

Influencing the national policy process: the role of health consumer groups

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Abstract

Introduction Whilst recent research has focused on consumer involvement at local level in the UK, there have been few studies of the representation of user, carer and patients' interests nationally. This paper concentrates on the role of health consumer groups in representing the collective interests of patients, users and carers in the national policy process.

Methods The research consisted of (a) a semi-structured postal questionnaire survey of 123 health consumer groups; (b) semi-structured interviews with key informants from 39 health consumer groups; and (c) semi-structured interviews with 31 policy actors.

Results Health consumer groups were diverse in their origins, scope and structure, and undertook a wide range of activities relating to policy and service provision. Whilst around half the groups described their primary purpose as service provision, over four-fifths identified influencing policy at national level as 'very important' or 'important'. Health consumer groups had developed relationships with civil servants, ministers, MPs and peers to widen their policy objectives. Key facilitators in the policy process included experiential knowledge, relationships with policy makers and working in alliances with other health consumer groups or other stakeholders. Key barriers included problems relating to the political agenda, problems with the consultation process, lack of resources and working within a context of unequal power relationships.

Conclusion Health consumer groups are becoming increasingly involved in the health policy process and collectively are becoming an increasingly influential stakeholder. They have a key role to play in ensuring that the patient, user and carer voice is heard in the policy process.

Introduction

Over the past two decades, organizations that seek to promote or represent health consumers have become part of the UK health policy net-

work. Health consumer groups are now extensively engaged in the health policy process. They are involved in media campaigns, parliamentary lobbying, and have extensive links with government. This has taken place in a favourable policy

climate. Since the mid-1990s a succession of official policy documents have endorsed and promoted patient and public involvement in the health field.¹⁻⁵ However, groups have also pushed for a greater role within the policy process, alongside their traditional functions of promoting self-help and raising awareness of issues and conditions.

Despite their increased activity, little is known about the impact of these groups within the policy process, particularly at the national level. Research in this field has been shaped by long-standing assumptions about the chronic weakness of consumer interests compared with producer and professional interests.^{6,7} Previous studies have noted the impact of groups' involvement in specific areas of policy or in relation to particular agendas.⁸⁻¹¹ However, the only comprehensive study across condition areas, which found that groups were unable to compete with dominant interests and were unwilling to work together effectively to challenge them, did not explore the interaction between groups and policy makers in any detail.¹²

This paper presents the findings of a 30-month Economic and Social Research Council (ESRC)-funded study on the role of health consumer groups in the national policy process. It explores the ways in which groups are involved in policy making and provides an overview of the current issues facing health consumer groups as they seek to represent the interests of patients, users and carers. The paper is split into four parts. First the origins, scope, structure and activities of the health consumer group sector is described. The paper then examines the involvement of health consumer groups with the government and parliament. The third section examines the key strengths of groups when seeking to influence policy, and the fourth, explores key barriers faced by groups in the policy process.

The research was undertaken in three phases between late 1999 and summer 2001. First, a semi-structured postal questionnaire survey was undertaken with groups identified in five condition areas (arthritis, cancer, heart and circulatory disease, maternity and childbirth, and

mental health), plus groups with generic interests that spanned all condition areas and 'umbrella' groups. Groups operating solely in Scotland, Northern Ireland or Wales were excluded, as were local and regional organizations. The effective response rate was 66% ($n = 123$). This was followed by semi-structured interviews with key informants from health consumer groups ($n = 39$). The third phase consisted of semi-structured interviews with 31 key policy actors (civil servants, MPs and representatives from professional associations, research charities, the pharmaceutical industry and general consumer groups). The research was designed in order to identify any differences in activity between groups with different characteristics (membership, size and focus) and to explore the differences between condition areas. However, the particular aim of this paper is to provide a general overview. Differences between different types of health consumer group are explored in more detail elsewhere.¹³

Origins, structure and activities

Health consumer groups are part of a wider voluntary health sector including research charities and welfare support groups. They serve a myriad of conditions, from rare diseases that affect a tiny minority, to more common conditions such as asthma or diabetes. It was beyond the scope of the project to cover every medical condition. However, the research sample was chosen to reflect a range of patient and carer experiences, from life-threatening diseases such as cancer and heart disease to life-changing conditions such as pregnancy and childbirth.

