

Connected Communities

Participants United

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Background

Executive Summary

Participants United brought together academic and community research partners to look at how issues of knowledge, power and voice are tackled when setting up participative projects. Creating a forum where a balanced exchange of ideas is openly supported; questioning notions of 'informed-consent'; considering how best to share credit for ideas and opinions formed collectively; ensuring there is genuine value and benefit for participants taking part in research and reflecting on the role of the academic as researcher and participant formed the basis of the *Participants United* summit and the discussion that followed online and offline.

Researchers and Project Partners

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With

Active Energy (The Geezers)

Bespoke's Community journalists

Stemistry

Dave Clay

Key words

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Participants United

Introduction

Researchers on the *Participants United* project were drawn together because they share – with others – the notion that the creativity and experience of communities, residents, groups and individuals is equally valuable to that of academics, other professionals and those in power over them. As researchers, each of us endeavours to work collaboratively with communities and individuals, participating in academic research projects to find ways of ensuring all voices are heard, that they are listened to, and that credit is given where it is due. As a further goal, all are committed to designing projects that lead to radical change in the ways that participants are included in, or become responsible for, the decisions that affect their lives. The group also shares a strong desire to communicate this to the academy, informing and improving the way universities engage with communities through research.

Approach

The Participants United project was devised so that the principal research took place with all the participants at a two-day reflective summit hosted by UCLan. The summit was preceded by a preparatory workshop with each of the participating groups. Its intention was to ensure that those taking part understood fully what they were committing to, whilst being reassured they would be under no pressure to take part. The Preston-based summit was designed as a series of open, focused, but non-directive exercises to elicit ideas and develop contributions in the spirit of Light et al (2009) and Egglestone and Rogers (2010).

Participants

Participants comprised those who had previously been involved in a research project as subjects or participants working with researchers and with whom the researchers had an established relationship. The groups were brought into the Participants United project by facilitators who had been part of research processes previously. Facilitators were also invited to join the summit, to reflect on their contribution and to ease the integration of groups.

Egglestone and Rogers' group had formerly participated in a large EPSRC Digital Economy research project called 'Bespoke' (www.bespokeproject.org). Light's group, *The Geezers*, were drawn from the East End of London. The Geezers had worked with a team of researchers at the University of London as part of an arts project investigating values and future technology with older people (Light et al 2009). The group working with Wakeford was drawn from a project based at Newcastle University. *Stemistry* (www.stemistry.com) is a contribution made to science by members of the public who come together to discuss stem cell research and respond using creative writing.

Process

People have different motivations for engaging with research projects. One common theme emerging from this and other work is that there must be some mutual benefit – and that benefit must be real, not perceived.

During the preparatory workshop researchers invited their groups to identify someone relevant to their activities they 'would-like-to-meet' during the summit. For example,

the community journalists asked to meet a documentary film-maker who could advise and mentor them. A documentary film-maker accessed through the connections of the researchers attended the Preston summit and met with community journalists.

This *would-like-to-meet* session is a significant one in the politics of working with the groups. The social good of participation can be seen in the actions of what is offered to participants during the project. As Dray et al point out (2011):

Part of understanding what we have to offer and to gain involves understanding and being clear about the benefits that will come from conducting our work successfully in the field. Quite often there is no immediate benefit to the group who is helping us with our work, despite the long-term potential of our learning. For us, on the other hand, there may be a series of professional accolades: As researchers, we may be able to generate publishable research findings and disseminate our work. (Dray et al 2011)

Participants United also attempted to address the imbalance of power caused by the remuneration of professional researchers and the 'free' contribution of the participants. The team acknowledged that participants' time is not free and experimented with a form of compensation offered to individuals for their loss of earnings. This is not payment for participation but recognition of participants as people who may be sacrificing payment from their usual means of livelihood in order to take part in a research project. Similarly, researchers were sensitive to participants' domestic arrangements, recognising that their absence may require paying for carers or bringing the family along.

Beyond the duration of the project and on completion of any formal contribution to the

research some participants expressed their wish to remain informed about the outcome of the project whilst others expressed the view that they share the ownership of any intellectual property (IP) and are appropriately remunerated or rewarded if it is exploited for commercial gain. This is problematic for many institutions as few collaboration agreements or IP contracts include the contribution made to a research project by those participating in the process. Participants United attempted to address these issues, establishing a creative commons agreement with each of the participants at the beginning of the research project. The agreement, adequate for the purposes of this project, simply reads: *I understand that any materials published from this project will be under a Creative Commons licence that will enable me to use them should I wish.*

Findings

Our analysis of results from Participants United raised the following three key issues that any research attempting community engagement project should address:

1. Respect for Autonomy and Beneficence

Community engagement often draws on the traditional medical model, under which experts inform 'lay' people about a research procedure that is to be performed on them. This often fails to respect the autonomy of individuals, including their desire for different benefits to those envisaged by the researcher, and thus could be regarded as unethical in these terms (Beauchamp and Childress 2001). More recently, some engagement processes have allowed patients and service users to join with professional researchers, not as subjects but

professional researchers, not as subjects but as co-investigators, thereby contributing their own expertise to the research process.

