

Target Article

# Patient and Citizen Participation in Health: The Need for Improved Ethical Support

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Patient and citizen participation is now regarded as central to the promotion of sustainable health and health care. Involvement efforts create and encounter many diverse ethical challenges that have the potential to enhance or undermine their success. This article examines different expressions of patient and citizen participation and the support health ethics offers. It is contended that despite its prominence and the link between patient empowerment and autonomy, traditional bioethics is insufficient to guide participation efforts. In addition, the turn to a “social paradigm” of ethics in examinations of biotechnologies and public health does not provide an account of values that is commensurable with the pervasive autonomy paradigm. This exacerbates rather than eases tensions for patients and citizens endeavoring to engage with health. Citizen and patient participation must have a significant influence on the way we do health ethics if its potential is to be fulfilled.

**Keywords:** decision making, primary care, public health, health policy

Globally, efforts to involve patients and citizens in decision making in the field of health are well established across a range of issues in health care provision and public health (Kahssay and Oakley 1999; WHO 1978). This breadth is evident in the work of the World Health Organization (WHO) that refers to engagement in the context of primary care and public health. The need for person-centered care is central to the 1978 Declaration of Alma-Ata that states, “People have a right and duty to participate individually and collectively in the planning and implementation of their health care” (WHO 1978). The importance of public involvement to sustainable improvements in public health is promoted in a number of WHO documents, including the Ottawa Charter (WHO 1986), Sundsvall Statement on Supportive Environments for Health (WHO 1991), and initiatives on specific health issues including malaria (WHO 2002) and tuberculosis (TB) (WHO 2012).

Participation efforts have two primary drivers. First is the promotion of sustainable health and health care grounded in a sound, publicly accessible evidence base; the second is the conviction that involvement is intrinsically valuable, given its democratic commitment to promoting the interests of citizens (Charles and DeMaio 1993; Epstein and Peters 2009; Florin and Dixon 2004, 159; Tenbensen 2010). Beyond this, the practical aims of participation are multiple, often overlapping and sometimes conflicting, namely, to change health-related behaviors; empower citizens to take greater responsibility for their own health; control health costs; improve the quality of health care provision; and improve patient experience. Within the health

systems of Western, developed countries, participation programs occur within the “subdomains” of “treatment, service delivery, and broad macro- or system-level decision-making contexts” (Charles and DeMaio 1993). Different terminology is used to describe participation efforts: patient and public involvement (PPI), lay participation, consumer activation, and citizen engagement (British Medical Association [BMA] 2011; Carpini, Cook, and Jacobs 2004; Charles and DeMaio 1993; Hibbard et al. 2004). Though diverse, these initiatives share the conviction that sustainable improvements in health cannot be achieved by imposing change on people, but require their active participation. In this article the terms involvement, engagement, and participation are used interchangeably to signify efforts in health care provision and public health to involve people more actively in policy and practice.

Ethical issues are central to the viable development of healthy behaviors, practices, and policies that promote and sustain health. This has long been recognized in relation to the challenges presented by the physician–patient relationship and is, increasingly, also the case in public health programs (Beauchamp and Steinbock 1999; Dawson and Verweij 2007; Jonson 1998). It is argued here that in their current form the most prominent accounts of health ethics do not serve participation initiatives well. Citizens (as actual or potential patients and members of the public) require better support to identify and work through the multiple values-based challenges they encounter in their engagement with health. This is particularly important when the issues under discussion go beyond or conflict with the dominant ethical

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language of individual autonomy and choice. This article contends that private and public participation in health requires developments in health ethics if its potential is to be fulfilled.

The first section of the article provides an overview of the different forms of private and public engagement in health and concludes by pointing to some of the challenges that exist for involvement. The article then turns to examine the resources that health ethics provides for private and public engagement initiatives. Finally, the conclusion briefly points toward ways for health ethics to develop and support patient and citizen participation in health and health care.

## **ROUTES TO ENGAGEMENT: PRIVATE AND PUBLIC**

Efforts to engage people in health practice and policy can involve them as individual patients or as members of the public. Florin and Dixon distinguish between “patient involvement,” which refers to people “making decisions about their own health” and “public involvement,” which engages “members of the public in strategic decisions about health services and policy at a local or national level” (Florin and Dixon 2004). Individual and public engagement can require quite different things from participants. Jones and colleagues suggest patient involvement is essentially “private participation” (Jones et al. 2004, 94) in which individuals promote and protect their own preferences and values. Public involvement, in the context of treatment services and public health, can request citizens to “put aside their particularistic preferences . . . and participate for the common good” (Tenbensel 2010). In the United Kingdom, the Nuffield Council on Bioethics has explained:

What characterises “public” discourse . . . are the qualities of non-privacy (not being carried out in isolation from public influence or scrutiny) and non-partiality (not being framed by private or sectional interests). (Nuffield Council on Bioethics 2012, xx)

Creating citizens who are able and willing to be actively involved in a range of health topics necessitates helping them work through a variety of issues and doing this from different perspectives. This includes clarifying their private preferences, and determining what is publicly required (practically and ethically), and articulating how these two spheres sit together. In addition, the overlap between public and private perspectives—for example, health policy can benefit from being informed by the private experience of citizens—requires careful management and support, as do the tensions and conflicts that can arise between private health concerns (self-interest) and the well-being of the wider public (the common or public good). The article next outlines in more detail some of the different routes that are taken to patient and citizen participation in health.

