BACKGROUND
This project aimed to investigate how health consumer groups (HCGs) engaged in the national policy process. There had been no systematic study of this topic, though Wood (2000) has since explored the activities of patients’ associations in the UK and the US. Our research proved to be timely as it took place in the context of new NHS institutions, processes and policies (DOH, 1998; DOH 2000), and explored the views of HCGs on the development of these increased opportunities for participation and involvement.

In our proposal, we discussed several theories and models relevant to interpreting the role of HCGs in policy making. Alford’s (1975) model of structural interests in health care, which postulates a ‘repressed’ community interest relative to the ‘dominant’ interests of professionals and the ‘challenging’ interests of bureaucrats, provided a useful starting point. It questioned the extent to which HCGs, as representatives of the community interest, could ever challenge existing institutional biases. However, it also drew our attention to the importance of institutional changes in enabling HCGs to challenge dominant interests. This was also suggested by the policy networks literature which relates the composition of networks, and the relationships between their members, to policy outcomes (Marsh and Rhodes, 1992). Of particular interest, was how network composition and relationships might have changed in recent years and to assess the impact of this on policy (Moran, 1999; Richardson, 2000). Also relevant was Baumgartner and Jones’ (1993) exploration of the process through which ‘excluded’ groups (in our case HCGs) challenge dominant interests by targeting alternative decision making venues, promoting alternative agendas, re-defining policy problems and by emphasising their own particular skills, expertise and resources. This again focused attention on the interaction between HCGs, other interest groups and government. It also required us to examine how, and to what extent, HCGs could generate institutional and policy change.

Theories of the democratic process were also important. The shift towards more inclusive decision making fora involving discursive problem-solving practices has attracted increasing attention (Dryzek, 1990). We were interested in the role played by HCGs in these developments, and how they, as associations, contributed to the democratic process (Hirst, 1995). Also relevant was the work of Schmitter (2001) whose concept of ‘participatory governance’ views organisations as ‘holding’ the interests of particular constituencies and being accountable to them. He sets out a number of conditions including: participants’ acceptance of certain rules of the game, their openness to argument, and the nominal equality of participants. Schmitter’s conditions also provided a useful basis for assessing the role of HCGs as stakeholders.

We also drew on the literature on pressure-group politics. We investigated the internal dynamics of HCGs, to understand how their resources and tactics shaped interaction with other HCGs, other interest groups and government. Existing typologies - Whiteley and Winyard’s ‘OPAL/FRAS’ typology, (1987); and Grant’s ‘Insiders/Outsiders’ model (1995) were used to examine the relationship between HCG characteristics, strategies and influence. We also identified different types of HCG and attempted to relate this to policy influence (see p.7-8). Moreover, we drew on the new social movements literature to help explain group formation, development and cohesion (Byrne, 1997). Finally, in order to take account of the different contexts of HCG activity, we examined groups in five condition areas (arthritis, cancer, heart and circulatory disease, maternity and childbirth, and mental health) - chosen to reflect various health conditions.
experiences and different government priorities. Also included were groups whose interests spanned these condition areas.

During the research we considered the concept of ‘social capital’. Putnam (2000) has argued that voluntary groups are shaped by underlying values of trust and reciprocity and represent a source of ‘social capital’. However, we found this difficult to measure, partly because our interviews were with officials rather than grass-roots members. Instead we adopted the term ‘social resources’ to describe the strengths that group leaders said they derived from interaction with their members/clients, and the public.

Objectives
1. To explore how a sample of national health consumer groups represents the interests of patients, users and carers within the policy process through:
   • analysing their aims, objectives and strategies;
   • examining their internal organisation and relationship with their members and grass-roots support;
   • investigating how professional and business interests are incorporated and financial resources are mobilised.

2. To describe and analyse how these health consumer groups interact with central government departments and agencies, Parliament, and the media in relation to policy making.

3. To examine alliances between specific health consumer groups and investigate the particular role of umbrella consumer organisations in promoting alliances.

4. To assess the contribution of theoretical perspectives and models to an understanding of the role of health consumer groups and in particular to assess whether different strategies and modes of interaction are related to group characteristics.

We are satisfied that we have achieved these objectives. Some conceptual, definitional and practical problems arose, but these were handled effectively (see below). Throughout the project, the team worked with an Advisory Group comprised of academics, individuals from HCGs and civil servants.

