
Community-Based Research Decision- Making

Experiences and factors affecting participation

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With the exception of participation as research subjects or patients, members of the public's participation in research decision-making has for many years been marked by their exclusion. Scientifically produced knowledge was seen as the sole reliable source of robust knowledge, and producers and holders of this knowledge were amongst the few seen as capable of making decisions or setting policies associated with research production (Irwin & Wynne 1996; Ravetz 1971). However, in the post World War II period, scientific and technical knowledge alone has gradually come to be seen as insufficient for solving complex societal problems: normative choices and consideration of economic, ethical and moral interests are also necessary (Jasanoff 2007).

Community-based research (CBR) is an approach to research which makes use of the knowledge of members of the public, also referred to as community members. Public participation in CBR means that members of the public work in collaboration with university members, 'in all phases of the research process, with a shared goal of producing knowledge that will be translated into action or positive change for the community' (Lantz et al. 2006, p. 239). As an approach to research with tenets that support active public engagement, participation in the decision-making or governance of community-based research therefore appears to be an essential and integral component. However, specific focus in the literature on the organisation and implementation of decision-making in community-based research is sparse, and there is a paucity of material which addresses the theory and practice of governing CBR, and the contributions of community members. In particular, participation in the governance of community-based research appears to be poorly understood, understudied and underdeveloped (Barrington Research Group 2004). Not properly evaluating the importance of the public's participation in governance can limit knowledge production through research and potential benefits for communities. We were therefore interested in determining the experiences of community members in governing community-based research as a basis for understanding their participation, and designed a qualitative study to investigate this.

In this article we discuss the importance of participation in the governance of community-based research, using Arnstein's (1969) theory of public participation in governance as a guide. We describe the study methods and the findings, and follow these with a discussion. The terms, participation, engagement and inclusion, are often used interchangeably in the literature and in day-to-day usage, and we follow this precedent. The terms, public, member of the public, lay or local person and community member or citizen, are also used interchangeably and similarly in this article.

Building on a definition of governance by Dietz and Stern (2008) which is, 'any of a variety of mechanisms and processes used to involve and draw on members of the public or their representatives in the activities of public or private-sector organizations that are engaged in informing or making environmental assessments or decisions' (Dietz & Stern 2008, p. 12), we came to define governance in the context of community-based research as an organised process whereby members of defined communities, in collaboration with academic researchers, democratically participate in making decisions towards producing new knowledge from the context and experience of their lives. The context for our study was Canada, where public research funds are the major source for community-based research projects.

PARTICIPATION IN GOVERNANCE IN THE CONTEXT OF COMMUNITY-BASED RESEARCH

Of the many descriptions and definitions of governance in democracies, focus is given to decision-making through interactive structures and processes regarding sharing, allocating and coordinating of responsibilities, resources and knowledge (Flinders 2002; Fung 2007; Kaufmann, Kraay & Zoido-Lobatón 2000; Sloat 2003; Stoker 1998). The concept of participation is also valued in decision-making, with participation of the public seen as a 'good thing' (Arnstein 1969).

In the context of community-based research, which is understood as an approach or orientation to research in which people from universities and communities bring their different knowledge, experiences and skill sets, collective decision-making or governance takes place, with the goal being generation of new knowledge to address social and health problems (Green et al. 1995; Israel et al. 1998; Lantz et al. 2006; Minkler & Wallerstein 2008). Definitions and principles of CBR also clearly affirm that both community members and academics should participate in all aspects of the research (Cargo & Mercer 2008; Hall, Tremblay & Downing 2009; Ibáñez-Carrasco & Riaño-Alcalá 2011; Israel et al. 1998, 2003; Mykhalovskiy & McCoy 2002; Williams et al. 2005).