### **Private Routes to Engagement**

In the clinic, efforts to engage individuals on their own health are evident in initiatives that promote person- or patient-centered care as a way of “refocusing of medicine’s

regard for the patient’s viewpoint” (Laine and Davidoff 1996, 152). The Institute of Medicine has described patient-centered care as one of six areas that are central to health improvement efforts (Institute of Medicine 2001, 39ff). It defines such care as that which “is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions” (Institute of Medicine 2001, 40). Others are more specific regarding the ethical content of person-centered care, stating that it “emphasizes patient autonomy, informed consent, and empowerment” (Edwards and Elwyn 2009, 4). These principles are at the heart of traditional accounts of biomedical ethics and an assumption that there is a natural affinity between engagement and autonomy-based ethics. This point is examined in more detail later.

### **Shared Decision Making and Self-Management**

Shared decision making is a particular expression of patient-centered care that seeks to establish a form of clinical decision making that lies between paternalism (“doctor knows best”) and the provision of technical information to patients to allow them to decide for themselves (“patient sovereignty”) (President’s Commission 1982, 36). Shared decision making provides a way to help patients work through their preferences and achieve “values clarification” (Llewellyn-Thomas 2009; O’Connor, Llewellyn-Thomas, and Flood 2004). That is, in cases where there are no clear evidence-based solutions on which course of treatment should be adopted, health care teams help people to work through their values and preferences (O’Connor et al. 2004, 63). Decisions on issues across the life course raise ethical challenges that require this type of values-based—not only evidence-based—support. This is, for example, the case in respect of issues like prenatal screening, the use of hormone replacement therapy (HRT), and the discontinuation of active treatment toward the end of life.

Within person-centered care, self-management is another route toward greater participation. The justifications for self-management include the practical, financial, and ethical benefits of people self-caring. High rates of chronic disease make it important that conditions like diabetes are self-managed by patients for a variety of reasons. First, given that the conditions are lifelong it is most efficient for people to manage their own health issues. Indeed, those living with a condition have knowledge about how it affects them that health professionals lack. Second, self-management decreases the burdens placed on health services; third, self-management is based on the normative conviction that “patients deserve to be partners in their own care” (Holman and Lorig 2000, 526; Lorig et al. 2001). Thus, the “partnership paradigm” of care seeks to empower people to live with chronic illness and acknowledges that they are experts on “their own lives” (Bodenheimer et al. 2002, 2470). Bodenheimer and colleagues explain that a significant difference between traditional care and the expert patient paradigm is that where the former provides patients with “information and technical skills, self-management

education teaches problems-solving skills" (Bodenheimer et al. 2002, 2471). In person-centered care this includes the need to weigh ethical priorities as well as the empirical evidence base.

### Social Context of Person-Centered Care

It is important to emphasize that person-centered care involves not only private issues, but also many social factors that influence health. This is because a patient-centered approach necessitates "understanding the whole person in context" (McWilliam and Freeman 1995, 75). In this respect, Mead and Bower state that "the concept of patient-centeredness can be seen as associated with a broadening of the scope of medicine from organic disease" to wider issues that impact on health (Mead and Bower 2000, 1088). In making this point, Mead and Bower refer to the claim of Grol and colleagues that patient-centered care results in health professionals "feeling responsible for non-medical aspects of the presented problems" (Grol et al. 1990). The ramifications of this could require more from health care professionals than it is feasible for them to deliver (Coulter 2002, 107). But it is not only health care teams who have a responsibility to respond to the social drivers of poor health; all stakeholders—citizens, patients, and policymakers—must participate in addressing these wider issues. Participation initiatives present opportunities to engage in the dialogue needed to identify issues that have a detrimental impact on health and generate practical remedies.

Self-management has also been identified as presenting issues that require a broader approach. In her work on self-management, Greenhalgh notes:

Self-management programmes based on the expert patient model remain the preferred policy in many countries, but the evidence base for their efficacy is weak. It is time to move beyond them and embrace richer, more holistic models which consider a person's family, social, and political context. (Greenhalgh 2009, 631)

This again carries important implications for how patients (and citizens) identify and think through relevant issues. More specifically, it raises questions over the range and degree of responsibility that different people and agencies (families, close contacts, governments, third sector organizations) have within the "self" care scenario. This focus creates concerns over self-management acting as a tool that allows some to abdicate responsibility at some stage in the prevention-treatment-caring chain. Ultimately, efforts to empower patients need to go beyond supporting the capacity to choose and embrace the need to identify and seek to direct the wider socioeconomic factors that influence health.