Formation

It was clear from the questionnaire responses that health consumer groups were not a recent phenomenon, and indeed two groups in the questionnaire sample formed before 1900. However, the most significant growth in groups took place since the 1960s, and in particular over the past two decades (see Table 1). This finding

Table 1 Date of health consumer group formation

	All groups (%)
Pre-1940	3
1941–1960	7
1961–1980	25
1981–till date	66

Source: Questionnaire 1999 (due to rounding up totals exceed 100%).

supports Wood's¹⁴ claim that growth since 1980 has been rapid. In interview, it was clear that different traditions, ethos and values had shaped the formation of groups. The older groups in the sample had been formed for philanthropic and altruistic reasons to support those in need. By the 1960s/1970s, groups were forming as part of a wider social movement aiming to improve the rights of vulnerable groups. In recent years, a catalyst for formation was 'pain and loss experiences', events associated with the body such as illness, injury or death¹⁵ where people have come together to offer mutual support and campaign to improve services. It was also clear that over the past two decades there had been significant growth in the number of alliances between health consumer groups. A catalyst for the formation of alliances was a recognition of the need to work together on issues of common concern (e.g. new legislation or government policy).

A number of groups in the sample were formed by people with direct or indirect experience of the condition in question, either as a patient, user or carer. Some groups evolved out of, or were established by, other health charities (e.g. the King's Fund helped found the Afiya Trust, 1996). Indeed two groups in the sample, Cancerlink and Contact a Family, still play a significant role in the support and development of health consumer groups. Doctors and other health professionals have also assisted in the formation of health consumer groups by supporting patients (e.g. the National Ankylosing Spondylitis Society, 1976). Doctors have also made a particular contribution as patients: Cancer BACUP (1985), for example, was formed by a doctor with ovarian cancer.

Activities

The questionnaire data showed the breadth of activities undertaken by groups such as: providing information; publicity/raising awareness; providing advice/support; building networks; fundraising; promoting self-help; influencing national policy; education and training; recruiting members; patient/carer advocacy; promoting research; influencing local policy; providing goods/services; and undertaking research. While the majority of groups indicated they were involved in a broad range of activities, it was clear from the questionnaire data that groups believed their main purpose was to provide services (48%) rather than influence policy (16%). Services were provided for members, although in a few organizations, particularly in the mental health sector, services were provided under contract to clients. Yet there was also support for Evers'¹⁶ argument that most voluntary organizations are 'polyvalent', undertaking both service and policy-related activities and considering these to be equally important, with about a quarter of groups indicating that they were equally committed to both. However, it was clear that the majority were engaged in policy activity: 82% stated that influencing policy was 'important' or 'very important' at the national level and 63% said this was the case at the local level.

The activities of health consumer groups tended to shift over time to meet new demands or reflect changing circumstances. A small number of interviewees described how their organizations' focus had changed over time. For example, in interview the spokesperson from the Stroke Association (1899) said that the organization had originally been established to provide support for people with tuberculosis. Other groups had changed in response to wider social and political changes. For example, interviewees from two arthritis groups discussed the increasing politicization of the sector because new treatments were available, and there was a growing perception that patients were being denied access to them.

The interviews showed that the groups faced difficulties in choosing priorities because of resource pressures. As a consequence, some groups chose not to attempt to influence policy, although even self-help and support activities can be construed as political activities (and therefore are policy relevant) because they raise expectations.¹⁷ However, for some groups in the sample, in particular the formal alliances or umbrella groups, the main objective was to influence policy.

Income

There was a considerable variation in the size and income of groups. A small minority of groups accounted for most of the sector's income (see Table 2). The total income of the groups in our sample was approximately £206 million, yet only six groups accounted for 77% of this (approximately £158 million). Fifty-four per cent of groups with an income of £100 000 or less per annum shared less than 1% of the total annual income recorded for the whole sample. This breakdown is similar to figures for the voluntary sector as a whole.¹⁸ In interview, a very small number of groups claimed to be in a financially precarious position.¹⁹

Although a majority of health consumer groups received funding from members and/or donations from the public, the questionnaire showed that a significant number also received income from official sources such as central government (33%), the National Health Service (NHS) (19%) and local authorities (14%). Interview discussions showed that groups were concerned about the implications of receiving

funding from statutory and commercial sources, believing that it might undermine their independence. Groups were also worried that an over-reliance on specific project funding would distort their priorities and shift them away from their core functions. For some groups, these concerns meant that they would not seek funding from official sources.