While conducting principled community-based research is important, it is also necessary to have useful models for the production of knowledge by 'non-traditional' researchers, to guide their participation and the inclusion of lay knowledge (Callon 1999; Gibbons et al. 1994). Not all community-based

research principles and models of knowledge co-production specify participation in the governance of community-based research per se, although for some contexts, such as development, some authors have offered typologies of participation (Cornwall 1996, 2008; Pretty 1995). Arnstein's (1969) theory of public participation offers a critical basis for analysing a combination of the nature or depth of public participation in decision-making and the decision-making power that accompanies it. Her typology, referred to as the ladder of citizen participation, illustrates steps that correspond 'to the extent of citizens' power in determining the end product' (Arnstein 1969, p. 217). Higher rungs on a continuum of participation indicate active public participation and involve decision-making. Power is distributed such that citizens have a direct say in the decisions that affect their lives. On the lower steps, citizens do not participate, are prevented from participating, or participate without power, with the consequence that the public is excluded from democratic benefits. Arnstein's typology of participation has continued to offer a basis for analyses of the nature or depth of public participation in decision-making, and the decision-making power that accompanies it, with implications for equity (Arnstein 1969; Fung 2006; Gustafsson & Driver 2005; Hatch et al. 1993).

REPRESENTATION AND TRUST IN COMMUNITY-BASED RESEARCH DECISION-MAKING

Representation in governance is an important issue that has potential consequences for research outcomes (Brown et al. 2005). However, there are diverse opinions on who should represent certain populations in making decisions about research. For example, members of communities interviewed for a collaborative research project (the Seattle Partners for Healthy Communities) thought that representatives of formal community-based organisations were more likely to focus on their own agendas rather than representing communities as a whole. Grassroots activists without institutional membership were also viewed as likely to miss the bigger picture of a community issue (Koné et al. 2000).

Discussions of participation and representation have also raised issues of trust as a constant theme in the literature of community-based research. Trust amongst research collaborators, and between collaborators and the communities that they represent, is purportedly a critical and necessary quality for the successful development of CBR collaborations. Trust can help to counter reluctance to participate, can address scepticism of the value of research and can lead directly to better quality, more relevant research (Mattessich, Murray-Close & Monsey 2004, O'Fallon & Dearry 2002). Trust, however, is not inevitable or immediate and some evidence suggests that trust may actually decline when collaborators become more familiar with each other, also suggesting that relationships are fluid, not always

stable, and that trust cannot be viewed as a constant (Provan et al. 2003; Provan & Kenis 2008). Even in collaborations where inclusion, particularly of the vulnerable or marginalised, is assured, meaningful participation and representation are not, and trust as a qualitative indicator of inclusion, participation and representation is difficult to measure. Selection of any one of inclusion, participation and representation for critical focus is problematic, as to operate effectively each must operate in relation with the others. One solution lies in including a broad enough spectrum of stakeholders in the collaboration to mirror the problem (Gray 1989). Collaborative governance, ‘... a collective decision-making process that is formal, consensus-oriented, and deliberative ...’ is one ‘species’ of governance that appears to offer an approach to solving complex problems in community-based research (Ansell & Gash 2008, p. 544; Chrislip & Larson, 1994).

METHOD

To collect descriptive and experiential data of respondents’ participation in CBR governance, we designed semi-structured in-depth interviews to be conducted with a purposeful, non-probabilistic sample of community and university members who had first-hand experience of participating in governing CBR collaborations. Equal numbers of community and university members were sought to help present balanced views of participation from different perspectives.

Potential participants were recruited via announcements of the study through electronic mailing lists and networks that included community-based research amongst their interests, and through the authors’ personal contacts. Potential participants either self-referred or agreed to participate in reply to an invitation sent by email. If potential participants had had first-hand experience of governing community-based research either as members of the university or the community, they were then given information about the purpose of the study, a list of general thematic questions to elicit discussion and information about their experience in CBR governance, how they might expect the interview to proceed including any associated risks of participation, and their rights in participating or not participating in the interview. Anonymity was assured through the removal of any personal and geographical identifiers and references to the studies in which participants were involved. Interviews were digitally recorded and transcribed by a professional transcriber. The research study was approved by the University of Ottawa Research Ethics Board and a certificate of ethical approval issued by the university’s Research Grants and Ethics Services (Certificate of Ethical Approval File #06-08-37).

Coding and Analysis

Coding of respondents’ experiences and observations was carried out by determining discrete units of meaning to which a code was applied, similarly to Charmaz (2006) who suggested ‘line-by-line’

coding. In order to organise data in line with Arnstein's (1969) theory of participation in governance, the following questions were posed: 'Who participates in making decisions?'; 'When does participation in governance take place?'; 'Where does governance take place?'; 'What enables participation in governance?'; 'How is community participation assured in decision-making?' Answers to these questions can indicate the location of control and power at different stages of research and can suggest the effects of participation on different actors (Cornwall & Jewkes 1995).