### Public Routes to Engagement

Public participation initiatives associated with health endeavor to make the field more citizen centered in much the same way as health care provision aims to be patient centered. Public engagement exercises take a variety of forms; for example, they provide participants with information;

ask for their opinion; and incorporate them as active partners within policy formation (Arnstein 1969; Charles and DeMaio 1993; Feingold 1977). The expression of public engagement activity that collaborates most closely with citizens, from the conception to completion of a project, is arguably community-based participatory research (CBPR). This approach seeks to develop research which is "community based, rather than merely community placed" (Minkler and Wallerstein 2003, 3). Building on the assets within communities, the aims of CBPR include the intentions to "share control over all phases of the research process," use knowledge for the benefit of all, and address social inequalities through co-learning and empowerment (Israel et al. 1998, 178-179). More widely, Weldon usefully summarizes some of the methods used to engage the diverse citizen body within public engagement efforts: citizen juries, deliberative polls, focus groups, Internet consultation, public debates, Web debates, and more artistic media such as theater and exhibitions (Weldon 2004, 20). Public participation is not restricted to public health, but is also relevant within different levels of care provision.

### Public Engagement: Health Care Provision

In the context of health care provision, public involvement initiatives have been utilized on a range of issues, including debates on how health services should set priorities given limited resources (Bruni, Laupacis, and Martin 2008; Mitton et al. 2009). The drivers of this type of participation are to help the public accept the difficult decisions that need to be made, and second, to respect the view that "the public should have real influence on how these choices are made" (Sabik and Lie 2008). But even when participation initiatives are utilized, ensuring that citizens have confidence in the process requires a rigorous, transparent framework for engagement-led decision making. This approach is needed to illustrate how public views have been weighed and incorporated or dismissed in the outcome. This process must include an account of the values and ethical convictions that explain, consistently and in a publicly assessable form, the rationale for the decision(s).

### Public Engagement: Public Health

With respect to public health, engagement initiatives have taken place across a range of topics including infectious disease prevention and the public implications of developments in biotechnology. Participation efforts have, for example, been dedicated to the measures needed to support an adequate response to pandemic influenza. WHO emphasizes "public engagement and involvement of relevant stakeholders should be part of all aspects of planning" for response to pandemic influenza (WHO 2007, 3). As with engagement in health care, these involvement efforts have sought to cultivate the trust needed for prevention measures to work by providing the public with information at an early stage (Department of Health Pandemic Influenza Preparedness Team 2011; WHO 2007, 3), and to ensure that policy is informed by public opinion (Public Engagement

Pilot Project and Pandemic Influenza 2005). The latter kind of involvement is based on the assumption that

the process which will best reflect society's values is a public engagement process which involves both stakeholders, including experts, and citizens with diverse backgrounds and perspectives. (Public Engagement Pilot Project and Pandemic Influenza 2005)

Public engagement efforts have also involved members of the public in debates on new health technologies to inform them and solicit their views. The development of genetic technologies has led to many engagement initiatives, internationally, that range from information provision to deliberation (Cox et al. 2009; Dunkerley and Glasner 2007; Etchegary et al. 2013; Godard, Marshall, and Laberge 2007; O'Doherty and Burgess 2009). Similarly, initiatives in various countries have consulted the public on their views on xenotransplantation given the infection risk it carries for third parties and questions over the acceptability of transplanting animal tissue into humans (Australian Government, National Health and Medical Research Council 2003; Canadian Public Health Association 2001).

### Challenges for Public Participation

As in patient engagement, ethical issues play an important role in public participation efforts. Policy debates in health have, for example, long been marked by a need to balance the tension between public interests and the freedoms of individuals (Gostin 2008). Efforts to cultivate a greater role for citizens in health policy and practice raise a number of specific issues. First, people are likely to be most familiar with engaging in health as patients and focused on promoting their self-interest. Invitations for them to have a greater role in health debates as citizens, focused on the wider public good that goes beyond and that could conflict with their own needs and preferences, may lead many to unfamiliar territory. Thus, such requests need to be accompanied by guidance explaining the ethical aims and context of the initiative—as well as the basic empirical information on the topic under examination. This context should involve specifying what public participation requires from individuals and how these requirements relate to and differ from the drivers of patient-centered care. In doing this there is a need to be mindful of the confusion that could be created by the need for citizens to “assume different roles at different times depending on their interaction with the health care system” (Wait and Nolte 2006). Thus, efforts must be made to articulate the aims of public engagement in a manner that avoids circumstances in which participants “are not clear themselves, on which perspective to adopt in any given health care decision-making context” (Charles and DeMaio 1993, 893). These initiatives should be based on an explanation of how the different forums citizens actively participate in relate to each other in terms of their practical requirements and values-based tensions.

