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## Public participation: more than a method?

### Comment on “Harnessing the potential to quantify public preferences for healthcare priorities through citizens’ juries”

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#### Abstract

While it is important to support the development of methods for public participation, we argue that this should not be at the expense of a broader consideration of the role of public participation. We suggest that a rights based approach provides a framework for developing more meaningful approaches that move beyond public participation as synonymous with consultation to value the contribution of lay knowledge to the governance of health systems and health research.

**Keywords:** Public Participation, Human Rights, Methods, Values, Consultation

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As Whitty and colleagues (1) note, there is scope for increased public participation to influence decision-making and service delivery in healthcare. In a number of countries, the last 20 years have seen an explosion in public participation in health systems governance, health research governance and health promotion.

In a recent paper, Evans tracked the evolution of public and patient involvement in research in the UK through an analysis of policy documents (2). Similar to Mockford *et al.* (3), he found public and patient involvement to be deeply imbedded in research funding structures, but concluded that the drive to involve raced ahead of the establishment of an evidence base for participation.

More recently, researchers have sought to build this evidence base and to establish what might be the optimal approaches to formalised participation (4). Whitty and colleagues provides an interesting comparison between two approaches: discrete choice experiments and citizens juries (1). The authors go on to argue that combining the quantitative (discrete choice experiments) with the more qualitative (citizens juries) can ‘maximise the value of public input to health policy decision-making processes’. Within research and health service delivery, since the first attempts at participation, there have been efforts to achieve ‘genuine’ participation, as envisaged in Arnstein’s (5) now well cited work. However, before those engaged in promoting participation unravelled how to ensure such sharing of power, the concept of participation was appropriated. In so doing, ‘participation’ has all too often come to simply mean consultation. The focus in recent health systems reforms has been on establishing mechanisms of participation, allowing the research enterprise, health services and governance structures to continue largely with ‘business as usual’.

While we continue to grow a body of literature charting the

impact of different approaches (to which this papers adds), the literature on public engagement and participation in health has embarked on a somewhat uncritical route. It has been observed that researchers have a tendency to focus on the technical, methodological aspects of practice (6). While this is valuable, we would argue that it sometimes occurs at the expense of a more deep rooted exploration of our practices. Wilsdon *et al.* (6) argue that researchers often focus on the hardware of participation (the how to, methods, approaches, guidelines etc.) rather than the ‘software’ of values, norms and codes that shape scientific practice. If we are using the terms engagement and participation as proxies for consultation this is less problematic. Difficulties arise where the goal is to develop methods of genuine participation that can effectively ‘maximise the value of public input to health policy decision-making processes’, share power and valorise all knowledge equally.

Of course, we are not the first to make this observation. For example, Cooke and Kothari’s (7) edited book ‘*Participation the new tyranny?*’ critiqued the appropriation of participation in ‘development’ and Mosse (8) cautioned against an ‘uncivil’ society. In the public engagement in science literature, there has been considerable debate about the limited value attributed to lay knowledge (9). The challenges of participation are also well documented and there is a wealth experience to be tapped from majority world countries. Our focus in this commentary is on how to embrace formalised participation. Can top-down participation, implemented as part of legislation and wider health system reforms, achieve ‘genuine’ participation?

In the past year, we have sought to challenge and explore the notion of formalised public participation through a collaboration between academics engaged in health services research, health and human rights research, human rights law and mental health research. This collaboration has allowed us

to challenge our understanding of public participation and to consider the value of public knowledge and the virtue of participation. As researchers with a strong commitment to producing research that improves services for patients and the public, our efforts to engage have taken us back to unpick the assumptions that participation is always a good thing.

