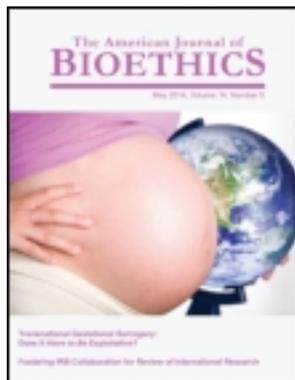


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Patient and Public Participation in Health Care: Can We Do It Better?

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Open Peer Commentaries

Patient and Public Participation in Health Care: Can We Do It Better?

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Williamson's article "Patient and Citizen Participation in Health: The Need for Improved Ethical Support" (2014) provides an insightful overview of the ethical issues raised by patient participation in health care. Williamson makes a distinction between two different routes of user engagement in health care, referred to as private and public participation. Private participation is what we might traditionally see as patients being involved in decision making about their own care; and the public forum, where patients or the public are involved in health policy or strategic decisions, a more recent and possibly more contentious area of user engagement.

Williamson's article is a timely consideration of the ethical issues that impact upon private and public participation and gives a very thorough consideration of a number of areas and underlying theoretical problems with the concept of both types of participation. In this commentary we want to build on Williamson's contribution to highlight areas where further conceptual and empirical work would be valuable.

To begin to develop work in this area, the concept of public participation needs to be unpacked further so that the different types can be delineated more clearly. One area where public participation is becoming commonplace is in the research arena. In the United Kingdom there has been increasing emphasis on the importance of patient and public involvement (PPI); this sees patients and the public working as research partners with the aim of conferring legitimacy on the research process, including its design, conduct and dissemination (INVOLVE 2012). Internationally, most medical research funding bodies require some degree of patient and public involvement as a prerequisite for funding. It is also seen as good practice to involve patients and public in health care policy and service enhancement. For example, in England in the recently reorganised National Health Service (NHS), NHS England has representatives from the public

on its policymaking committees and the National Institute of Clinical Excellence includes patient panel members in its technology assessments.

Public participation can cover a variety of activities, and all these activities require different types and levels of expertise, have different goals, and seek to provide a variety of benefits for both the individual participating in the engagement process and society in general. For instance, when she discusses the challenges for public participation, Williamson cites the democratic impetus of public engagement as being a key function. This is one specific type of public engagement—to access general public opinion on a particular issue (such as the Human Fertilisation & Embryology Authority [HFEA] did, in the United Kingdom, when it held a public consultation on the ethical acceptability of sex selection for social reasons [HFEA 2002])—and requires a very different form of justification and process than that needed for a patient "representative" on a research study steering group. In other places in the article, public participation is seen to play a role that would facilitate a kind of accountability for reasonableness approach, along Norman Daniels's lines, in making health care decisions (Daniels and Sabin 1997). Here public participation is playing a different role in the decision-making process, one that is giving the process itself legitimacy. Hence, these different forms of public participation provide different kinds of benefits to wider society (from improving the sensitivity and appropriateness of trial design to improving the democratic process in health policymaking) and have different justificatory arguments.

There are places in Williamson's article where the two forms of participation—public and private—are run together, and we argue that it is useful to make a clear distinction between the two forms to facilitate analysis. One area where the two forms of participation, public

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and private, differ substantially is the role autonomy should and does play. At the individual level, autonomy is operationalized by legally and ethically bound informed consent, which gives practitioners the permission they need to perform the treatment or intervention. Although all patients with capacity in nonemergency settings have to give informed consent to treatment (however assumed and generally relatively uninformed), not all people can be involved in the public aspect of health care decision making.

The problem of the paramount nature of autonomy, which Williamson discussed throughout her article, has a different resonance at the different levels of participation. At the private level, patient participation (informed consent based on autonomy) is, in theory, about protecting patients from unwarranted interference. In practice, we would argue that the stark notion of a rational individual making decisions free from any interference is more of a rhetorical device than an accurate depiction of how medical decisions are made in practice. As Williamson notes, the reality is usually more complex, with few patients making decisions that are truly autonomous. Thus, as Williamson says, there appears to be a disjunction between what is claimed at a theoretical level and what happens in practice, and this needs to be more fully recognized in the literature (see Mendick et al. 2010). We would argue that theory needs to catch up with practice and that decision making often involves others, rather than the autonomous individual acting without social influence. A relational autonomy model more accurately reflects practice and is also more beneficial for the patient (Entwistle et al. 2010). Gilies and colleagues (2012) describe a shift in thinking about autonomy in clinical trials toward more relational understandings that consider the ethics of communication between trial staff and potential patients. In their study, practitioners communicated in ways that aimed to help patients to consider invitations or requests to participate in trials by “responsively enabling” them to review and “deliberate” about what was being offered.