Second, the democratic impetus of public engagement must find ways to manage the need for policy to uphold a

certain quality standard and do so in a manner that is publicly defensible. Tenbenschel, for example, critically summarizes the centrality of the values, opinions, and preferences of citizens in public engagement in health policy:

By the end of the 1990s, the predominant argument was that citizen input helps to shape and define the key *values* that can then underpin policy decisions, and indeed that knowledge about values was the key component of the public's “expertise.” (Tenbenschel 2010, 1583, emphasis in original)

Soliciting information on what individuals think about health policy does not necessarily mean—and practically cannot mean—that all citizen views should be adopted. Indeed, the involvement of the public actually exacerbates the question of which or whose values should direct health policy (Carpini et al. 2004; Macedo 2010). Even if a majority of the members of the public are in favor of a particular course of action—for example, preventing the development of a new health technology or distributing scarce resources in a specific way—it does not ethically follow that this view should be adopted. This means public engagement efforts must find ways to manage the tension between their democratic impetus and the need for quality assurance when informing policy positions and practice.

Finally, the public has expressed concerns that engagement is a hollow exercise that seeks public views when decisions have already been made (Bruni et al. 2008; House of Commons Health Committee 2007, 5). To address such issues it is imperative that participation adopt rigorous standards of transparency and accountability because without these, public involvement could “undermine, rather than enhance public trust” (Turnbull and Aucoin 2006, 7).

Public and private engagement is thought by some to have so much potential to promote sustainable health that it constitutes the “blockbuster drug of the century” (Dentzer 2013; Kish 2012). This is based on evidence that patients benefit from being more engaged in their health (Stewart et al. 2000). But more widely, concerns have been raised regarding its effectiveness (Mead and Bower 2002). Despite this, initiatives promoting and relying on participation seem likely to grow for the foreseeable future. This is partly because the lack of evidence for success does not necessarily signify a lack of actual or potential benefit. In addition, private and public engagement is based on the ethical conviction that it is important to incorporate the views of patients and citizens within health. Thus, a lack of evidence for effectiveness could signify the need for additional research or improved involvement techniques to deliver on its democratic aims.

In summary, this overview of citizen and patient engagement has highlighted a number of significant issues for efforts to support and improve its development. Firstly, decisions in health and health care—even those deemed “private”—need to take account of the relational and social factors that influence them. This point is relevant for all stakeholders in health systems. Second, participation efforts must endeavor to cultivate a more representative and democratic approach to health that carries the trust of

citizens, while also generating sustainable, quality-controlled policy and health care practices. Third, requesting citizens to step beyond their self-interest and personal preferences to prioritize the public good necessitates supporting them to act in this capacity. Although phrases such as “patient and public involvement” suggest a comfortable relationship between private and public participation, currently the rapport between these two elements is, at best, uneasy. This is because in liberal democracies there are frequently conflicts between the interests of private individuals and that of the wider community. Thus, asking citizens to increase their involvement in both spheres without adequate support is a task people may not be equipped to conduct effectively. To explain and unpack these issues, the following section examines the type of support health ethics provides for participation initiatives.

### **HEALTH ETHICS: SUPPORT FOR PARTICIPATION INITIATIVES**

This section briefly outlines the commitments associated with the tradition of autonomy-based ethics that dominates the health sphere, before examining its limitations for addressing the three themes that have emerged as significant in the previous discussion: namely, the importance of relational and social support; the need to balance a democratic impetus with quality control; and the requirement to support people most familiar with engaging in health as self-interested individuals, to participate in a manner that prioritizes public interest(s). Finally, this section of the article assesses the contribution of alternatives to autonomy-based ethics that are currently less influential in public debates on health, but that may aid efforts to promote improved, sustainable health through patient and public participation.

#### **The Autonomy Paradigm and Participation**

The importance of ethical issues within the health field has long been most prominent in the context of the doctor–patient relationship (Jonson 1998). While the initial interest of Hippocratic ethics was the duties of physicians, biomedical ethics has turned to focus on supporting the interests of patients—both approaches are rooted in “the tradition of individualism” (Veatch 2012, 116). The values that lie at the heart of biomedical ethics can be presented as an “autonomy paradigm” of ethics (Jennings, Callahan, and Caplan 1988, 8). This paradigm rejects paternalism, supports the right of competent patients to decline even potentially lifesaving treatment, and requires individuals to authorize medical treatment performed on them. These freedoms are enshrined in law and the medical codes to which health professionals are held to account. Autonomous decision makers are distinguished by their ability to make decisions that are informed, intentional or deliberate, and uncoerced (Beauchamp and Childress 2001, 59; Faden and Beauchamp 1986). The classic account of biomedical ethics is the “four principles” approach

that has developed since it was first published in 1979 by Beauchamp and Childress (1979; 2013). They state:

Personal autonomy is, at a minimum, self-rule that is free from both controlling interference by others and from limitations, such as inadequate understanding, that prevents meaningful choice. (Beauchamp and Childress 2001, 58)