We have learned many valuable lessons in the process not least that it can be difficult for professionals to set aside their views and aspirations regarding participation and get into 'the shoes' of patients and public. Many of the challenges surrounding engagement are either not recognised or 'glossed over' thus creating a gulf between the rhetoric and the reality of genuine engagement and the objective of 'true and equal' partnership working. Some of the most important lessons we have learnt relate to the research process, including data collection, implementation of research findings and dissemination. While efforts are made to provide education and training for service user researchers regarding the importance of following the research protocol and for example, interview technique, it can be challenging for peer co-researchers to develop data collection skills in the timeframe of the project. To mitigate this we found regular mentoring to be essential where such issues could be addressed. However, this can lead to resentment and be perceived as the professional taking the 'upper-hand'. The importance of professionals respecting the expertise and at the same time recognising limitations to involvement from service user researchers in terms of the demands of the work either emotionally or in terms of volume needs to be openly discussed and respected to prevent emotional overload or interference with benefit payments.

Depending upon the situation it is possible that for some patient and public participants emotional and or clinical issues may arise that health services researchers are unfamiliar with. Planning for such incidents is a necessary consideration and requires openness and honesty. Being able to manage situations when patients and public representatives have not been able to carry out the agreed work can also lead to discontent and needs to be considered when planning. A further area for clarification is what to do should a fundamental disagreement arise about when and how to introduce an intervention or the selection of a specific client group. None of these practical issues feature in policy documents, but are fundamental to the concept of genuine engagement and parity of esteem.

Our view is that it would be timely to consider the role of public participation in health systems governance, health research governance and health promotion more critically. This may well be reinforced by our desire to give public voices a status and legitimacy within the healthcare communities in which we work. Participation requires behaviour change of everyone engaged in participation processes. For example, focusing purely on the structures of participation fails to acknowledge the skills and time and resources required to participate fully. Furthermore, we may forget to ask questions about the acceptability of different approaches to public and patient participants. How to manage 'uncivil' elements of civil society and ensure participation of the most vulnerable and silenced? We need to consider what evidence, data, knowledge is presented, how it is presented and who presents it. How

we value all people's knowledge is not only about systems but about all stakeholders changing what they value in the process of participation.

A rights based approach offers one potential way forward, incorporating learning from associated fields such as participatory action research and civil society/service user led engagement. The right to health is enshrined in the United Nations (UN) Declaration of Human Rights (10) and further established in the UN International Covenant on Social Economic and Cultural Rights (11), which defines "the right to the highest attainable standard of health". This legally binding Covenant also sets out States Parties obligations to protect, respect and fulfil the right to health. General Comment 14 on the right to health, while not legally binding, provides robust guidance on the implementation of the right to health. A rights based approach to health is inclusive of healthcare and the social determinants of health and is underpinned by core principles including accountability, participation and non-discrimination (12). Such an approach embraces the social, political and economic context in which people experience health (13). Formal mechanisms of participation, such as those explored by Whitty *et al.* (1), may provide one form of participation in advancing a rights based approach.

Potts' monographs on participation and the right to health (14) and accountability (15) illuminate and describe in clear terms the State obligations of participatory processes. She identifies five broad mechanisms of accountability, which are linked to participation: judicial, quasi-judicial, administrative, political and social accountability. Civil society may be involved in all five mechanisms of accountability in some way.

A key advantage of a rights based approach is the accountability it brings to bear on States Parties and duty bearers, including social accountability through participation (16). However, as Bovens (17) has shown, in order for there to be accountability; in order for State Parties to engage in accountability processes, it is important for there to be a virtue of accountability as well as mechanisms of accountability. Put slightly differently, in designing accountability mechanisms attention needs to be paid to the values of health sector management and of the public and patients (18).

The provenance of public participation, as mechanisms imposed by governments to engage with citizens, does not bode well for the fundamental shift we are advocating. However, at the very least, it would be beneficial in our relations with the public, to be aware of the roots of public participation and the lessons already learnt internationally. At the same time we see scope to explore a rights based approach as a means to reclaim the structures that have been put in place for social accountability to, for example, hold states to human rights obligations. To make this happen we need to work very hard to ensure that participation is something far more than a set of hardware methods: where participatory knowledge is valued and is seen as a virtue.

#### Ethical issues

Not applicable.

#### Competing interests

Authors declare that they have no competing interests.

### Authors' contributions

All authors contributed to the development of the ideas for this commentary. AB produced a first draft, which was developed collaboratively with the MS and MC.

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