The first steps in the analysis fell under the approach of qualitative description, which is a low-inference approach to help categorise and organise data and to describe 'the facts of the cases observed' (Sandelowski 1998, p. 376; 2000). Further steps utilising grounded theory as the analytical guide were undertaken through memo writing, iterative readings of the data, the making of connections and relationships of meaning between codes, and comparing participants' experiences to find differences and similarities and to develop abstractions (Charmaz 2009, p. 138). In vivo quotes from those interviewed are used to illustrate the results.

RESULTS

Fifty-five interviews were conducted with members of community and university research collaborations who had had first-hand experience of governance in community-based research. (One interview was discarded because data were not first-hand experiential data.) Forty of the participants were engaged in governance of community-based poverty, homelessness and food insecurity research. The other 14 participants were engaged in governance of a variety of community-based, health-related research studies. Twenty-six respondents were affiliated with the community (as individual members of the public and as members of community organisations). Twenty-eight respondents held university affiliations. University respondents were employed as academics and research project coordinators. Community members included paid workers and volunteer board members, users of community services, lay persons, and people with lived experience of the issues under study.

Analysis of the data suggested that the experience of participation by community members in governance of community-based research was shaped by four groups of factors, categorised as (1) pre-existing conditions, (2) arrangements of governance, (3) actions of academic researchers, and (4) actions of community participants.

1. Pre-existing Conditions – Research Funding as a Pre-condition of Participation in Decision-Making

Pre-existing conditions describes the conditions already in place before a community-university research collaboration is struck, or engaged in research. The experiences of community respondents suggest that there is one key pre-existing condition, research funding, over which they have little control and which strongly

influences or modifies their participation in research decision-making.

In Canada, public research funding agencies have formal arrangements with post-secondary institutions. Funding arrangements with community-based organisations (CBOs) are possible in some circumstances under prescribed conditions, but occur rarely. In the respondents' experiences, the majority of public research funds for community-based research are administered and managed by universities. Furthermore, although money may be allocated to CBOs, the research project money that CBOs receive may not adequately cover research-related costs, and this affects participation. As one of the community respondents explained, 'The fundamental issue on the community side is no core funding, and short term project money. It's a real barrier for involvement of community partners and their ongoing participation.' Some participants suggested that a lack of up-front access to funding, or delayed payment of expenses or transfer of funds to community members and organisations by the university fund-holder, necessarily limited community participation.

According to some respondents, arrangements were often made in the research proposal to cover costs to facilitate individual community members' participation in governance, including travel and childcare expenses, and costs of communication such as telephone or internet access. Otherwise, participation in governance by community members was voluntary and unfunded.

2. Arrangements of Governance

Arrangements of governance incorporate structures of governance such as steering committees, membership and formalised decision rules, which set the conditions for participation in decision-making. Certain structures or arrangements of governance in the respondents' experience provided descriptive boundaries for members' roles and responsibilities. Some collaborations used agreements or letters of understanding to describe and clarify expectations regarding the participation of community and academic members. Joint discussions with regard to arrangements of governance provided opportunities to determine and clarify all participants' positions and preferences. However, the findings suggested that discussions on the arrangements of governance were limited in the case of most of the collaborations.

In some collaborations, formal governance structures were actively resisted. In these cases, formal structures were seen to restrict participation and exclude participants, particularly community members who may not have had previous exposure to formal governance settings. As one respondent explained, 'If everything's formalized ... you also have a very structured and determinative relationship with your community members', which was seen as a deterrent to participation.

Flexibility, defined by one university respondent as 'a hallmark of participatory research', was proposed as an essential ingredient for organising governance. Although seemingly positive,

'flexibility' in one community-based research collaboration was seen as a ruse for limiting participation and ensuring that the community members of the research collaboration never met with their academic counterparts, despite the community's ongoing calls for meetings.

3. Actions of Academic Researchers

We have already seen in the first two categories of factors that academic organisations and researchers occupy a dominant position in decision-making and influence in shaping community members' participation. We now look specifically at actions taken by academic researchers as well as the reactions of community members to these actions.