Initiatives to increase patient and public participation take place in a health and social environment that is dominated by this ethic. Indeed, efforts to promote patient participation in health often see autonomy-based ethics as fundamental to their aims. This is because the importance the autonomy paradigm affords to safeguarding the choices of patients seems a natural ally to the endeavor of patient-centered care to promote patients’ values and perspectives. The World Health Report of 2000 states, for example, that respect for persons includes having the “Autonomy to participate in choices about one’s own health. This includes helping choose what treatment to receive or not to receive” (WHO 2000, 32). In the context of participation, Coulter (2002) notes that health care teams “need to listen to and understand patients’ expectations and preferences. They must respect patients’ autonomy,” as part of efforts to cultivate “a more active role for the patient and greater public involvement in health policy-making” (106). Beauchamp and Childress (2001) have emphasized that their account of autonomy includes “obligations to build up and maintain others’ capacities for autonomous choice . . . and enabling persons to act autonomously” (63). Coulter (2002, 8) draws on this commitment to positive enablement to support the notion that autonomy is key to efforts to promote patient-centered care. Similarly, Stiggelbout and colleagues (2012) argue that shared decision making should be the norm in clinical care given the “ethical imperative” laid down by the “widely accepted four principles. Not only is it essential for protecting autonomy (enabling individuals to make reasoned informed choices)” but it is also important in beneficence, nonmaleficence, and justice. Most recently, Danis and Solomon (2013) have stated that a key aim of patient involvement is to be “consistent with respect for people, in that strategies aim to enhance the patient’s right to self-determination” (402).

### **THE LIMITATIONS OF BIOMEDICAL ETHICS FOR SUPPORTING PARTICIPATION**

Despite claims that the autonomy paradigm at the heart of biomedical ethics is a key factor in patient participation, for a number of reasons it may provide inadequate foundations for such initiatives. Furthermore, the need to support citizens to participate in health, a role that requires something different to their experience as engaged or expert patients, could actually be impeded by traditional biomedical ethics. These issues will now be examined.

### Supporting the Relational and Social Dimensions of Health

The main criticism that has been leveled against bioethics and the autonomy paradigm is that it is too individually focused and fails to recognize the social nature of human beings (Fox and Swazey 1984; Wolpe 1998). Even those committed to some reading of autonomy acknowledge that the majority of “contemporary accounts of autonomy see it as a form of *independence*” (O’Neill 2002a, 28). As a result, it is often understood solely as the freedom and capacity to exercise choice or agency. On this account, autonomy is divorced from any notion of choice fitting within a broad understanding of the individual’s values or goals (Brudney and Lantos 2011), or as relating to their social context. However, we have seen that even the most individually focused area of engagement—patient-centered care—is concerned with “broadening of the scope” of biomedicine to address illness as patient’s experience it (Mead and Bower 2000, 1088). That is, although patient-centered care seeks to tailor treatment to specific individuals, to do so effectively it needs to engage with the preferential, socioenvironmental factors that impact on how individual patients experience illness and recovery. But it has been widely argued that the social dimensions of health are not well supported by the individual focus of biomedical ethics because “it ignores the social circumstances and power relations that affect choice” (Dodds 2000, 216). Thus, although Beauchamp and Childress allow for third-party support to help individuals act autonomously, this is not necessarily the understanding that predominates in social thought or practice. As a result, unless an improved reading is consistently utilized, the principle of autonomy may not serve as an adequate foundation for patient participation. For example, allowing a patient with a newly diagnosed serious condition to select treatment options alone can be seen as “abandoning the patient” (Gessert 2008). In such circumstances, even the most educated and medically aware patients can feel “lost” and in need of support from health care professionals and close contacts when deciding on whether to continue with treatment and which options to select (Epstein and Street 2011).

Furthermore, initiatives that aim to increase patient and citizen involvement in public issues will fare particularly badly within debates governed by an individually focused ethic. This is because such an approach does not afford sufficient attention to contextual factors, or promote a shared concept of the public good with which to inform exchanges—at least one that does not see the public interest as residing solely in the promotion of multiple self-interests. Efforts to address chronic health problems can too easily focus on the behavior of individuals, rather than the social situations that influence decisions or “choices” that undermine health. We have seen that a failure to connect self-care to wider questions of responsibility and justice through participation can overlook fundamental issues. As Spencer, Morris, and Thomas (1989) have starkly noted in relation to smoking-related harms:

It’s a curious logic that would define a woman’s problem as being that she smokes when she lives in damp, overcrowded accommodation on a low income and is depressed, single and expecting twins to a man married to someone else. (193)

Numerous attempts have been made to remedy the individual focus of autonomy. Particularly notable are efforts to develop a “relational” account based on the conviction that “persons are socially embedded and shaped by a complex of intersecting social determinants” (Mackenzie and Stoljar 2000, 4). Importantly for the focus of this article, it has been argued that a relational account of autonomy should be afforded a central role within patient-centered care. The suggestion is that this would help prevent an approach that “isolates the patient as decision maker” (Ells, Hunt, and Chamber-Evans 2011). Ellis and colleagues note that despite these efforts to move beyond the autonomy paradigm in health ethics and wider philosophical work, there are surprisingly few examinations of autonomy within literature on participation that point up the need for change (Ells et al. 2011; Lee and Lin 2010; Williams, Freedman, and Deci 1998). They continue to suggest that this lack of investigation will allow an inadequate interpretation of autonomy to continue to dominate health care practice (Ells et al. 2011, 85). For patient-centered care to be informed by an ethic that is sufficiently complex to address the wide range of issues encountered, it is necessary that the limitations of the current approach be widely acknowledged (in practice and theory). For participation efforts to experience the benefits of a more satisfactory account of autonomy, exponents of engagement must be involved in the development of an improved ethical approach to ensure that the needs of involvement are met in a way that is practically beneficial.

