny, and provide parties with enough confidence to work together despite differences in interest and experience. This in turn implies an ongoing commitment to engagement and responsiveness by the research institution. Public engagement professionals and researchers should think about spaces where healthy distrust can be negotiated and where it can be constructively expressed.

4.4 Understanding and addressing trust for effective engagement with biomedical research

We have seen that trust is multifaceted and influences many aspects of the relationship between a community and a research institution. However, we can start to unpack this complexity by highlighting and attending to some of its key ingredients. The ingredients of trust identified in workshop discussions and summarised above are not exhaustive, but they do draw on a wealth of experience from many countries and contexts. They provide an important start in making the role of trust visible and begin to point to practical ways of addressing trust in strategies for public engagement with research.

Equally, these ingredients of trust highlight areas of practice worthy of further exploration and investigation. The seven trust projects look at trust from different angles and attend to different combinations of relationships. As such they will help further understanding of how trust works in different contexts. It is hoped that this learning can be shared among the growing Wellcome Trust-linked public and community engagement ‘community of practice’. These projects promise to deepen the understanding of trust in each of the settings where they are being undertaken. They may also build a richer overall picture of the potential role that trust plays in engagement, in ways that will help all of the Wellcome Trust Major Overseas Programmes and Centres to strengthen their relationships with the public and communities in relation to their biomedical research.

Annex A: Workshop methods

Action learning sets

Action learning sets are typically used with small groups of five or six people who work in a similar field, with the group members meeting regularly every four to six weeks and taking it in turns to spend an hour or so focusing on their individual issues and situations. Action learning is a tool for individual and organisational learning that supports reflection upon and learning from practical experience. Each person in the group takes it in turn to introduce a challenge that they face in their work (in some depth), and then goes through a structured series of clarification questions that help them to reflect on the challenge. The process emphasises that the listeners should avoid being too quick to give advice or recommendations. By building a rich picture of the circumstances, the process can help the person presenting the challenge to look at it again. It can be a powerful way to find new perspectives on intransigent problems or suggest new, practical ways to approach them in future.

Useful resources:

- INTRAC's guide to action learning sets for small and diaspora NGOs: **intrac.org/data/files/resources/733/Action-Learning-Sets-An-INTRAC-guide.pdf**
- BOND guidance notes for action learning sets: **bond.org.uk/data/files/resources/463/No-5.1-Action-Learning-Sets.pdf**
- An action learning handout produced for the workshop, outlining its principles: **e-mops.ning.com/groups/group/show?groupUrl=trust-me-i-am-a-scientist** (registration required)

Rich pictures

The rich picture participatory drawing method makes use of people's ability to capture situations and relationships in pictures. This can sometimes help to get past received wisdom and commonly held assumptions and bring new ideas and perspectives to an issue. The method usually involves structured group work that supports people to contribute their own drawings of different aspects of a situation or problem, before prompting them to reflect on the drawings and discuss them together as a group. Drawings usually include people, places, organisations and the relationships between them, as well as emotions and feelings, hopes and fears, and relevant past and future events.

Useful resources:

- Wageningen University's guide to the rich picture method: **www.wageningenportals.nl/msp/tool/rich-picture**
- A short introduction to rich pictures and their general principles from the Open University: **systems.open.ac.uk/materials/T552/pages/rich/richAppendix.html**
- A series of eight short videos/podcasts by the Open University on the value and rationale behind using rich pictures to help conceptualise and discuss complex issues: **open.edu/openlearn/science-maths-technology/engineering-and-technology/the-art-rich-pictures?track=0e01275d09**
- A rich picture handout produced for the workshop, outlining the group exercise: **e-mops.ning.com/groups/group/show?groupUrl=trust-me-i-am-a-scientist** (registration required)

Theatre of the Oppressed

Forum theatre is a participatory theatre form and is one of the elements of the Theatre of the Oppressed. It was developed in Latin America by Augusto Boal as a way of working with theatre to tackle the overriding problems experienced by ordinary people. It has been developed and adapted all over the world in a wide range of contexts.

Forum theatre explicitly draws on theories about theatre and education. Consciously or (more often) not, it also draws on theories about policy making and the management of change. For more on the theories behind the Theatre of the Oppressed, please see the resources list below.

Forum theatre is a theatre form that is entirely determined and developed through participation. A typical session begins with exercises and games aimed at initiating a playful, creative approach to what may be a serious issue. A scenario or a set of images or tableaux is prepared by the group on an issue that is of interest and importance to them. When the work is shown to an audience or within the group, everyone is encouraged to intervene to change the situation or resolve the problems.

