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Policy Digest

Public and patient participation in health care and health policy in the United Kingdom

Since 1948, the United Kingdom (UK) has operated a National Health Service funded primarily through public taxation where health services are available based on need and free at the point of delivery with limited out-of-pocket copayment. Other European predominantly public taxation funded systems operate, for example, in Sweden, Denmark, Finland and Italy. Domestic policy decisions have been devolved from London and England to Wales, Scotland and Northern Ireland since 1999, although for the latter full devolution did not really occur until 2007. One consequence of devolution has been the growing divergence in policy and practice across the four countries within the United Kingdom. This digest summarizes the evolution of key policies across the United Kingdom and then identifies some of the distinctions between the four different administrations.

Globally, the United Kingdom has been in the vanguard of the promotion of patient-centred care and patient and public involvement, which is often traced to the founding of Community Health Councils in 1973.[1] This changed dramatically, and development accelerated following the passage of the *Health and Social Care Act 2001* that created new statutory duties on all NHS organisations in England that planned and provided publicly funded health and social care services to demonstrate that they engaged with patients and the public in the evaluation, development and delivery of services. This requirement continues to form part of the regulatory framework overseen by the Care Quality Commission. Successive legislation in England has increasingly elaborated the specification and responsibilities of publicly funded health providers and created different local mechanisms to support involvement; patient and public involvement forums (2003), which were replaced by local involvement networks (2008) which will be replaced by local HealthWatch groups. Structurally, this shift has also been apparent in the continuing evolution of the national system for managing patient dissatisfaction and complaints and the promotion of individual patient choice.

The establishment and roll-out of NHS Foundation Trusts created the potential for stronger connections between hospitals and their local communities. Whilst remaining firmly part of the NHS, their Board of Governors is elected by the public, patient and staff members and can serve as a vital conduit for shaping the way local services are provided and increasing the credibility and responsiveness of Foundation Trust hospitals through advising the executive board. Thus far, however, there is insufficient evidence that this potential is actually reflected in practice. Equally, there is little evidence that Foundation Trusts do create, promote or react more to a dialogue with the communities they serve than their predecessors.[2]

The NHS Constitution was developed and implemented in England in January 2010 following the passage of the *Health Act 2009*. A number of the sections relate to patient-centred care and patient involvement and frame these in terms of rights and commitments.

This individualization of involvement is also reinforced through the continued promotion of patient choice that is apparent in the policy statements and draft legislation of the current coalition government that came to power in 2010. This government has proposed radical changes to the NHS in England that gives more power to groups of general practitioners (family doctors) to commission (plan and contract) services for local populations (an average of 200 000 people) and changes the current system for promoting patient and public involvement. Previously, this had been the responsibility of a different body (primary care trust), and commissioners were required to engage with patients and the public and the local involvement network. Under current proposals, the local involvement networks are being transformed into local bodies named HealthWatch and some of their duties are being reframed from providing evidence of local people's experience of services to the provision of information to enable individual choice of services.

Local involvement networks (LINks) were created under the *Local Government and Public Involvement in Health Act 2007* in each of the 152 local authority areas (municipalities) across England. This new model for involvement was based on the interaction between networks of local community and voluntary organizations and interested people within a defined local authority area. These LINks are charged with bringing together the experiences and expectations of local people to evaluate and improve local health and social care services. They are not an inspectorate but a source of intelligence about what the experience of service users and what the priorities for health and social care services should be. Most importantly, all those responsible for commissioning – prioritising and contracting – services were required to engage with patients and the public and their local LINk when arriving at decisions. The new commissioning arrangements outlined in the Health and Social Care Bill 2010–2011 currently in the UK parliament makes no mention of HealthWatch, and the requirement to engage with patients and the public around prioritisation of services is vague.

Across the United Kingdom, there have also been shifts in medical education and an increasing stress on the 'new professionalism'[3] and the expert patient. Indeed, selected and trained members of the public now participate in the structured interview that is part of the interview process for potential medical students in many UK medical schools. In a range of NHS organisations, the appointment of health-care professionals involves patients and members of the public on interview panels. Current plans for the revalidation of doctors will include evidence of patient experience of the individual practitioners (see http://www.gmc-uk.org/doctors/revalidation/patient_and_public_involvement_in_revalidation.asp).

Although a high-profile focus on patient choice has been readily apparent in the United Kingdom since 2003, in implementation terms, the operationalization of individual choice has been limited and mostly focused on England (rather than Northern Ireland, Scotland and Wales).[4] Despite the differences in relation to patient choice, an emphasis on patient and public involvement as a central aspect of health policy is apparent in all of the devolved administrations but there are significant differences in the ways such policies are defined and involvement enabled.