### Ethical Support for Quality Control

When it is understood as independence, autonomy has little normative content to help people work through difficult issues. It suggests people should be allowed to choose freely, but provides no assistance on what they should or ought to best select—that is, the view that autonomy amounts to non-interference or “self-understanding . . . excludes evaluative judgment of the patient’s values or attempts to persuade the patient to adopt other values” (Emanuel and Emanuel 1992, 10). The difficulties this creates for participation are apparent in the context of both private and public engagement. In shared decision making the importance of “values clarification” in the relationship between health care teams and patients receives no substantive support over which values or options should be prioritized (Brock 1991). Furthermore, if individual values and preferences cannot be questioned, patients could expect all their requests—even those that are unrealistic or potentially harmful—to be fulfilled by health care teams. A case in point is requests for clinical interventions that are not medically indicated, including scans in nonsymptomatic individuals who think they may be at risk of cancer, and which could necessitate further invasive procedures, placing unnecessary risks

and costs on the patient or the health service (Cardasis and Brush 2011). Similarly, uncertainty over whose or what values should be prioritized in public engagement efforts are not resolved by an autonomy-based ethic that provides no clear way to assess or arbitrate between different individual preferences, let alone public ones. This concern is, for example, evident in the tensions that exist in efforts to formulate policy on the distribution of health resources utilizing public involvement, when something beyond individual preference is needed to arbitrate value conflicts.

Alternatives exist to the prevailing interpretation of autonomy. Particularly notable for firming up its normative content is O'Neill's account of "principled autonomy" that seeks to move beyond non-interference. O'Neill explains that principled autonomy "requires that we act only on principles that can be principles for all" (O'Neill 2002a, 96). As a result, certain behaviors, including requests that might in the long term denigrate trust in the health care profession, should not be sanctioned. However, even if they were developed, such moves are unlikely to have a significant impact. This is because the concerns that exist regarding autonomy and choice are exacerbated by the fact that the individually focused ethic that dominates the field of health has drivers beyond biomedical ethics. It is important for those endeavoring to secure greater patient and public participation and those seeking a less individualist account of health ethics to recognize the influence of these factors.

### Supporting Involvement Amid Market-Led Consumer Choice

Understanding autonomy as choice and noninterference is strongly associated with the aims of market liberalism. Gaylin and Jennings (2003) suggest that this environment has produced a "culture of autonomy" (4) that prioritizes the ideals of consumer choice, independence, and noninterference. Importantly, they claim this culture is "everywhere" even when the principles of biomedical ethics are not mentioned (Gaylin and Jennings 2003, 48). That is, the ideals associated with the "culture of autonomy" pervade public consciousness within liberal democracies. In the field of health the desire to allow or encourage the market to have a prominent role—within privately funded health care systems in the United States and increasingly in publicly funded health care in Europe—is linked to the belief that quality care will rise to the surface within a sea of competing service providers. The promotion of consumer choice in health is also thought to help deliver goals and principles fundamental to biomedical ethics:

Consumerism is presented as a mechanism for redressing the power inequality between health professionals and patients and as the logical extension of informed consent. (Tritter et al. 2010, 44)

However, understanding autonomy as unfettered, self-concerned consumer choice does not help efforts to promote decision-making partnerships between patients and health care teams in which decisions and responsibilities

are shared. Rather, this interpretation of autonomy is more appropriately associated with the notion of patient sovereignty and a decision-making style in which patients are provided with information and left to decide for themselves. Similarly, prioritizing individual consumer choice is at odds with public participation efforts that need to identify and promote public good(s)—whether through patient or wider citizen involvement. This is because the ideology that promotes consumer choice has "a very limited view of citizenship" (Pickard 1998, 228); Ignatieff (1995) goes further to claim that "the market solution is an attack on citizenship and democracy" (73). The implications of this for participation are significant. Namely, prioritizing consumer and market preferences works against efforts to involve citizens in public debates on health in a manner that encourages them to think beyond their self-interest and about the good of wider society. Currently, for example, concerns about the reemergence of preventable diseases like measles (Cohen 2013; Iacobucci 2013; Wallace et al. 2013) have led to efforts to bridge the "confidence gap" that obstructs the uptake of vaccination (Larson et al. 2011). Public engagement is central to these initiatives. Larson and colleagues argue that increasing public trust in vaccination must be based on a detailed understanding of public concerns and the socioeconomic contexts of citizens (Larson et al. 2011); they insist that "trust is built through dialogue" (533). Similarly, in the context of vaccination Pettett (2012) states:

We need to become more engaged in our role as patient and health care advocates at both the local and national levels. The challenges are abundantly apparent; the solutions are within our grasp; GET ENGAGED. (8)

However, unless a radically different value system is utilized to support such involvement, it is hard to see how participation can have the type of impact envisaged by those working to increase vaccination.

