

Commentary

Public Involvement and the Ageing of the Population: Incompatible Trends?

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Abstract

This paper begins by exploring the concept of public involvement within the current UK health policy context. It then discusses current levels of knowledge about older people's preferences, perspectives and experience with the health care system. It concludes by bringing these two discussions together to explore the compatibility of the ageing of society with government's declared aim of increasing public involvement in health.

Introduction

The citizen's voice and choice should make as significant a contribution to shaping health care services as the decisions taken at other levels of economic, managerial and professional decision-making (WHO, Ljubljana Charter on Reforming Health Care, 1996)

Over the past few years, public involvement has been a central pillar of UK health policy, with the English government aiming to transform the National Health Service (NHS) into a 'consumer-oriented' and 'patient-centred' primary-care led health service committed to 'local responsiveness' (Department of Health, 1999; 2000). In his projections for the future of the NHS, Derek Wanless advocated an 'engaged scenario' in which individuals as patients and potential service users took responsibility for their health risks and played a proactive role in health policy decisions (Wanless, 2002). These goals are echoed in international health policy circles. As early as 1986, the WHO Ottawa Charter for Health Promotion advanced the notion of community empowerment as a key driver of population health (WHO, 1986). Building on this and the Ljubljana Charter (WHO, 1996), the Council of Europe in 2000 suggested that the rights of patients and citizens to participate and determine the goals and targets of health care should be a prominent feature of any democracy (Council of Europe, 2000).

A concept central to the debate on public involvement is

that of empowerment. Arnstein, one of the architects of public participation, developed a ladder of participation in which she dismisses the concept of public participation as an 'innocuous euphemism' in the absence of citizen control (Arnstein, 1969). The Council of Europe defined empowerment as citizens having: i) the ability to influence the administration of the health care system and participate in decision-making processes, ii) the ability to further particular interests through citizen or patient interest groups, iii) representation in governance structures and iv) direct influence over care provision through the exercise of choice (Council of Europe, 2000).

Discussions of empowerment bring to mind themes of civic participation, active citizenship, governance and accountability. Indeed, one of the dominant theoretical approaches to public involvement stems from the political science literature, where citizen engagement is regarded as beneficial to maintaining a strong democracy and is viewed as a means of ensuring that the diversity of interests and allegiances that comprise 'the public' are equitably represented in the political process (Nolte & Wait, 2005). A parallel may be drawn to the movement towards productive engagement and civic participation of older people, as a means to ensure that they maintain a stronghold in our societies and do not get marginalised. This discussion is particularly topical in Europe, given the current implementation of the European Directive effectively banning discrimination on the basis of age in employment.

Within this context, this paper addresses the question of how the intended movement towards an actively engaged citizenry is compatible with the ageing of our population. There are already more people over the age of 60 in Britain than under the age of 16. The proportion of people over the age of 50 is currently 32%; in 2025, it will be 40%. The number of 'oldest old' is growing dramatically, from 2.4 million today to 3.5 million people in 2025 (ONS, 2002). It has been suggested that the older generation of the future – the 'new old' generation of baby boomers –

will be active, vocal and demanding consumers and citizens (Huber & Skidmore, 2004). Yet at the same time, there is evidence that social disempowerment of older people, social exclusion and possible inequalities in access, quality and outcomes of care (as well as other services) for older people remain an unfortunate reality in our health care system. In an editorial entitled 'when I'm 64: health choices', Coulter (2004) suggests that, by 2014, the definition of patients will be changed from 'a person who is receiving medical care' to 'co-producer of health, autonomous partner in treating, managing and preventing disease' (Coulter, 2004). In a separate commentary, she suggests that the 21st century patient is at once 'a decision-maker, a care manager, a co-producer of health, an evaluator, a potential change agent, a taxpayer and an active citizen whose voice must be heard by decision-makers'. Is it realistic to assume that this will apply equally to older and younger future generations alike?

Public involvement in UK health policy

Public participation has been described as 'the involvement of members of the public in strategic decisions about health services and policy at local or national level'. Florin and Dixon suggest that it is distinct from *patient* involvement, which refers more specifically to 'the involvement of individual patients, together with health professionals, in making decisions about their own health care' (Florin & Dixon, 2004). In policy documents, however, the delineation is less clear (Department of Health, 1999).