Membership and structure

There were also differences in membership numbers and composition. Some groups only allowed individuals or organizations to join, others allowed both; in total 92% of groups had some form of membership. Most were small, 56% had 1000 or less individual members, while only five groups had 10 001 or more individual members. The research did not seek to find out people's motivations for joining groups. However, research on self-help groups by Trojan²⁰ suggests that individuals have different motivations for getting involved, for some it is a way of connecting with others who have the same condition and share the same experiences, for others it is a means to effect change, either on the part of health professionals or politicians. Moreover, the motivation is not always positive. Small and Rhodes²¹ noted that for some patients with degenerative conditions (motor neurone disease, cystic fibrosis and multiple sclerosis) there is a reluctance to join or become active in groups because they would come into contact with people who had more advanced stages of the condition.

Just as there are different motivations for joining groups, individuals also take different roles in organizations. Some join and become actively involved in campaigns and volunteer or apply for leading roles in the organization, others simply receive newsletters and have no other contact with the group. However, group respondents stated that they drew extensively on the knowledge and experience of their members and wished to include them in decision making. They argued that their contact with their membership and the public was a valuable resource, for reasons to be discussed later. Nearly half of

Table 2 Health consumer group income

Income range	All groups (%)
< £10 000	16
10 001–100 000	38
100 001–1000 000	33
1000 001–10 000 000	8
10 000 001 plus	6

Source: Questionnaire 1999 (due to rounding up totals exceed 100%).

the groups had local branches; in 60% of these groups, the branches had autonomy from national headquarters, although for others this arrangement was more structured with local groups formally affiliated to the national headquarters. Local branches were often a means of linking with members and providing services, and were a useful fora for involving members in the organization.

Staffing levels and structures varied between groups, some were run from the founder's front room with a minimum of administrative support. Others were run from groups' offices (often in London) with specialist staff undertaking different roles including policy officer, membership officer and public relations. Nearly a quarter of groups had no paid headquarters staff and were run entirely on volunteer support, only 17 groups were able to employ more than 10, paid, full-time equivalent staff at headquarters.

The analysis of the questionnaire and interview data led to the development of a typology of health consumer groups:

- *Formal alliance organizations.* National groups whose membership consisted of other autonomous national organizations (e.g. Genetic Interest Group, Long Term Medical Conditions Alliance, Patients Forum).
- *Population-based groups.* Groups representing all patients, or a specific population subgroup within the health arena (e.g. Patient's Association, Action for Sick Children).
- *Condition-based groups.* Groups representing people with particular conditions (e.g. the National Ankylosing Spondylitis Society, National Childbirth Trust).

Whilst most studies would distinguish between alliances (or umbrella groups in voluntary sector terminology) and other groups, a third category was identified, namely population-based groups. These groups served all patients or a specific population group across a range of medical conditions and were more concerned with generic issues such as access and rights. Whilst condition-based groups were also concerned with these issues, they also provided help and

support in relation to their particular condition. For example, Carers National Association (a population-based group, renamed Carers UK in 2001) was concerned with carers' issues across a range of medical conditions, the National Schizophrenia Fellowship (renamed Rethink in 2002) was also concerned with carers issues, but provided specific support to those caring for people with severe mental illnesses. In comparison with condition-based groups, population-based groups tended to have a higher income, be London-based and were generally older, with only 46% of groups forming since 1981 compared with 68% of condition-based groups.

Relationships with government and parliament

The rest of the paper focuses on the involvement of groups in the policy process, in particular what they identified as the key facilitators and barriers. In general terms, the interviews indicated that health consumer group involvement was a consequence of a push by groups themselves to promote interests of patients, users and carers, and successive government policies to promote user involvement. More specifically, both questionnaire and interview data indicated considerable contact between groups and policy makers.

Three-quarters of health consumer groups responding to the questionnaire had been in contact with central government on policy issues within the previous 3 years, and almost two-thirds stated that opportunities for participation had increased over this period. A greater proportion of formal alliance and population-based groups had contact with central government than condition-based groups. Condition areas also showed differences in contact with cancer groups most likely, and arthritis groups least likely to report contact with central government. Most contact was with the Department of Health (DOH), with just under half of the groups reporting contact with civil servants and 30% contact with ministers at least quarterly.

In interview, groups described the strategies they used to influence policy. The majority of

groups were careful to select tactics according to the nature of the issue. For example, some groups worked carefully to build a relationship with ministers and would approach them if negotiations with civil servants were deemed to have stagnated, or where approaches to civil servants had been unsuccessful. There were several examples of where this had happened, resulting in changes to legislation and NHS guidance. Other groups believed campaigning worked better if they used the media and were willing to openly criticize government policy in order to get issues onto the political agenda. A key example of this was Age Concerns' campaign on the use of 'Do Not Resuscitate' orders on elderly people; the organization ensured that the media kept up the pressure on government to address the issue.²²

Health consumer groups were also involved in official committees and taskforces, such as external reference groups that helped develop the National Service Frameworks, the Modernization Action Teams which contributed to the NHS Plan, and the Expert Patients Taskforce. Several respondents mentioned involvement with the National Institute for Clinical Excellence (NICE), representation on appraisal groups and submission of evidence to NICE reviews.