In the preparation phase of the research proposal, community members' participation was often limited to agreeing to participate and expressing interest in participation by providing letters of support. Although both community and university respondents talked about collaboration development and the work needed before the research proposal was submitted to a funding agency, most suggested that, in this phase, community members did not participate in decision-making to any great extent. Furthermore, between submitting the research proposal and learning about funding decisions (usually several months later), little need was felt for meetings, as the funding decision was seen by academic researchers as signalling the real beginning of the research project.

How members of the community became participants in governance of community-based research was, in most cases, conditional on a decision and an invitation extended by academics. Academics invited some participants because they were known to have experiential knowledge related to the research problem, for example, of being homeless or food insecure, and presumed to represent a particular group or community. Their contributions to decision-making were therefore respected as legitimately based on their experience. Other participants, such as community workers, were invited because they possessed content expertise and they could provide access to research participants. Reflecting on knowledge, participation and representation, one respondent said:

we spend a lot of time thinking, 'Well, who should be at that (decision-making) table? ... do you want people who work in the front line or do you want management? Because they see the situation in different ways. They have different kinds of knowledge, and I'm not privileging one or the other, but you have to think about why would you want a manager there as opposed to the front line worker, or vice versa.

Why certain community members were invited to participate in governance as representatives of a 'community' of individuals with lived experience was problematic for some participants, raising questions regarding the real meaning of representation.

One community respondent questioned the repeated participation of some community members in a variety of local research projects as they were thought to have been invited ‘because they can speak the bureaucratic language’ and not because of their ability to represent a particular community. Another respondent felt the selection of representatives of lived experience made the process appear fair to outsiders and helped to ensure funding, but that this did not have any connection to ensuring participation: ‘you could feel as though you’re being used ... it looks good to have “x” number of community representatives sitting on a steering committee, right? I’m just here to guarantee funding.’

The participation of people with lived experience, characterised by one respondent as ‘people who are already dominated in so many aspects of their lives’, required academic members to approach the inclusion of vulnerable or marginalised people with sensitivity and care, not by adding to their oppression. In trying to give ‘legitimacy to the contributions of people who are living the experience and who may not be as articulate’, some collaborations took positive steps towards ensuring people participated as equals: ‘there wasn’t this hierarching [sic] the levels of participation in the group or marginalizing the people who were less involved. There was a lot more ethical consideration.’ In another collaboration, academics took special steps to ensure community members’ participation because they valued their participation: ‘we (academics) involve them (community members) in a substantive way. They are the conceptual engines of our project.’ However, some collaborations ensured representation but not participation. One respondent spoke of a lone community representative with lived experience on a governing committee ‘who was open to give as much expertise from his experience as was required, but he was not utilized as effectively as he could have been’.

Academics recognised, as one said, ‘no matter how equitable we try to be there’s always a tendency for academic researchers to dominate the discussion or to drive the agenda’. In some research collaborations, skilled facilitation appeared to enable participation in meetings. As one respondent noted from experience, ‘you could see that one or two people were dominating and you have to be quite careful and quite skilled in those situations and not just a nominal facilitator or chair’.

The amount of time that community members spent voluntarily in meetings was generally treated by academic investigators as a limited resource to be protected, respected and carefully expended. Respondents told of care taken in planning meetings to ensure participation. One spoke of ‘a very circumscribed participation in terms of honouring the time that they have’, and ‘to be very clear about what the time commitment is, and to use that very efficiently to draw out the expertise’.

Despite academics’ actions to ensure and enable participation, some community members saw themselves as quite

different in status from academic members, which negatively affected their 'voice' and their ability to perceive and present their own points of view as equally important and valuable. One community member said, 'Well these are not really my peers. These are academics, you know'.

4. Actions of Community Participants

This group of factors looks at how community members saw their own actions in their experiences of participation in governance, and how those actions were seen or understood by the academic researchers.

Community members' attitudes towards research influenced their decision to participate in governance of community-based research. Some community members wanted some understanding of research, or needed to value research in order to participate. Others needed to see some concrete benefits from their participation, although some adopted a position that research as an end in itself was important. On occasion, community members and community organisations showed reluctance to participate at all. Some community members' attitudes towards research were summarised in one university member's experience: 'for them there's no need for research. Research is just like a useless task for them.'