Public involvement in the UK is not a new phenomenon, with the first Community Health Councils, for example, having been set up in the 1970s (they were dismantled in 2002). Section 11 of the Health and Social Care Act of 2001 made it a statutory obligation for all NHS organisations to involve and consult the public (and patients) in service planning and in the development of proposals for change (Department of Health, 1999). All Primary Care Trusts (PCT) and NHS Trusts must now have Patient and Public Involvement Forums (PPIFs) as an integral part of their governance structures, replacing Community Health Councils. PPIFs are currently coordinated nationally by the Commission for Public and Patient Involvement in Health, although it was announced in 2004 (barely six months after its creation) that this Commission was soon to be abolished. Lay representation is also a key feature of the new NHS foundation trusts. Other mechanisms, such as Patient Advice and Liaison Services at the level of PCTs and NHS Trusts and an Independent Complaints Advocacy Services were set up to strengthen the complaints process for patients, with the Healthcare Commission acting as an independent complaints review body at the national level (Nolte & Wait, 2005).

The National Institute for Clinical Excellence (NICE), which conducts technology appraisals and issues clinical guidelines to Primary Care Trusts, has a Citizens' Council that allows for representation of the views of the public in NICE decisions. The Citizens' Council's role is distinct from the

mechanisms for involvement of patients, carers and patient groups in NICE health technology appraisals and clinical guidelines development.

The stated aims of current policies include: to make health systems more responsive to the legitimate expectations of the population, thereby improving health outcomes (Department of Health, 2004; Florin & Dixon, 2004); to improve accountability and trust (Donovan & Coast, 1996; Florin & Dixon, 2004); to provide greater transparency on decisions related to rationing and priority-setting (Donovan & Coast, 1996). Klein voices caution against the 'rhetorical exuberance' of current policies which suggest that incorporating public views into health policy decisions necessarily leads to increased accountability and 'cost-effective decision-making' within the health care system (Church *et al*, 2002; Klein 2004).

There are few published evaluations that may allow us to ascertain how well current public involvement policies have achieved these goals, partly because many policies are recent and because they often lack an evaluative, let alone a conceptual, framework. Indeed, the scope, objectives and desired outcomes of existing public involvement policies remain poorly defined (Nolte & Wait, 2005). Putting public involvement in practice poses several challenges, including financial sustainability and confusion about how public input, once obtained, is actually used to influence policy-making. Further clarity as to where these mechanisms fit into the broader policy context is needed (Nolte & Wait, 2005; Abelson *et al*, 2004).

This brings us to an important question of whether public involvement actually creates shifts in governance within health care systems. Rowe and Shephard suggest that public involvement is an instrument to inform decision making rather than a process that actually devolves power to local communities (Rowe & Shepherd, 2002). Others interpret public involvement as a 'legitimation' strategy or 'social technology', suggesting that public involvement initiatives may be used by governments to contain criticism and unrest, thereby deflecting some of the 'political heat' and giving legitimacy to otherwise unpopular policy decisions, especially in the field of rationing (Redden, 1999; Church *et al*, 2002; Lupton *et al*, 1997). On a brighter note, there is evidence that some recent public involvement models have evolved away from the 'top-down', 'paternalistic' efforts to extract information from participants of the past and may be securing better accountability within the health care system (Abelson *et al*, 2004; Department of Health, 2004; Nolte & Wait, 2005).

Ageing of the population: implications for health policy

The perspective of older people on the health care system appears paradoxical. The Eurobarometer survey found, for example, that people's satisfaction with their personal health decreases with age, as does their self-reported health. Yet satisfaction with the health care system increases with age, and this finding is consistent across all EU countries

surveyed (Mossialos *et al*, 1998). It would be a mistake, however, to interpret this as evidence of better care for older people. Study after study, in a variety of cultural settings, reveal that older people have lower expectations of care and of the health care system. Older patients are often less engaged in clinical decision-making than younger patients (Hamalainen *et al*, 2002). As a senior NHS manager once commented, 'older people are not very good at going out and asking...and the services aren't that good at finding unmet need' (quoted in Roberts, 2002). Some authors have suggested that these low expectations reflect a broader issue of internalised ageism amongst older people, with low expectations resulting from their feelings of unworthiness and fear of being a burden on public services.