Groups also worked through parliament to influence policy. The questionnaire showed that 45% of groups had at least quarterly contact with MPs or peers. In interview, groups said working in parliament was useful for building networks, acquiring and disseminating information, raising awareness and highlighting issues of concern. Lobbying parliament was seen as a mechanism for putting pressure on the government and influencing policy, most visibly in relation to legislative change, but also in subtler ways by shaping agendas and decisions regarding policy implementation. In interview, MPs said that they welcomed approaches from groups and regarded them as a valuable source of information.

Contact with parliament took the form of briefings, meetings, the appointment of MPs or peers as trustees, and through parliamentary committees. Select committee enquiries were

seen as an effective way of raising issues and concerns. For example, groups had given written and oral evidence to inquiries into medical errors and cancer research. Ten groups in the interview sample mentioned contact with All Party Groups, and in one case, provided administrative support. All Party Groups were viewed by many respondents (including ministers) as useful for exchanging information and co-ordinating activities. Groups also approached MPs and peers to table questions and initiate debates and these were generally regarded as ways of raising issues in relation to treatment, services and policy, and eliciting a response from government on such matters.

For some groups, policy influence was also achieved through the services they provided to patients, users and carers, or by lobbying other policy actors, such as health professionals directly. For example, Action for Sick Children believed its work with health professionals and local health authorities had done much to improve the experience of children in hospital. Mental health groups believed they had developed innovative services to better support those with mental health problems and their families, while Arthritis Care believed its work with arthritis sufferers to help them self-manage their condition had been a catalyst for the nationwide Expert Patients programme.²³

Sources of strength in the policy process

Experience

The questionnaire data showed that groups believed that their ability to bring the experience of patients, users and/or carers to the policy process was a key resource. They were able to bring a point of view that other stakeholders might be unaware of, and were able to use it to tackle the inherent assumptions of other decision makers. Analysis of the notion of 'expertise' showed that it had a number of dimensions:

- personal experiences of the disease or condition as patient, carer or relative;

- acquired specialist knowledge of the disease or condition and its treatment;
- knowledge of user/carer priorities and needs;
- information on the realities of service delivery;
- an understanding of the capacity for self-management of long-term medical conditions;
- knowledge of networks of expertise; and
- knowledge of the workings of the policy process.

The analysis of the interview data showed that group officials placed great emphasis on the relationships they developed with their membership and the public. This enabled group leaders and spokespeople to claim to represent the interest of patients, carers and users. Numerous mechanisms were used to support and interact with those in contact with the organization, including help lines, web-sites, service provision (including equipment, care and treatment), and through the use of research. For example, the National Schizophrenia Fellowship, Manic Depression Fellowship and the National Association for Mental Health (MIND) undertook a joint survey of service users to obtain their views of current treatment options for severe mental illness.²⁴ A maternity group logged calls to its advice line and used the data as a way of identifying issues of concern to their members or the public. It is important to note that while some services were only available to their membership (e.g. newsletters and magazines), others such as telephone help lines and information leaflets were available to the public as well.

Groups used these social networks to consult their membership, clients and the wider public about proposed policies and service developments. In addition, these were used to identify individuals who might be willing to represent the group on official committees and advisory bodies. For some groups, it was important that those who represented the organization had experience of the condition in question, as a patient, user or carer; others employed professional staff (although some gave preference to those with experience of the condition).

Groups also used formal democratic processes such as annual general meetings and elections of

group officials, as a way of facilitating participation. They helped group officials maintain a dialogue with members. Interviewees were aware that some members faced difficulties in participating in the organization. In particular they were aware that the conditions themselves could pose a barrier to participation as one respondent said

...some of the very active people may fall ill...and then you lose continuity.

Groups would attempt to overcome these barriers by ensuring that meetings were always arranged with the needs of participants in mind.