Some community members separated the governance or decision-making role from the research operations. One respondent, for example, found that community members 'don't want to be bothered. They don't want to have to get called in on the operational stuff'. And an academic respondent noted that:

we try and involve all people in every kind of decision ... but you also get push back from community members and from agencies who say 'Well you're the expert. You propose something and if it sounds good we'll do that ... you take that role, you take that responsibility and that's fine with us.

Sometimes community members who might have initially been interested in participating left a research collaboration because, as this respondent explained, 'it winds up being too hard ... It's a painstaking process ... it requires a lot of time and effort'. In addition, the quality of relationships with academic researchers also influenced decisions to participate or not. A small number of community members stated that, because of negative experiences, they would not collaborate with particular academics and their universities in the future. These negative experiences were attributed to their collaborators' failure to involve them in decision-making, and for academic partners failing to carry out their agreed upon responsibilities. Lack of clarity with regard to community members' roles and responsibilities also proved frustrating.

Disseminating and translating knowledge after the completion of research was a phase in which community members in this study rarely participated. Community members seemed to associate knowledge translation with academic writing, rather

than translation of research results for a wider public that included community members. Whether or not this was the understanding of knowledge translation given, assisting in the production of reports and peer-reviewed academic literature was ‘not necessarily valued by people in the community sector [even though] we would always invite somebody from the agency to contribute ... but that’s not the business they’re in’, as one academic explained. Acknowledging that community members expect different outcomes for their participation, including resources for implementing programs or changes suggested by the research findings, one community member said:

They [community members] don't give diddly squat [sic] about authorship, order and pure academic journals ... What they [the community] might care about is, what do you need for your work to continue? We know what we need.

One exception that appeared to augment the amount and quality of community members’ participation was when community-based organisations rather than universities hosted research projects and had a significant role in supervising research staff. Some community and university respondents equally felt that, when a research project was located at the university, the power and culture of the university dominated community partners and diminished community member participation. As one community respondent said, ‘We have located in the community deliberately from the very beginning knowing that universities tend to absorb, and you become part of that system’. When located in the community, as opposed to the university, community member participation was felt to be assured.

DISCUSSION

In this study, the experience of community members’ participation in governing community-based research was influenced by certain groups of factors. The research projects were supported by institutional arrangements that gave academics fund-holding power, determined academic control and limited budgets, or excluded budget categories which could have assisted community organisations or individuals to participate more readily. While arrangements of governance in the form of documentation, membership, bodies and meetings can create frameworks for defining and enacting participation, lack of attention, and sometimes resistance to these, may have meant that many collaborations did not have the ‘governance discussion’ at any time, and consequently had limited input to decision-making. The third group of factors, actions of academic researchers, suggested many ways in which academic members’ actions and decisions affected participation of community members and resulted in participation that was controlled by university members, without input by the community. Community members also modified their participation in response to funding arrangements and actions of academics.

Participation in decision-making by community members was tied to the acts or decisions of 'others' with power to set limits on resources and place constraints on participation. These same 'others' were largely responsible for determining arrangements of governance, again setting the terms of participation. Although some community participants showed reluctance, 'push back', and the occasional reported refusal to participate, most pondered their participation and made decisions to participate at a level that was satisfactory to them. Compared to the experience of the study's community respondents, Arnstein's (1969) highest participation levels (citizen control, delegated power, and partnership) were not attained, with the possible exception of one of the respondents who recorded comprehensive and direct community control of decision-making. Most respondents' experiences of participation suggested middle and lower level participation. Arnstein suggests that, at these levels, it is not possible for participating citizens to have any significant impact on decision-making. For collaborators who expect or consciously seek higher level participation, lack of opportunity to participate is likely to be problematic and frustrating.

At the lower rungs of the ladder of participation, Arnstein (1969) uses 'therapy' and 'manipulation' to describe non-participation. Her attribution of the terms 'chicanery' and 'sham' to the activities of power-holders at the lower rungs of the ladder suggests that, once exposed to participation in governance where they are essentially disregarded, community participants who are aware or become aware of the pretence are likely to be twice shy of a future experience of participation, which did occur, as some of our respondents reported. According to Arnstein's thinking, because participants do not object to the terms of their participation in decision-making, and do, in fact, participate, they are likely unaware of manipulation by academic power-holders. However, our data suggest that most community members were aware of their limited levels of participation, but found a means of justifying the level and adjusting their participation so that it was 'good enough', without much in the way of consequence or personal harm. Perhaps more importantly, lack of awareness of a 'less-than-optimal' participation can apply to non-reflective power-holders as well. Furthermore, efforts made by academics to accommodate the limited time and resources of community members may have had the inadvertent side-effect of reducing participation and minimising the contributing role of community members to decision-making.