Further research, however, suggests that older people may be poorly served by the health care system (Bowling, 1999). In surveys of older patients, many people express frustration at not feeling that they are listened to by staff (Office of Public Management, 2002). One study revealed that most older patients did not agree with a nursing assessment of their abilities (Harkness *et al*, 2002). Commissioners of health services may have lower expectations of what older people need compared to younger people. In the push to create a more efficient system, quality of care offered to older people may be compromised, be it in terms of longer waiting times, less attentiveness to detail, or less choice being offered in treatment options (Ellis, 2002). There is evidence that the drive to increase access by decreasing waiting times may allow more people to be treated more quickly, but this increased flow of patients puts huge pressure on already strained staff (Bowling, 1999; Shaw *et al*, 2004). Time to communicate with the patient, to do detailed medical histories assessing co-morbidities, may get lost. Shorter hospital stays, if not coupled with appropriate rehabilitation services, may not allow patients the needed recuperation time to return to full health. Also, if adequate social services or community health services are not available, prevention and follow-up care may be inadequate.

It was in great part on the basis of these findings that the National Service Framework (NSF) on Older People was adopted in England in 2001, which had as its first objective to 'root out age discrimination'. But ageism, or age discrimination, is often an 'invisible and unchallenged part of day-to-day culture' (Ellis, 2002, p. 23). Most restrictions in access to services are dictated not by explicit protocols but by historically-inherited practices and staff behaviours. Surveys of medical staff reveal little awareness of systematic ageist policies but point instead to ad hoc, but ingrained, ageist behaviours and practices. Audits of practices following the publication of the NSF found that much progress had been made in changing ageist behaviours and practice in the health service (Office of Public Management, 2002). However, staff still found it difficult to focus on providing patient-centred care in chronically resource-constrained environments. How best to communicate information to older patients and to deal with the counter pressure of relatives was also viewed as a constant concern.

Whilst it is essential to acknowledge the existence of age discrimination within our health service, it would be equally ageist to conform to the view of older patients as necessarily passive and suffering in deference or of older people as a homogeneous group of frail, dependent, sickly and disempowered individuals. Age equality may be promoted by encouraging further engagement of older people in service planning and decision-making, providing and facilitating access to better information (Office of Public Management, 2002; Roberts, 2002). We need a more positive culture in the care of older people to emerge, which fosters inclusion, independence and citizenship as productive and meaningful messages as opposed to focusing on 'rooting out' poor practice and negative behaviours (Roberts, 2002). Practical solutions include training and education of staff around issues of communication, and the development of workable models that may facilitate engagement of older people and their carers, and the provision of better information to encourage patient-centred care (Roberts, 2002). The adoption of a 'whole citizenship' approach that views older people as an integral part of our society, as opposed to marginalised and disempowered victims, is thus essential (Lancet, 2004).

Age trends in patient participation and public involvement

The literature provides little insight into the public's perspectives on public engagement in health policy or how involvement policies may be more or less appropriate for different age groups. Anecdotal evidence suggests that people who do participate in civil society tend to be older, more affluent and better educated. Surveys on civic participation confirm this trend, as do voting patterns in older versus younger people (European Social Survey, 2002). Yet how these translate into the health policy arena is unclear. Also, age is likely to act in synergy with other factors to determine individuals' willingness to be involved in health policy. From the public involvement literature come voices of caution against the idea that there is a 'dammed-up demand for greater participation, only waiting for the institutional changes needed to open the floodgates of public involvement' (Klein, 1984). Public involvement policies in the UK have been initiated primarily by government, and many initiatives assign the user a reactive rather than a proactive role. It remains to be seen to what extent the public, and indeed different segments of the public, will capitalise on these trends (Wait & Nolte, 2005).

