

## Guest editorial

### **Bridging divides: patient and public involvement on both sides of the Atlantic**

This themed section grew out of a series of three British-American medical sociology conferences, the most recent of which was convened in Boston, Massachusetts, in 2008. The two previous meetings took place in the UK: the first at Royal Holloway College, London University in 1999, and the second at the University of Edinburgh in 2006. This series of small residential meetings was organized around plenary sessions and small working group sessions in order to create an opportunity for small group discussion and personal interaction that is not typically available in larger conference formats. The meetings have been highly successful with over 100 delegates representing countries from across Europe, North America and Asia and working in a wide range of academic and non-academic positions, including not only sociology but also public health, communications and policy fields.

The topic of user involvement was a central theme in the last meeting, with a thematic focus on 'Expanding Comparative Frames for Medical Sociology: Professionals, Patients, and the Public'. One of our goals for this themed section has been to capture some of the tensions and different conceptions of user involvement from the perspective of scholars in different countries. To this end, we sought submissions from conference participants but also medical sociology and health services researchers in the United States, UK and other countries.

Healthcare systems are very differently organized around the world and nowhere is this distinction more dramatic than between the UK National Health Service (NHS) and the frag-

mented quilt of providers and insurers in the United States. These differences have significance for the definition, meaning and implementation of patient and public involvement (PPI).

One of the key differences that is apparent in the pattern of health care in these two countries is the primacy of the UK state as both funder and provider of healthcare services. For residents in the UK accessing health merely requires attendance: access to the NHS is an integral element of being a European citizen.

In the United States, by contrast, there is no nationwide system of government-run healthcare facilities open to the general public. There are some limited public programmes, but the vast majority of funding and provision is private and typically mediated through insurance companies and managed care organizations. In terms of state-sponsored health care, the United States is a primary provider through the Department of Veterans Affairs (previously the Veterans Administration) that provides benefits to veterans and their families; the medical system includes 153 medical centres and provided care for 5.5 million people in 2008.<sup>1</sup> In addition, U.S. Medicare and Medicaid programmes provide a limited level of insurance primarily to people who are older (65+) and those in poverty respectively.

For most Americans, health care is procured through employer-sponsored group insurance plans (although this number is declining due to increasing costs of health care being passed to employees), and a smaller percentage of people purchase insurance privately. This insurance can then be used in any of a range of healthcare facilities and with a menu of providers,

depending on the provisions of the specific programme. To the extent that insurance is obtained through work, health insurance is not portable if a person loses his or her job. Similarly, if it is obtained through a spouse's employment, insurance may be lost in the case of death or divorce. As a result, when we consider the number of people who are periodically without coverage, the number of uninsured swells to 1 in 3.<sup>2</sup>

The U.S. Census Bureau estimated that the number of uninsured Americans increased by 8.7 million people between 2000 and 2007, due primarily to a decline in employer-funded health insurance coverage (a trend that is expected to continue).<sup>3,4</sup> Of the 47 million uninsured people in the United States, approximately half are people of colour, a population that has been shown to be at increased risk of not receiving the health care they need, even after taking into account racial and ethnic differences in insurance coverage, economic and health conditions.<sup>5-7</sup>

These distinctions have important consequences for the definition of patient and public involvement in the UK and the United States. In the United States, being an active patient – exercising choice within a medical consultation – is normative. At a broader level, seeking to influence healthcare organization, delivery or policies is, like most political action in the United States, framed in terms of protest and lobbying. As a result, PPI in the United States typically takes the form of participation in health social movements, and research into PPI is often framed as investigations of such groups and events. In stark contrast to the UK, the target for public involvement in the United States is something other than privatized formal healthcare system. In the UK, on the other hand, involvement is increasingly understood as a way for individuals and communities to participate in shaping and improving how NHS services are organized and delivered. The emergence of this agenda is related to the development of policy and legislation, particularly in England, since 2001. In this context, PPI occurs across a range of domains directly connected to

NHS, including treatment decisions, service development, evaluation of services, education and training of health professionals, and research cycles.

Extrapolating from the case of the United States and UK, we see a critical need for more research that compares PPI work cross-nationally and across different types of healthcare systems. An additional impetus for this special section, therefore, is to help generate research that: (i) compares PPI across different national contexts; (ii) engages with health-related policy; and (iii) engages with theory, broadly defined. We observe that in health services environments there is increasing attention to PPI in evaluation, development and policy, but there remains a need for increased research attention to these issues in ways that will move beyond the focus we see in current research to topics such as patient decision making and patient involvement in research.

In terms of submissions to this themed section, we had relatively few papers from the United States, underscoring the ways that PPI appears less, or at least differentially, meaningful in that context (an issue we return to below). Still, the five articles contained in this special section represent analyses of data and healthcare policies from England, Wales, the United States (Massachusetts), Morocco and Brazil. They touch on issues as diverse as the relationships between national healthcare systems; relationships between national law, policy and PPI; the importance of collective vs. individualistic expectations in the support, maintenance and changing of PPI; and the differential development of PPI in different countries. Together, this collection of papers makes an important contribution towards explaining why PPI occurs differently across nations and how it feeds back into research, policy and practice. Considered together, these papers also gesture towards the future of PPI globally and on both sides of the Atlantic.