Alliances

In the questionnaire, nearly nine of 10 respondents claimed that their group had links/alliances with other user/carer organizations. In interview, those groups who had joined alliances claimed that this was a source of strength. The analysis of the interview data identified three types of alliance, collaborative networks of groups which worked together on issues of joint concern. Other groups were members of informal alliances, which held regular meetings over a number of years and whose administration was shared between groups, such as the Mental Health Alliance, which had come together to voice concerns over proposed changes to the 1983 Mental Health Act. Health consumer groups were also members of formal alliance organizations. Within the health consumer group sector, there has been a general move towards formally constituted alliances over the past two decades, for example, the Genetic Interest Group developed out of an informal alliance. Formal alliances worked to support their members organizations and to lobby government and parliament on their behalf. Groups worked together because it enabled them to share workloads, pool knowledge and expertise and raise their organization's profile. They believed that working through alliances strengthened their voice in the policy process. Whilst groups were generally positive about working in alliances, they noted that there were difficulties

in reaching consensus over issues, competition for members, resources and public attention. From the interview data, it was clear that those working in both formal and informal alliances placed an emphasis on maintaining consensus. For some groups, this meant avoiding policy issues where damaging divisions could arise. Other policy actors, valued the work of cross-condition formal alliances such as the Patients Forum, in maximizing contributions to policy development and in achieving consensus in the health consumer group sector.

Health consumer groups also developed alliances with other stakeholders in the policy process, in particular with health professionals. These alliances were also formed over issues of joint concern, although the analysis of data suggested that groups were more cautious in developing these working relationships. The questionnaire data showed that just under half of the groups had at least quarterly contact with doctors' organizations. For some groups, these links were formalized through overlapping membership of executive and advisory groups. About half the groups in the questionnaire survey included doctors on their main decision-making body. The interviews revealed that a number of health consumer groups were represented on committees established by professional bodies to consult with patients, users and carers. Health consumer groups and professional organizations undertook a number of joint activities including conferences, research and in some instances lobbying, for example a number of professional organizations were members of the Mental Health Alliance. In response to concerns over the rising caesarean rate, medical and midwives associations and health consumer groups undertook research and made representations to parliament. In interview it was clear that groups were more cautious about developing relationships with professional associations, fearing 'capture'. A few groups distanced themselves from the medical establishment, although they did work with individual health professionals, considered sympathetic to their cause. In general although, developing good working relationships with health professionals benefited

health consumer groups because they were considered to be a more powerful stakeholder in the policy process, and it was believed that it would be easier to work with them than against them.

Relationships with civil servants and ministers

The evidence presented under the section 'Relationships with government and parliament' showed that most health consumer groups sought to build links with civil servants and ministers. Developing good working relationships with civil servants, was considered to be key in making policy impact. Some groups cited examples of where they had worked very closely with civil servants, or where civil servants had effectively blocked policies, and in some cases access to ministers. As one respondent said in relation to achieving progress on issues relating to NHS complaints:

It depends on the sort of relationships I think, you have with those that are running it.

These links were often critical in creating awareness and getting issues on the agenda at a senior level, for example, the spokesperson from Arthritis Care described how links to a minister helped get the Expert Patients initiative onto the agenda. Ministerial support was also believed to be crucial in moving things forward when policies had stalled, in one example, a group representing carers was able to use links with a minister to ensure proposed changes to legislation were implemented.

Groups were seen by ministers and civil servants as repositories of expertise. This expertise was particularly welcomed if it was based on systematic research and offered solutions alongside criticisms. In interview they claimed that involving health consumer groups was useful in ensuring policy was more attuned to the needs of users and they believed that it would improve policy outcomes. Civil servants and ministers wished to work with groups that had the ability to engage with their members and their 'client-base'. Civil servants and ministers generally recognized the capacity of groups to represent

the interests of patients, users and carers, although they believed that groups could not claim to represent the wider public interest because it was beyond their scope and purpose.

Whilst links with policy makers were undoubtedly important, it should not be assumed that they were always easy to establish or maintain, the next section looks at the barriers faced by groups in the policy process.

Key barriers in the policy process

Agenda

Groups identified a number of barriers in the policy process, in particular working within the agenda of others, such as the media and government. A number of groups were concerned that the media had its own agenda in reporting health stories. For example, the majority of mental health groups were concerned that the tabloid press focused too much on public safety issues, and was uninterested in reporting more positive stories. Even those groups that could attract sympathetic coverage were concerned that the media stories did not always reflect the condition accurately (e.g. focusing on young women with breast cancer although they were not the group at highest risk).

However, a core difficulty was the need to get issues onto the government's agenda. There was a strong belief that influence and access varied according to condition areas. In particular, groups in the arthritis and maternity sectors were concerned that their impact was limited by the fact that the conditions were not currently government priorities.