Useful works by Augusto Boal:

- *Games for Actors and Non-actors* (London: Routledge; 2002). This work sets out the principles and practices of Boal's revolutionary method, showing how theatre can be used to transform and liberate everyone – actors and non-actors alike. Details are given of many exercises. This is the most practically useful book for doing the kind of work described here.
- *Theatre of the Oppressed* (London: Pluto Press; 2000). A guide to the theoretical underpinnings of the Theatre of the Oppressed.
- *The Rainbow of Desire: The Boal method of theatre and therapy* (London: Routledge; 1995). This is Boal's account of the therapeutic ability of theatre to liberate individuals and change lives, which sets out the techniques that help us see for the first time the oppressions we have internalised.
- *Legislative Theatre: Using performance to make politics* (London: Routledge; 1998). 'Legislative theatre' is an attempt to use Boal's method of forum theatre within a political system to effect social change.
- *The Aesthetics of the Oppressed* (London: Routledge; 2006). In this work Boal speaks about the subjects most important to him – the practical work he does with diverse communities, the effects of globalisation, and the creative possibilities for all of us.

Digital storytelling

A digital story is a short (1–4 minute) digital video that tells a story from someone's personal experience. A digital story is constructed from a personal scripted narrative soundtrack and still images, and is produced using a workshop method developed primarily by the Center for Digital Storytelling (**storycenter.org**).

A digital story is not a full or complex account of someone's life experience – it is a deliberately selected glimpse, a chosen moment, a stylised version of an experience carefully crafted to convey something of that experience to others.

The stories are produced through a participatory process in which individuals script, record, photograph and edit their own material. At the heart of this process is the story circle, where participants tell their stories, listen to other participants' reactions to them, and can develop and refine their narratives in a mutually supportive environment. The images come either from the storyteller's own personal photographs or are found or made by the participant during the workshop.

The digital storytelling process can help people make sense of their experiences and draw on the past to start to plan the future, and the resulting stories can enable others to understand how the storyteller sees the world. Through hearing stories we can learn about how others think, feel, act and are treated, examine their motives, develop shared meanings, and even be persuaded to act.

Useful resources:

- The Center for Digital Storytelling: **storycenter.org**
- Digital Empowerment – an EU project with a useful set of resources to support trainers: **www.digem.eu**
- Alex Henry's blog about the different applications of digital storytelling: **curiositycreative.wordpress.com**

World Café

World Café is a simple, flexible method for facilitating structured dialogue with large groups of people. Care is taken to create a relaxed, informal atmosphere and prepare focused and relevant questions. A series of rounds of discussion then build cumulatively on one another – people move to a new table after each round, with a table host providing a summary of the previous discussion for the newcomers. A final plenary harvests ideas and insights from the discussion and explores them further. Documentation may include visualisations of key ideas.

Useful resources:

- The World Café webpage dedicated to the method, which provides a range of background information and resources: **theworldcafe.com/method.html**
- A brief guide to World Café: **theworldcafe.com/pdfs/cafetogo.pdf**

Annex B: Workshop materials

The literature review on public engagement with health research in developing countries can be found at:
wellcome.ac.uk/stellent/groups/corporatesite/@msh_grants/documents/web_document/wtp057428.pdf

Workshop participants can access workshop presentations via the e-MOPs website, at:
e-mops.ning.com/group/trust-me-i-am-a-scientist

References

Abelson J et al. What does it mean to trust a health system: a qualitative study of Canadian health care values. Health Policy 2009;91(1):63–70.

Goldacre B. Bad Pharma: How drug companies mislead doctors and harm patients. London: Fourth Estate; 2012.

Hall MA et al. Trust in physicians and medical institutions: what is it, can it be measured, and does it matter? Milbank Quarterly 2001;79(4):613–39.

Kamuya D. Trust and Health Research in Developing Countries: Summary of the issues. London: Wellcome Trust; 2013. wellcome.ac.uk/stellent/groups/corporatesite/@msh_grants/documents/web_document/wtp057428.pdf

Le Carré J. The Constant Gardener. London: Hodder & Stoughton; 2001.

O'Neill O. A Question of Trust. BBC Radio 4; 2002. bbc.co.uk/radio4/reith2002/

Rose H, Rose S. Genes, Cells and Brains: The Promethean promises of the new biology. London: Verso; 2012.

Wellcome Trust, MRC. Public Perceptions of the Collection of Human Biological Samples. London: Wellcome Trust and MRC; 2000.

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