



The voluntary sector and health policy: The role of national level health consumer and patients' organisations in the UK



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ABSTRACT

This article explores the policy role of health consumer and patients' organisations (HCPOs), an important subset of the UK voluntary health sector. Based on research findings from two surveys, the article examines the activities, resources and contacts of HCPOs. It also assesses their impact on health policy and reform. There is some evidence that HCPOs can influence policy and reform. However, much depends on the alliances they build with other policy actors (including other HCPOs), their resources and leadership. HCPOs seem to have more impact on the detail of policy than on the direction of travel. In addition, there are potentially adverse consequences for HCPOs that do engage with the policy process, which may partly explain why some are wary of such involvement. For example, it is possible that HCPOs can be manipulated by government and other powerful policy actors such as health professionals and the drugs industry.

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Before the creation of the UK National Health Service (NHS) in 1948, voluntary organisations had a major role in the funding and provision of health services. The NHS did not, however, sound the death knell of the voluntary health sector. People still volunteered to provide health services, raised charitable funds for health causes, and formed campaigning organisations to promote improvements in health services and public health. Indeed, the voluntary sector flourished rather than declined in the era of big government (Alcock, 2011; Lewis, 1999).

Furthermore, in the neo-liberal era, its profile rose further. From the late 1970s, successive governments developed policies on state-voluntary sector relationships. These efforts intensified under the New Labour Governments of Blair and Brown, which redefined the voluntary sector as the 'Third sector' to include 'social enterprises' and mutual organisations (for a definition of social enterprise see DTI, 2002). These governments sought to strengthen partnerships with the sector, build capacity and offer a bigger role in public service planning and provision, a process characterised as 'hyper-active mainstreaming' (Kendall, 2000). The current Coalition government, in the context of economic austerity and public sector budget cuts, has emphasised the importance of voluntarism and self-help as part of its 'Big Society' rhetoric, suggesting that the

rolling back of state provision can be offset by voluntary action. This government has adopted the term 'Civil Society' as an even broader articulation of the sector (Cabinet Office, 2010).

The UK voluntary health sector is significant. It has been shown that in England alone, over a quarter of charities and social enterprises are active in health and wellbeing, with just under a fifth stating this as their primary focus (Ipsos MORI, 2011). If organisations involved in social care are included, the significance of the voluntary sector is even greater. In 2007 it was estimated that 35,000 third sector organisations in England provided health and/or social care services at a cost of £12 bn per annum, equivalent to 14% of the total health and social care budget (IFF Research, 2007). Similarly, the voluntary sectors in Scotland, Wales and Northern Ireland are extremely important contributors to health and social care in these parts of the UK (Baggott, 2013).

The merits and potential contribution of the voluntary health sector have been acknowledged by several high profile reports on health policy in the past decade (for example: the review of public health by Wanless, 2004; the Darzi Review of the NHS (Cm 7432, 2008); and the Marmot Review of Health Inequalities, 2010). These and other reports (see for example, Curry et al., 2011; House of Lords Select Committee on Science and Technology, 2011), identified the sector's various roles: promoting self-help and self-care; identifying health needs, trends and threats; ensuring that user and public perspectives informed service planning and delivery; campaigning and lobbying on health issues; giving voice to marginalised and disadvantaged groups; preventing disease and

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promoting health through the provision of information; identifying and overcoming barriers to disease prevention and health promotion (such as social attitudes, cultural norms and/or economic disincentives); facilitating the integration of services (by interacting with multiple agencies); providing services that are more flexible and suited to users' needs; harnessing and mobilising community resources and assets; linking into wider voluntary sector networks that promote health; and raising funds to facilitate and undertake research.

Contemporary policy in England, articulating a greater role for the voluntary health sector, has its roots in the 1960s (in the form of Ministry of Health guidance and a statutory grants scheme under Section 64 of the Health Services and Public Health Act 1968). More recently, the policy framework has become more extensive and detailed, and has included commitments to strengthen the sector's role in service provision, its participation in partnerships and collaboration; and its involvement in the policy process (Wyatt, 2002; Cm 6374, 2004; Cm 6737, 2006, Cm 8134, 2010). Governments in the other countries of the UK have also introduced their own policies to promote and involve the voluntary health sector (Baggott, 2013).

Given the apparent rise of voluntary health organisations in recent decades, and their engagement with the policy process, one would expect them to be a key focus for those studying health and social policy. While there certainly has been greater academic interest over the past decade or so (and not just in the UK, as we shall see later), this has perhaps been less than expected. Moreover, many studies focus on the internal features, structures and activities of these organisations, their interaction with members and service users, and relationships with health professionals. Although these are important, there appears to have been a relative neglect of their involvement and influence in the policy process, despite efforts to increase voluntary sector involvement in this arena (Baggott, 2013).