2. Framing

Community engagement is often framed by the concept of people being in need of what experts have to offer, because they are sick (in the context of medical research), ignorant or both. Knowledge exchange then channels participant input towards the generation of data that will improve medicines or services.

3. Empowerment

Those convening any engagement process must negotiate its place on a spectrum of empowerment. At one end are processes that are driven by hierarchical decision-making structures in the commissioning body, often lacking openness and the appearance of a commitment to major change based on their conclusions. At the other end of the spectrum are collaborative processes in which multiple interest groups jointly shape a transparent dialogue process (Wakeford and Singh 2008).

Practical suggestions:

Informed Consent

Laying the foundations of any mutually beneficial relationship between participants and researchers starts with ensuring that project goals are negotiated. This process begins before the submission of a formal application for funding to ensure that goals and values of all parties are not compromised by any funding conditions. Either way, establishing clarity about the purpose of the research, uses of the data, the ownership of the data and the experiences that will likely ensue is a fundamental component of informed

consent. All parties must be able to express their interests and discuss the benefits of more collaborative models of production or other acknowledgements of the shared nature of the undertaking, such as recompense in kind.

WLTM

Given that the rather self-serving goal of understanding more about participation is yet another occasion of asking something from the groups that will benefit the researchers more than other participants (who probably do not stand to gain from the publications that ensue), *would-like-to-meet* (for example) works to redress the immediate balance for those present in the room, in case other benefits do not accrue from getting involved.

Shared benefits

Space needs to be made within the research process for discussion and activity that directly benefits participants. Many participants compared their input to the research process to individuals working on manufacturing production lines where they insert a component but never see the final product. Some would be happy to contribute in return for acknowledgement of their part in the process and sight of the product at the end of the process. Whilst this is possible where researchers are using data to inform the producing of tangible objects creativity needs to be applied to the issue of how participants might engage with results from research where there is no physical object at the end of it. The basic tenets of regular communication and a clear understanding of each stage of the process apply in both cases. Some individuals expect to be able to accrue benefit from the research immediately, rather than at some point in the future beyond the project itself. Researchers would do well to consider the potential benefits to participants

within the discussion framework of informed consent. Participants United has experimented with some of these ideas offered here to complement others where good practice is a principle of the research process.

Legacy planning

All parties involved in research need to think about the processes and structures that need must be in place (and maintained) to ensure that where benefits, financial or otherwise, accrue to participants there is a mechanism for ensuring these are appropriated. Similarly, a Creative Commons agreement may be adequate to protect the rights and ownership of shared intellectual property, but for those non-academic participants without access to resources and the means to enforce a Creative Commons licence researchers may reinforce the imbalance of power the establishing of the agreement was there to address.

Conclusion

Whilst the situations above tackle the process and outputs of collaborative research, the co-design of methods (or the agreement to prioritise effective dialogue over formal research methods) is crucial to the success of any engagement. Current research enquiry procedures make this aspect difficult.

Research projects require that research questions are stipulated before commencing field studies or identifying and consulting with research subjects. Whilst this approach is not unreasonable, it has weaknesses. It places emphasis on the researcher framing the research, the funding body commissioning the research and the institution contracted to deliver the outputs and evaluation. All three are gatekeepers by default. All parties

must 'sign-up' to the research project before the researcher identifies any participants. Participants are then research *subjects* in the colonial sense of the word. Even adopting the most well-meaning and equitable ways of working, this process is what Light and Miskelly (2008) have called *benign imposition*. Participants United worked within the current system of pursuing funding, then involving partners and gaining consent, but it has used the processes of the research to open up a critical space and time for discussion to try and lessen the imposition. One of the ideal outcomes of the project would be the adoption of a structure where researchers continue to be accountable to the funders, but are also more emphatically responsible to partners on the ground. At present, there is the potential to take what is needed to make the research successful with no thought to the needs of the community.

Unfortunately, this imbalance of power is inherent in the current process of university research and it is difficult to imagine any significant improvement without dismantling the hierarchical commissioning structures and dispensing with the requirement to start research with a research question. Enabling individuals, groups and communities to set their own research agenda by framing the questions they would like to ask is fundamental to notions of agency and ability to design the engagement process. There is a considerable body of work in the health and agriculture sectors has shown that this participatory approach is possible (Cook 2012, Pimbert 2012).

In the project reported here, we have been striving to incorporate these principles in a small way, represented most clearly by the *would-like-to-meet* sessions, where partners' purposes are pursued, and the structures put in

place to share ownership of outputs, such as the Creative Commons licence. As a consequence of working in this way, we trust that policy makers benefit from having a richer and more comprehensive evidence base as we slowly move towards participatory paradigms of research (Wakeford 2011).

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