### ALTERNATIVES TO THE CULTURE AND PARADIGM OF AUTONOMY: CONCERN FOR PUBLIC INTEREST(S)

This section briefly examines two related attempts within health ethics to address public issues by utilizing a social paradigm that presents an alternative to the individualism of the autonomy paradigm. In this respect, the article draws on ethical work around biotechnologies and the development of public health ethics. Both fields have a close relationship with public engagement and present an alternative account of the relationship between individuals, their social contexts, and the formation of values. However, it is argued that so deeply rooted are the problems facing efforts to engage people in public debates on health that these more socially aware accounts also encounter considerable problems.

#### The "Communitarian Turn" in Biotechnology

Efforts to address the socioethical challenges presented by emergent biotechnologies have witnessed a "communitarian turn" away from autonomy (Chadwick 1999, 297). In

the context of genetics, for example, it has been argued that within a decade developments led to a shift in the norms and principles governing such technologies, from “autonomy, privacy, justice, quality and equity” to “reciprocity, mutuality, solidarity, citizenry and universality” (Knoppers and Chadwick 2005, 75; Chadwick 2011, 54). This shift was influenced by issues such as the importance of sharing genetic information for the good of others (Knoppers and Chadwick 2005, 76); the inadequacy of individually based informed consent when dealing with technologies, such as xenotransplantation, that carry an infectious disease risk for society (McLean and Williamson 2005); and the implications of forensic DNA databases for society (Patyn and Dierickx 2010, 319).

The development and introduction of new biotechnologies is a field in which there has been much public engagement work undertaken. Indeed, the move toward a social paradigm of ethics based on “solidarity,” “reciprocity,” and “citizenry” is presented as a corrective to seeing “autonomy as the ultimate arbiter, at least in the bioethics of the developed world, but also an appreciation of the need for a participatory approach” (Knopper and Chadwick 2005, 75). However, the suggestion that this alternative ethical approach helps to support participation overlooks a number of difficulties. First, articulating a social paradigm of ethics without explaining its relationship to autonomy convincingly to engage and win their confidence. This is because the dominance of the autonomy paradigm in society means that, for many, highlighting social principles and norms “does not help to determine how best to relate that foundation to our individualist culture” (Callahan and Jennings 2002, 172). Second, so deeply rooted is the culture of autonomy that any social turn may find it hard to become established and sustainable. In this respect, Dickenson (2013) notes that the “communitarian vision” for how biotechnologies would benefit society and how it should (ethically) be regulated did not last long before giving way to the market-led and “the now-dominant personalized medicine paradigm” (viii). Thus, without deeper support the development of a social paradigm of ethics was insufficiently grounded to secure sustainable improvements in health through participation. Ethical work in the field of biotechnology is not alone in creating difficulties for and imposing limitations on participation when utilizing a social ethical paradigm.

### Public Health Ethics: A “Distinct” Field

Like those working on biotechnologies, ethicists interested in public health more broadly have also sought to go beyond autonomy. This shift is necessitated by the focus of public health on protecting and promoting the health of whole populations, rather than that of individuals. The Institute of Medicine explains that “public health is what we, as a society, do collectively to assure the conditions for people to be healthy” (Institute of Medicine 1988). The “collective action” or “organised efforts” (Institute of Medicine 1988; Winslow 1920, 30) used to promote public health are

generated by government-level policy in which individuals are required or expected to participate. This focus on community-level interests creates a “deep divide” between bioethics and public health (Bayer and Fairchild 2004, 475). A central issue for public health in liberal democracies dedicated to protecting individual freedoms is the extent to which its focus on community interests and the common good can or should trump the liberty of individuals. This conflict is evident in a range of issues including whether HIV infection should be an exception to mandatory reporting and testing requirements (Bayer and Fairchild 2006); the degree to which government should seek to alter individual “lifestyle” choices related to obesity, smoking, and alcohol consumption to control chronic disease; the level of risk that needs to be associated with an infectious disease for limitations to be placed on individual behaviors or movements; and whether stigma should be used as a public health resource, given its negative implications for individual liberties (Bayer 2008).