An equally important question when assessing the potential for public involvement mechanisms to serve as a vehicle for the voice of older people is that of equity and representation. There may be an *inverse law of participation* whereby those in greatest need to further their interests (i.e. with the greatest health care needs) have the least capability to do so. Older patients, particularly if they are very sick, socially isolated, poorly educated or poor, may fall into this vulnerable category and risk being excluded from representation in public involvement bodies (Klein, 1984). With the growth of the older population, the 'older'

segment of our society will encompass greater cultural and ethnic diversity as well as greater inequalities in terms of education and wealth. In our future society, public involvement policies will need to allow for such diversity of interests and expectations to be represented, otherwise they will run the risk of exacerbating existing health inequalities.

Whilst not confusing public involvement with patient participation, it is helpful to look at age-related patterns from patient experience. A comprehensive European survey, led by the Picker Institute, attempted to gain some insights into the expectations, needs and possible evolution of patients in the future¹ (Coulter & Magee, 2004). The study was conducted across eight European countries. In the UK, eight seven-person focus groups were formed. Overall results were revealing: for most patients, the most trusted source of information remained the physician. In addition to detailed information about their condition and treatment options and outcomes, individuals expressed the need for better information about the NHS and health care in general, in terms of the quality of different services and individual professionals' outcomes. This contradicts findings, from the UK and elsewhere, that the public is apathetic to publicly-available performance and quality information about the health care system (Marshall *et al*, 2003). The key difference may be that individuals feel concerned about these data only once they become service users and thus see themselves as directly affected by the information. This reinforces the need for further understanding of how individuals' expectations and motivations may drive their willingness to get involved in health policy and more personal health decisions (Nolte & Wait, 2005).

The survey also revealed an interesting picture of the role that age may play in motivating individuals' information-seeking behaviours. Previous studies have pointed to a age effect in information-seeking, with younger patients being more assertive about their ability to complement knowledge received from their doctor (IPPR, 1998). Studies of patients suffering from cancer, however, suggest that much sicker patients may prove more reluctant to seek out further sources of information, possibly because they feel this may disenfranchise them from the physician's trust (Boudioni & McPherson, 2000). In this survey, it was people with chronic illness, parents of children at home, women and, to a slightly lesser extent, older people and those who had been in hospital recently, who were seemingly the most proactive information-seekers. A definite gender effect was apparent, with younger men feeling detached from information on health and not thinking it was relevant to them. Men of all ages, notably those aged 50–65 years, preferred to rely on others for information and stuck to the adage 'it's not an issue until it goes wrong' (Coulter & Magee, 2004, p. 194).

Interestingly, focus group participants expressed reserve about empowerment and suggested that their interactions with the NHS were still dominated by a 'them' and 'us'

paradigm. A sense of powerlessness was associated with lack of information and feeling that the traditional images of the all-knowing doctor and the grateful but largely ill-informed patient persisted. Those who did not report feeling powerlessness tended to be younger (under 50), more confident and articulate. With a view to the future, patients interviewed expressed significant reserve and caution at embracing the vision of a future health service where patients, armed with the right information, shared decision-making with their clinicians. They felt that they lacked the right information to be able to fully engage in a true dialogue with their clinicians (Coulter & Magee, 2004).

Can any of these findings be extrapolated to public involvement? The critical role of information and health literacy² as a vehicle to patient empowerment has been documented extensively (Kennelly & Bowling, 2001; Quinn *et al*, 2003). Age has also been found to be a barrier to health literacy, namely in cancer (Hofman *et al*, 2004), HIV (Henderson *et al*, 2004) and surgery (Chew *et al*, 2004). It seems reasonable to assume that health literacy may play a similarly enabling role for individuals' ability and willingness to get involved in health policy, and that health literacy may be influenced by age. Surveys of older people reveal that *access to information* is perceived as a significant barrier to their engagement in health (Quinn *et al*, 2003). Similarly, individuals participating in public involvement initiatives often express the need for significantly more information about the issues concerned to be able to contribute effectively to health policy decisions (Lenaghan *et al*, 1996; Lomas, 1997; Office of Public Management, 2002; Roberts *et al*, 2002; Abelson *et al*, 2004).

Empowerment for the older generation?