The data and our analysis support Arnstein's (1969) framework to some extent, with the factors shaping participation showing who had the opportunities, designated responsibilities and power and control to make decisions. However, with participation in governance generally conditional on the structures and actions of 'others', explaining the willingness of community members to voluntarily engage and continue participating in governance of community-based research seems to require further thought. Given

that community members appeared to have little in the way of control, resources or power in participating in governance of CBR, how can any participation be explained?

With the exception of those who were somewhat scathing of research, community members appeared to uphold the importance of research and to give commitment to the production of knowledge, regardless of the conditions or requirements of participation. They participated at a level that they deemed satisfactory, that is, they determined a level of participation that they were prepared to be satisfied with, even if in their own estimation their contribution was limited.

Community members were willing to make certain investments in participating in decision-making as long as the returns on investment were judged as proportional to the effort and risk of participating. Community participants determined risks, assessed expenditures and losses of time, money, resources and status, and measured their input to governance to bring about a process that they were satisfied with, but not necessarily one that was participatory in any ideal sense. As one respondent explained this approach, 'it matter(s) more that there be real benefits generated than it does to have some sort of hyper-participation'. Another said:

I don't care if I participate all the time, every time, on every decision. As long as there's transparency, as long as I see the money goes where it should go, I'm happy to be a member. I don't have to be the chair as long as those benefits are flowing. As soon as I see no benefits to my people or my organization, I'm going to bail.

Limited participation in decision-making was therefore not bad, but 'good enough', from community members' perspectives, as long as some benefits were apparent. Most community participants did not feel they had a lot to risk by a limited role in decision-making.

The suggestion of 'good enough' participation from the perspective of community participants in the governance of community-based research places a different emphasis on traditional accounts of participation and non-participation in CBR. As already noted, much of the CBR literature has centred on the importance of trust for participants (Centers for Disease Control and Prevention 2008; Horowitz, Robinson & Seifer 2009; Myser 2004; Oberly & Macedo 2004; Smith 1999). Attentiveness to developing trusting relationships in community-based research is intended to address problems of participation (Beyrer & Kass 2002). However, trust that is needed to participate in research as a research participant may have a different quality to the trust that is needed to participate in governance. To participate in decision-making may be more influenced by what potential decision-makers feel they have to gain or lose personally and organisationally, which may relate more closely to issues of assessing 'risk' than to issues of trust or assessing potential for harm.

CONCLUDING THOUGHTS

Further investigation of research relationships, co-design of community-based research and collaborative governance models might be helpful to academics, members of the public and community organisations. In addition to acquiring practical knowledge of different cultural approaches to collaboration which might be important for ensuring decision-making participation in multicultural and multi-ethnic societies such as Canada, and understanding interpersonal behaviour in groups, further development of collaborative governance theory could be helpful in the selection of governance/decision-making models for use in the context of community-based research. The development of methods of assessing or evaluating governance of community-based research and measuring satisfaction with participation, whether employing quantitative or qualitative approaches, can take on board ideas of 'good enough' participation to account for the fact that not all participants may be concerned with reaching ideals, but nonetheless are still interested enough to provide a voice of 'public reason' in governance of CBR. Also proposed for further investigation is the role of skilled and critical facilitation, which has potential to help maximise the quality of community members' participation (see, for example, Minkler 2004 and Stoecker 2009).

Notwithstanding these suggestions for future research, Arnstein's (1969) typology, which recognises differing levels of participation and their effects on distributing power, when applied to decision-making in the governance of CBR projects, continues to be a useful basis and tool for raising sharply the issues of non-authentic participation, and for challenging pretensions by some power-holders who make use of lightweight evidence to demonstrate participation in governance.

Community-based activities which are intended to deepen university-community relationships are becoming more common in Canada. Community-based research is one such activity in which they engage. Research collaborations can take steps to ensure favourable conditions for more equitable distribution of power, knowledge and resources. Better understanding by all participants of the theory and practice of participation in governance or decision-making in community-based research shows promise for maximising democratic participation and knowledge co-production.

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