The role autonomy plays at the level of public participation is very different depending on the form of public participation, which, as noted earlier, can encompass many different activities with numerous functions. If we consider the role a patient representative might play on a committee that decides which drugs are going to be recommended (such as those organized by National Institute for Health and Clinical Excellence [NICE] in the United Kingdom), as Williamson notes, there could be difficulties with whose values should prevail and the challenges of bringing in private experience (as it must do at some level) into a public sphere. In these committees PPI contributors risk being seen as unable to leave behind a personal agenda if they draw on their private experience as “evidence” to justify their stance on a particular issue. At one level a response to this is that patient representatives are sought because of their membership of a group and the private experience of the knowledge of illness and treatment that this brings. This can help policymakers understand how the illness and the treatments affect the everyday life of people. Therefore, in this example, the in-

volvement of the patient is not about exercising their own autonomy but providing a greater wealth of experience and viewpoints.

This comes back to the question of what the goals of such participation are: Are they to broaden the debate to bring in other, until now, neglected viewpoints and then use this as a form of evidence to “feed” into the decision-making process? Or is it important that the “public” or patients are involved in the actual decision-making process—and how far should that involvement go, on what basis should these individuals make decisions (they are not experts and they are not elected to make decisions on behalf of others)? These are key questions, and these two forms of public engagement require both different practical measures and theoretical justifications.

We offer a possible solution to the issues raised with the first of these functions of public engagement, that of adequately considering neglected viewpoints. We agree that the “deliberative turn” provides a potential resource to help engage patients, yet question Williamson’s skeptical opinion that practical approaches to identifying patient preferences through relational exchange are “too demanding to be viable.” We argue that qualitative research may have a potential role in addressing such tensions, by facilitating the exploration of public and patient opinions to inform the process of decision making, legitimizing research agendas or projects. In a recent study (Woolfall et al. in press), we used interviews and focus groups to explore the views of parents to inform the development of a challenging paediatric emergency care trial. EcLiPSE (Emergency use of Levetiracetam vs. Phenytoin in Status Epilepticus) is a randomized trial to compare two medicines (levetiracetam and phenytoin) to treat prolonged seizures in children aged 6 months to 18 years. Challenges in conducting the trial were identified during the design stage, including a vulnerable target population; the need for the intervention to be delivered during a medical emergency; and insufficient time to obtain informed consent. We involved 17 parents whose children had a range of acute and chronic health conditions, 7 of whom (41%) had children who had experienced seizures. Our findings provided insight into how parents perceive deferred consent in the pediatric emergency care setting. Parents made recommendations that were used to inform practitioner training, approaches to recruitment, and consent methods to assist autonomous decision-making at the individual level.

If conducted with rigor and reported in a transparent manner (Tong et al. 2007), qualitative research provides a means of presenting public opinion on a particular issue to inform decisions in health care that could overcome some of the limitations of the deliberative model that Williamson highlights. This model of consultation provides a method of involving more meaningfully the patient population of interest, rather than relying on the views of a few individuals who are subject to the influence of their own private agenda or experiences.

In conclusion, the purposes and justification of each form of participation need to be established so that

we can ascertain whether it is adequately fulfilling its function and to improve on current practice. Some of the problems Williamson highlights in regard to the restrictions of relying on a particular model of autonomy could be overcome at the private level by adopting a relational model of autonomy that does not reduce it to self-determination and at the public level by adopting a conception of involvement that does not rely overly on selective individual opinions. ■

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Ensuring That We Promote Participation in Health for Everyone

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We share Williamson’s (2014) view that promoting active lay participation in health is critically important and that more work is needed to develop an ethical framework adequate for both justifying and promoting its wider practice. As Williamson notes, existing frameworks are particularly ill-suited to promoting engagement for populations exhibiting pervasive health and social disparities. However, while these issues are introduced during the course of the article, some of the terminology used by Williamson shifts the focus away from these populations, which in turn raises questions about how broadly her work should be applied. In particular, we are concerned that the omission of consideration of these populations limits how an ethical framework might be used to explore some of the relevant ethical issues involved with promoting greater participation among individuals from disenfranchised populations.

First and principally, important nuance is lost when “engagement,” “involvement,” and “participation” are used interchangeably. In the community-based participatory research (CBPR) and community engaged research (CEnR) literature, some but not all of which Williamson cites, engagement is considered to be an active two- (or more-) way *process* by which greater lay participation or involvement in laypeople’s health is made possible (Ross et al. 2010a). CBPR developed out of a desire to make sustainable positive change in population health in real-world contexts, particularly those characterized by highly disparate health and social outcomes. To address a lack of trust in the medical community that has hindered more traditional research, CBPR has become a research orientation focused on establishing relationships as a necessary first step of a systematic effort to involve the community in research (Wallerstein and Duran 2006). Additionally, it has been argued that CBPR

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