Predicting the future solely on the basis of the past is fallacious. Thus the question may be raised of how older generations in the future might look like in terms of their attitudes to, and expectations of, the health care system: will age-based inequalities remain and get exacerbated or will they disappear as the 'new old' baby boomers affirm their rights and achieve true empowerment within our future society? And by the same token, will we belong to a society where age diversity is embraced as positive, or will the culture of youth and marginalisation prevail?

A recent report from Demos attempted to tackle this question. The authors suggest that the three most unknown areas for future older generations are i) what their wealth and living standards might look like, how social and intergenerational equity will impact upon these (i.e. current discussions about pensions and income distribution); ii) the older generation's definitions of quality of life, economic participation, and public and community goods, and how these may differ from those of younger generations, and iii) their attitude to political engagement and their readiness to use their power as a group to create electoral clout (Huber & Skidmore, 2003).

A look at the generational characteristics of baby boomers suggests divergent prognoses for the future engagement of older adults in health policy. The 'new old' are more individualistic and confident, suggesting that they are less conformist and deferential and will fight more for their rights, being less trusting of public authority. Yet they also have lower social capital, defined as 'features of social organisation, such as civic participation, norms of reciprocity and trust in others, that facilitate cooperation for mutual benefit' (Huber & Skidmore, 2003, p. 66). They may thus be less likely to become politically engaged than previous generations. Will this translate into lesser interest in health policy on the part of older generations? It is difficult to guess whether trends for public participation in health will follow general trends for civic engagement in the future, or if other factors, such as further disinvestment from the state, greater availability of health information or cross-border care within the EU, will have a greater influence. Economic theory suggests that health care markets are characterised by an imbalance of interests, with the public having less incentive to participate in key decisions than, for example, managers and providers (Marmor & Marone 1980; Charles & DeMaio, 1993). This may change, however, if information asymmetries are reduced and more patient choice in services, namely through the growth of the private sector, is available.

Another potential scenario is that changing disease patterns, with an ever-growing share of the burden of illness towards chronic conditions amenable to primary prevention, might make individuals less detached from health policy issues. The emphasis by governments on the responsibility of individuals for their health risks may shift individuals' values and sense of personal ownership for all aspects related to their health, including the health care system. Former EU Commissioner David Byrne remarked that the achievement of optimal health outcomes is a shared responsibility between the health care system, the government and individual citizens (Byrne, 2004). One recognized challenge, however, is the exclusion of messages directed towards

older people from many health promotion campaigns (most recently the source of debate in Parliament concerning alcohol policies). The need for a lifecourse approach, which views health and health promotion along a lifelong continuum, is needed urgently as it remains far from reality at present.

It is also important to recognise that governance is by no means a zero-sum game: even if individuals of all ages do become the 'co-producers of health' and 'active citizens' envisaged by Coulter (2004), the responsibility for governments to foster a responsive health care system and promote population health remains intact. Specifically, we must ensure that policies address age, as well as other forms of diversity. Health inequalities are growing in the UK, a striking example being that within the city of London alone, there is an 8-year gap in life expectancy between boroughs. Inequalities in access, quality or outcomes of care may occur because of age, socioeconomic status, gender, race, ethnicity and educational level, or indeed many of these factors combined. Promoting equality in health care thus requires consideration of age as one of many factors that may contribute to inequalities.

Finally, the fact that the older segment of the population is growing represents a unique opportunity to create the needed wholesale shift towards a society, and a health care system, that embraces age diversity as well as other forms of diversity. This country still lacks an overarching strategy on ageing (Huber and Skidmore, 2003). The older generation, be they the 'new old' or the 'current old', have a crucial role to play in shifting the political agenda, by 'stimulating a new public debate about the 'legacies' passed from one generation to another and the responsibilities of older generations towards the future.' (Huber & Skidmore, 2003, p. 100). The solution for empowerment across all generations may lie somewhere between affirmative action and well-meaning 'democracy-enhancing' policies. Where public involvement policies in health fit along this spectrum remains to be seen.

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Notes

- ¹ The survey was conducted in 2000, prior to the implementation of public involvement policies in the UK.
- ² Health literacy is defined as 'the degree in which individuals have the capacity to obtain, process, and understand the basic health information and services needed to make appropriate health decisions' (Parker *et al*, 2003, p. 147).