Yet even groups that were in priority areas sometimes found it difficult to influence policy. Despite its status as an official government priority, groups in the mental health field saw a lack of public support as a barrier to influence. As one mental health group respondent stated:

If you are cancer, or heart disease, or children then I think it is much easier to drive the political agenda in those areas, but when you are in mental illness, it is harder to drive, you're often on the back foot.

Cancer and heart disease groups, while recognising that they were pushing at an open door, did not accept that influence automatically followed. Nor did other policy actors, including ministers and civil servants, believe that health consumer groups in these priority areas were necessarily more influential. It was accepted, by groups and policy makers alike, that these groups would have greater opportunities to exert influence. However, whether these opportunities would be taken was another matter and this depended the quality of the input from the group and circumstantial factors such as the political acceptability and practicality of proposals.

Consultation process

A common problem mentioned in interviews was poor communication and feedback on policy developments from the DOH. Many groups were confused by the structure of the department and some said that this was a deterrent to commenting on policy development and raising issues. Others, while priding themselves on their knowledge of Whitehall, felt that more could be done to identify clearer contact points for groups on policy matters. It should be noted that the DOH has since been reorganized with an explicit focus on engagement with stakeholders, including patients, users and carers.

Other problems related to insufficient time for consultation. Groups found it difficult to canvas views of members given the short timescales given for comments. There were problems too with confidentiality requirements that inhibited open discussion with their members on some issues. The latter was particularly a problem for those groups who wanted to share ideas with a wider constituency and promote engagement in a wider sense.²⁵

Resources

A key barrier to lobbying activity was a lack of funding. As discussed earlier, the majority of groups had limited financial resources. Involvement with government meant that scarce

resources had to be diverted from core activities such as providing information and advice to members. In interview many respondents believed that government did not sufficiently recognize these opportunity costs. They felt that government should reimburse their staff costs in the same way it offered payment to health professionals who attended meetings. Some also believed that the government should make a financial contribution for what they regarded as 'free advice'.²⁶ Lack of financial resources also restricted the way in which groups were able to interact with government. For example, only a minority of groups were able to employ staff to work specifically on policy issues. Those groups that were unable to do so believed that this put them at a disadvantage. Indeed, the interview data suggested that those health groups that had a dedicated policy officer were more knowledgeable about the policy process and how to engage effectively with government.

Power relationships

Groups also described difficulties in working in policy arenas where other powerful interests such as government and non-government experts and the medical professions were strongly represented. Examples were given of the difficulties faced by health consumer groups working in arenas where they were outnumbered by other experts. Some interviewees commented that the NICE review process was dominated by professional and political agendas and that evidence based on the views and experiences of their members were not as highly rated as evidence from other sources. Civil servants and MPs also commented that health professionals, research charities and commercial interests were the most dominant stakeholders in the policy process.

Conclusion

The research has shown that health consumer groups should now be considered as key stakeholders in the policy process. They have a knowledge base grounded in the experience of their members and the wider public with whom

they are in contact. They can claim to be the legitimate representatives of patients', users' and carers' interests because of the way in which the user perspective is incorporated through both formal and less-structured interactive processes. They have forged alliances which have strengthened the sector, particularly for smaller groups who have been able to develop both managerial and political capacity. Health consumer groups have had considerable success in highlighting issues of concern, and this has increased their confidence in the policy process. As has been shown, they are involved in the policy process and there are indications that collectively they are becoming an increasingly influential stakeholder.

Health consumer groups are used to working in a complex and unstable policy environment. This is set to continue. Government relationships with the voluntary sector as a whole have been under review, as has charity law. The specific implications for the health consumer groups have yet to be established. These developments sit alongside traditional challenges such as securing adequate funding, maintaining the organization and working alongside powerful institutionalized interests.

Groups are also having to work through the implications of devolution, including the need to foster new working relationships with decision makers and their memberships in different nations within the UK, and negotiate different structures for incorporating the consumer interest. Community Health Councils have been abolished in some parts of the UK, but not others. In England, a Commission for Patient and Public Involvement in Health has been established which will oversee patient and public involvement at the local level. At the moment it is unclear as to how health consumer groups will work alongside the Commission, although representatives from the sector have been involved in the emergence and development of the organization. In particular the balance between statutory and voluntary aspects of patient and public involvement has yet to be fully worked out. However, what is clear from this research is that health consumer groups undoubtedly have

a key role to play in ensuring that the patient, user and carer voice is heard in the health policy process.

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