This paper seeks to explore the policy role of voluntary health organisations in the UK over the past two decades, focusing mainly on England. It examines their particular role in seeking to promote and represent the interests of patients, users and carers. It addresses four areas: conceptual issues and definitions; creation, policy focus and resources; contact with the policy process, including other health policy stakeholders; and finally, impact on policy. The article draws on a landmark study of UK health consumer and patients' organisations (HCPOs – see below for definition) by (Baggott et al., 2005), in particular a questionnaire survey conducted in 1999 (hereafter, the 1999 survey), and a more recent survey undertaken in 2010 (hereafter, the 2010 survey) which explored the aims and activities of HCPOs and their involvement in public health campaigning and lobbying (Baggott and Jones, 2011).

1. Methods

The 1999 survey used a postal questionnaire to map the characteristics and activities of HCPOs working in and across a number of condition areas. It sought information on their internal structures, aims, activities and the type and frequency of contact with policy makers and health policy stakeholders. It was sent in Autumn 1999 to 243 organisations, 57 of which were subsequently excluded as they did not meet the inclusion criteria (response rate 66%, $n = 123$). A fuller discussion of the research methods, including follow-up interviews, is given in (Baggott et al., 2005). Subsequently, in the summer of 2010, 312 HCPOs were invited to complete an online structured questionnaire, hosted by Speedsurvey. Organisations received an email request and link to the survey, responses were downloaded and transferred to SPSS. Two follow-up emails were sent, achieving a response rate of 39% ($n = 122$).

It should be noted that the later survey used a different sampling method. Unlike the former, it did not focus on HCPOs in specific condition areas. Moreover, organisations were identified through membership lists provided on the websites of several large alliance organisations (a more systematic approach than was previously possible). However, as will become clear, the different methods produced similar results.

2. Conceptual and definitional issues

In its widest sense the voluntary health sector includes several types of organisation: Single issue campaign groups seeking to change policy and practice (on issues such as smoking, food policy, alcohol abuse, pollution); patients', carers' and service users' organisations; groups representing the wider public, or a section of the population, such as older people or ethnic groups; protest groups; voluntary service providers; umbrella groups and alliances; research charities; philanthropic organisations and foundations; and social enterprises, co-operatives and mutual organisations. Some organisations fall into more than one category. For example, patients' organisations may fund research, provide services, and engage in single issue campaigns.

It is impossible to focus on all these different types of group within the confines of this article. Instead, we concentrate on an important subset of organisations within the voluntary health sector, those that seek to promote and/or represent the interests of users and/or carers in the health arena. We initially termed these 'health consumer groups' (Baggott et al., 2005). Subsequently, following efforts to devise a broader term for use in the analysis of patient, user and carer organisations across several European countries (Baggott and Forster, 2008) the term 'health consumer and patients' organisations' (HCPOs) was adopted, since clarified as 'voluntary sector organisations that seek to promote and/or represent the interests of patients, users, carers, and the wider public in the health policy arena' (Baggott and Jones, 2011).

Such definitions are open to challenge because of the contested nature of terms such as patients, users, consumers, citizens and the public. Some recoil from the word 'consumer', because it implies a commercial or customer-oriented relationship with services (Long, 1999). Others, however, (see, Williamson, 1992) argue that 'consumer' captures an active form of citizenship and is capable of representing a broader constituency of interest, not merely the narrow realm of individual customer preferences and choices. As Mold (2010) notes, 'consumer' has been interpreted in different ways and this has shaped the discourse around public service reform (see also Clarke et al., 2007; O'Hara, 2013). There has also been debate about the appropriateness of the term 'patient'. For many, it implies passivity, weakness and sickness, and for this reason has been challenged, notably in the arenas of disability, maternity and mental health. Some have adopted their own terminology, for example, some mental health groups prefer the term 'survivors' (Crossley, 2006).

A further point to consider is whether HCPOs constitute a health social movement, defined by Brown and Zavestoki (2004, p.679) as 'collective challenges to medical policy, public health policy and politics, belief systems, research and practice which include an array of formal and informal organisations, supporters, networks of cooperation and media'. There is considerable ambivalence in the literature on this question. Some see HCPOs contributing to a wider patient or health consumer movement (Allsop et al., 2004; Borkman and Munn-Giddings, 2008; Scambler and Kelleher, 2006; Williamson, 2008). In particular, they do this by developing expertise and knowledge, identifying new issues and challenging the status quo (on issues such as patient consent, rights to information and explicit standards in healthcare). Furthermore, some

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