To provide a more appropriate response than traditional biomedical ethics to such ethical challenges, public health ethics has developed as a branch of bioethics. It also draws on a social, communitarian paradigm and principles like solidarity, social justice, and stewardship (Beauchamp 1976; Callahan and Jennings 2002, 170; Nuffield Council on Bioethics 2007). These principles aim to provide ethics with the capacity to cross the “border” from the autonomy paradigm to an approach that more easily accepts the need to place restrictions on individual freedoms (O’Neill 2002b). But using public health ethics as a resource to articulate when it is acceptable to restrict liberties to protect public health risks being undermined by those who argue that this ethical approach is a “completely new,” “distinct,” or “somewhat separate” health ethic (Beauchamp 1976, 105; Kass 2004, 235). As with work on biotechnology, this dichotomizing entrenches ethical tensions, rather than helping to navigate them. This is because it does not provide people with an account that makes sense in terms of the autonomy paradigm, with which they are likely most familiar. It has been argued that for ethical arguments to be “sustainable, they must be at least mutually compatible and, ideally, framed within the same overall system” (Coggon 2010, 238). This is not the case with the social and autonomy paradigms of health ethics. Rather than helping to build trust, the presentation of an alternative ethic may be seen as a sleight of hand that is turned to whenever liberties need to be constrained.

### CONCLUSION: IMPROVING ETHICAL SUPPORT FOR PARTICIPATION

Ethical issues are fundamental to patient and public engagement. Despite the large volume of work that exists on various facets of participation in health, it remains important to develop appropriate ethical support for the challenges it presents in the clinic and public sphere. This is because traditional bioethics, the culture of autonomy, and the social paradigm of ethics—individually and collectively—fail



to meet the challenges presented by participation. Indeed, given the pervasiveness of noninterference and choice in liberal democracies, the turn to a social paradigm risks entrenching incommensurable positions, rather than articulating the theoretical foundations and practical strategies to work through them. The implications of this standoff have a long history:

There is a real conflict between the clinical model based on individual transactions and the public health model based on social contract with entire communities. The consequence of this is that there is a great deal of rhetoric about public participation but marked unwillingness to really engage in processes which would bring it about. (Ashton and Seymour 1990, 37)

Efforts to improve health and health care through involvement must give serious consideration to how to overcome the difficulties that exist. One element of a more adequate response is for work on patient-centered care and public policy to recognize the role of normative issues in such conflicts and the importance of addressing them through an improved ethical response. More specifically, there needs to be an acknowledgment in theory and practice that the emphasis on citizen choice as determiner of policy and practice is inadequate as a foundation for private and public engagement. This focus obscures the need for a fully fledged concept of citizens as stakeholders that enables people to contribute to the private and public spheres and operate more successfully across them. A more complex ethical framework must be arrived at that allows patient and public participation to be person-centered while being responsive to the interdependent nature of human life; allows it to be democratically rooted but not directed by the vagaries of subjective preference; and allows policy formation to become public in a more meaningful way.

The type of approach that is required is evident within work in the health sciences that utilizes a social ecological framework. This highlights the interrelated nature and equal importance of personal and socioenvironmental determinants of health (McLeroy et al. 1988; Stokols 1996) and the need for interdisciplinarity to respond effectively to challenges across the health field (Grzywacz and Fuqua 2000; Stokols 1996). This strategy has been influential in health promotion (McLeroy et al. 1988; Stokols 1996). Significantly, there are also indications of the benefits social ecology offers public involvement (Cleary and Egdman-Levitan 1997; Greenhalgh 2009; Stokols 1996). Furthermore, systems thinking, which shares elements of an ecological approach (Stokols 1996), has begun to inform clinical ethics as a way to help situate individual experience of health within its wider socioeconomic contexts (Foglia and Pearlman 2006; MacRae, Fox, and Slowther 2008; Seeley and Goldberger 1999). However, much work is needed to determine how health ethics should respond to this work and how it might benefit from utilising a similar framework. Within the context of involvement it is necessary to go beyond a consideration of the complex interplay of factors that impact on the health of individual patients, to articulate a richer

account of the roles and responsibilities of citizens—and other stakeholders—within the public forum.

Another resource that could help improve the contribution health ethics is able to make to patient and public participation is the “deliberative turn” in service provision, policy, and political philosophy (Abelson et al. 2003; Dryzek 2000; Gutmann and Thompson 1997). The development of patient and citizen participation is part of this turn. We have seen, for example, that a deliberative approach has for some time been the preferred style of engaging patients in the clinic and is also a driver for public involvement. Deliberation helps to deliver on the democratic impetus of participation and could assist different (but ultimately related) areas of health ethics to be mutually enhancing. Deliberation prioritizes the identification of good arguments for holding different positions, rather than relying on restrictive paradigms (Gutmann and Thompson 1997). Again, work is needed to assess how integrating this approach more prominently in health ethics can avoid being too demanding to be viable. But promoting health through participation requires an awareness among all partners that reliance on the principles with which they are most familiar—autonomy as noninterference, and choice—though user-friendly, is inadequate. The identification of patient preferences through relational exchange and the solicitation of individual citizen voices to inform public policy both require a more complex, overarching methodology and account of values if they are to realize their aim of sustainable health and health care. ■

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