Barnes and Coelho and Hughes *et al.* both offer comparative analyses of how PPI policies emerged and developed across two countries, the former examining Brazil and England and the

latter comparing England and Wales.<sup>8,9</sup> Barnes *et al.* note that while public participation in health is official policy in both Brazil and England, this orientation has very different origins in each country, thereby shaping implications of what PPI may deliver in the respective environments. In Brazil, PPI has emerged from social and political movements to decentralize decision making, resulting in 5500 health councils involving over 100 000 citizen participants. In England, by contrast, the impetus derives from a diverse set of origins, but with greater emphasis on service improvement than democratic objectives. As a result, ongoing tensions exist over PPI as 'local knowledge' vs. 'local representation'. Despite aspirations that increased public involvement would result in more equitable access and better health outcomes, this has not been the case. Similarly, Hughes *et al.* argue for the importance of understanding PPI in its regulatory and institutional context, comparing the cases of Wales and England.

Applying Habermas's Theory of Communicative Action, Hodges explores how public and patient participation in the construction of a mental health charter were articulated and framed in the published document.<sup>10</sup> The ways service users engaged with a local mental health forum but had their views translated is, argues Hodges, a way of enhancing legitimacy in both strategic and communicative terms. Exploring a different form of interaction Lorenz and Kolb's article draws on a series of research projects that adopted visual participatory methods in Morocco and the United States.<sup>11</sup> They illustrate that such methods can identify issues that are salient to local people but often unseen by academic researchers or policy makers and can be used to facilitate debate and prompt action.

Tritter suggests a theoretical framework for conceptualizing PPI and then goes on to explore the tensions between the patient choice agenda and involvement in policy and practice.<sup>12</sup> He highlights the ways in which in a number of countries within and outside Europe these policy areas are both emergent and contested within broader concerns about health reform, the

marketization of health services and the commodification of health care.

Together these papers help us to consider the value of comparative international research but also recognize the extent to which national history and culture are significant mediators that refract and reframe the transfer and translation of policy and practice from one arena to another. Health care in the United States and the UK is a product of post-war policy-making and was framed in relation to existing infrastructure. The differences between the systems have been driven as much by history and politicized evolution as by ideology. But where are they going now and what are the implications for the PPI?

There is significant divergence between the four nations in the UK, England, Northern Ireland, Scotland and Wales – that have been exacerbated by devolved decision making. What is also apparent is that both the patient choice and the PPI agenda are far more elaborated in England. In Northern Ireland devolved government is very recent and PPI is only emerging as an important policy arena and is often intertwined with the statutory obligations under Section 75 of the Northern Ireland Act 1998 that include Equality Impact Assessments. In Scotland the 14 regional NHS Boards provide strategic leadership and performance management for the entire local NHS system and have a duty to involve people in decisions about planning, delivering and improving health services and are scrutinized based on a self-assessed annual report by the Scottish Health Council. Public focus and patient partnership is facilitated through the Public and Partnership Forums that are networks of local people organized in all 40 of the Community Health Partnerships that are responsible for delivering local health and social care services in an area. Wales, as Hughes *et al.* explore in their article, also has a distinctive take on PPI that contrasts with England.

In the United States the current healthcare structure emerged after the Great Depression and the role of the state was soon overtaken by the increase in employer-paid health benefits in part as a way of attracting workers in the tight

employment market in the 1950s and 1960s. Later, with the growing recognition of the lack of control of healthcare costs, managed care organizations (largely health maintenance organizations) replaced fee-for service models as the dominant form of healthcare organization and provision. It is worth noting that key players in this arena such as Kaiser Permanente had long adopted this model but the mainstreaming of the approach was new. In the 1990s the Clinton administration sought to reform health care in the United States but was unsuccessful in part because of the strength of lobbying from the health insurance industry.<sup>13</sup> Now President Obama has once again put healthcare reform on the national agenda.

Throughout the 2008 presidential campaign cycle, Obama and health policy experts alike emphasized the notion that successful reform would require building on existing infrastructure and accommodating existing powerful political and business interests. To date, one resulting strategy has involved the extension of existing public programmes (such as Medicare and Medicaid) while also restructuring of the present insurers and potentially creating new programmes along the way. At the same time, a major lesson from the failed Clinton reforms was that the substantial proportion of Americans who were happy with their insurance coverage were highly resistant to programmes that might eliminate it, and opponents of reform policy were extremely effective at mobilizing this fear on behalf of their political agendas. While recent polling shows that most Americans today are receptive to significant healthcare reform, these past lessons remain in the background of today's discussions. These social, political and economic pressures are, in many ways, at odds with health policy reform objectives of containing costs, improving access and maintaining quality of care.

As a result, tensions continue in the reform effort with regard to questions such as whether to create a mandate requiring everyone to buy insurance; how costs, particularly the disabling administrative costs associated with having so many providers and payers, can be reduced while also allowing for individual choice;

whether pharmaceutical and big business interests can be politically and economically folded into a reformed model; and whether increasing costs can be stemmed while also increasing coverage and decreasing disparities exacerbated by the dominance of the current employment-based insurance system. Answers to these questions have focused on making small changes gradually rather than expecting to overhaul the entire system at one time – focusing on, for example, coverage, cost control, coordinated care and choice.<sup>14</sup>

The implications for PPI in the United States, the UK and globally are difficult to predict, but the ongoing dominance of big business lobbies, both politically and as part of the healthcare infrastructure, suggests that the types of regulation and transparency apparent in countries with strong PPI may not be forthcoming in the near future. Critical research that focuses on not only the continued changes in the policy arena but their impact on individuals is needed to help make transparent the trade-offs between industry, politics, medicine and health.

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