

What is public engagement with health research?

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

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

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

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

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

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

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

True engagement should be more than dissemination of research findings.

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

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

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

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

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

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

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

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

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The Wellcome Trust

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