Scotland

The Scottish approach is presented as patient focus, and public involvement and the National Health Service is framed by mutuality defining members of the public and NHS staff as partners⁄co-owners of the NHS and jointly accountable. *The NHS Reform (Scotland) Act 2004* placed a duty on all NHS Boards to undertake public involvement and equal opportunities and establish *Community Health Partnerships* and with the aid of local *Public Partnership Forums* enable effective and formal dialogue with its local community

The Scottish Health Council was established in April 2005 to support and monitor how NHS Boards discharge their patient focus and public involvement responsibilities and assess and report on NHS Board's consultations with local communities (see: http://www.scottishhealthcouncil.org/shc/Home)

The *Better Together: Scotland*'s Patient Experience Programme was launched in 2008 aiming to obtain information on patients' experiences of the services they receive. This is supported by the new *Participation Standard* that is a new assessment tool which, from April 2010, has been used to measure patient focus and public involvement activity across NHS Scotland. It focuses on three key areas: patient focus; involving people in service planning, improvement and change (public involvement); and the corporate governance of participation.

Wales

The history of public and patient involvement in Wales is quite distinct from England, and this orientation was highlighted with the publication of the *Health (Wales) Act 2003*, and key guidance documents identifying how to 'do' involvement and how such activities related to the NHS.[5,6] NHS services are organised on the basis of seven Local Health Boards that are coterminous with seven Community Health Councils (CHCs). CHCs are independent of the NHS and with the associated 23 area associations lead public and patient involvement locally. Prior to any changes to health services within NHS organizations, the CHC must be consulted. The CHCs also provide advice, support and an advocacy service for complaints. It has been argued that the initial focus on localism in NHS Wales as promoted 2003 Act is giving way to a centralization of power[7] (see: http://www.wales.nhs.uk/sites3/home.cfm?orgid=420).

Northern Ireland

The Department for Health, Social Services and Public Safety Northern Ireland issued guidelines on personal and public involvement in September 2007.[8] The development of such issues has been far lower on the policy agenda and is far earlier in its evolution than in the other countries in the United Kingdom and is complicated by the integration of health and social care services. While statutory requirements to consult and involve people are integral to Section 75 of the *Northern Ireland Act 1998* and Section 49A of the *Disability Discrimination Act, 1995* additional and specific duties have been placed on health and social care bodies by section 19 of the *Health and Social Care (Reform) Act (Northern Ireland) 2009*. In particular, this required all such organisations to prepare a consultation scheme that demonstrates how they will engage with the Patient and Client Council (PCC) and clients and carers.

The PCC was established in April 2009 and is charged with representing the interests of the public by engaging with the public to obtain their views on services (see http://www.patientclientcouncil.hscni.net/home). In part, this is accomplished through engaging with health and social care (HSC) organisations to ensure that the needs and expectations of the public are addressed in the planning, commissioning and delivery of health and social care services. It also promotes the involvement of patients, clients, carers and the public in the design, planning, commissioning and delivery of health and social care as well as advice and information to the public about involvement. The PCC also has the responsibility to assist individuals with complains about health and social care services.

Conclusions

Overall, one can characterise patient and public involvement in the United Kingdom as in tension between individual and collective and between involvement and choice. In Tritter's Framework,[4] most patient and public involvement in the United Kingdom is *indirect* involvement where information is gathered from service users by health professionals and managerial staff to inform service delivery and development but health service managers and clinical staff make the final decisions. There is some *direct involvement* where patients and the public taking part in actual decision making but this is not required by policy but instead is an operational decision of individual NHS organisations. Similarly, there is more stress on *individual* rather than *collective* involvement, and this is particularly apparent in England where individual patient choice is a dominant policy motif. The promotion of involvement in relation to priority setting as party of commissioning decision is evidence of proactive involvement (rather than reactive). In England, the current government appears to be diluting this responsibility.

The relationship between the NHS and patients, individually and collectively, continues to be a central element of health policy in all countries in the United Kingdom. The different countries in the United Kingdom are at different stages of development. The current Health Minister recently pledged that 'First, that patients must be at the heart of everything we do, not just as beneficiaries of care, but as participants, in shared decision-making. As patients, there should be no decision about us, without us,'[9] The question remains whether such statements, particularly in England, are mere rhetoric or will be made a reality.

Jonathan Q Tritter
Professorial Fellow, International
Centre for Governance and Public
Management, Warwick Business School

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