Methods
Definitions and concepts
As this was a relatively new area of research, we devised the following definition to aid data collection. A HCG was defined as ‘a voluntary sector organisation that seeks to promote and/or represent the interests of users and/or carers in the health arena at national level’. Our focus was on groups articulating health service user/carer interests and to retain this, we excluded research charities and professional associations. Other organisations excluded were: general consumer organisations (health was only part of their brief) and disability organisations (they had already been extensively researched). Local/regional groups and statutory organisations (such as CHCs) were excluded as well as organisations that provided help-lines only (their role was too limited). Some of these organisations were interviewed in the third phase of the research in their capacity as important policy actors.

Although in our original proposal we referred to the importance of ‘umbrella groups’, in practice this term was imprecise. We therefore devised a new typology based on the different constituencies of HCGs:

- Formal Alliance Organisations (FAOs) - defined as national groups whose membership consisted of other autonomous national organisations, including HCGs.
• Population Based Groups (PBGs) - groups representing all patients or a specific population subgroup within the health arena (e.g.: children; ethnic minorities).
• Condition Based Groups (CBGs) – groups representing people with particular conditions.

**Phase One: Questionnaire**

As no single database of groups existed, various printed and internet sources were used to identify potential groups that appeared to fall within our definition, although data was limited. A semi-structured postal questionnaire was developed, using our theoretical framework to identify key questions, to obtain factual and attitudinal data. This was piloted and revised. In Autumn 1999, the main questionnaire was sent out to 243 organisations. Despite prior checking, a number of responses did not meet our criteria and were excluded. The effective response rate was 66.1% (n=123). The data were analysed using SPSS 7.5. Qualitative data from open ended questions were included in the phase two analysis.

**Phase Two: Interviews with HCGS**

HCGs were selected to ensure to ensure a mix of characteristics such as size, condition area, date of formation, and type of group (including the Whiteley/Winyard typology) were represented. Face-to-face interviews with senior staff from 39 HCGs were undertaken using a semi-structured schedule. The questions and a statement of confidentiality were given prior to the interview. Most interviews were taped and transcribed and all were coded in NVIVO. A grounded method of analysis (Strauss and Corbin, 1990) was used to identify core categories. A further analysis within categories enabled the identification of dominant themes and negative cases.

**Phase Three: Interviews with key individuals**

In order to collect data on their views of HCGs, face-to-face or telephone interviews were undertaken with 31 key policy actors (civil servants, MPs, leading members of professional associations, research charities and general consumer groups) identified through the questionnaire or Advisory Group. The notes taken were written up and analysed using a grounded method.

**Findings**

Except where indicated, the percentages given relate to questionnaire findings. Other findings are derived from interview data.

1. **Aims and activities**

Health consumer groups (HCGs) were extremely diverse. This was reflected in their core aims and objectives, focus and scope, and in the priority given to different activities. However, all shared a concern to meet the needs of patients and carers. In doing so they engaged in a range of support and policy related activities. The former included providing practical support for individuals and local groups, information for patients, carers and for the wider public. It could also include offering services, training and education, and undertaking research. Policy-related activities included raising awareness, influencing local providers, professionals and central government. When asked to state their main purpose, 47.9% stated that it was to provide services, 15.7% to influence policy. However, it was clear that many more groups were engaged in political activity - 81.5% stated that influencing policy at national level was ‘important’ or ‘very important’ to them. There was some variation by type of group: FAOs and PBGs placed more emphasis on influencing national policy than CBGs.

2. **Status, traditions, formation and growth**

90.9% of HCGs had charitable status. 9.4% were formed before 1960, 24.8% between 1961 and 1980 and most (65.8%) were formed after 1981, supporting Wood’s claim that growth since 1980 had been rapid (2000: 36). Although data on the formation and growth of HCGs was scarce, we found that HCGs drew on a number of different traditions: the philanthropic, the
pursuit of rights, self-help and most recently, particularly in relation to CBGs, the identity politics associated with new social movements. In the case of CBGs, specific triggers included personal experience of illness and media coverage. In a few instances, professional activity was an important catalyst. The impetus for the formation of FAOs came mainly from within the HCG sector, motivated by a concern to influence policy.

3. Human and financial resources
There was considerable variation in HCGs human and financial resources. 23.6% had no paid headquarters staff. Only 15.5% had more than ten paid full-time-equivalent staff. A few (5.6%) had an income of over £10m per annum, a third between £10,001 and £100,000 (38.3%), and 15.9% less than £10,000. Although a majority of HCGs received funding from members and the public, a significant proportion received income from official sources: central government (33%), the NHS (19.3%) and local authorities (13.8%). Many groups were critical of central government funding, claiming too much emphasis on project rather than core grants. This discouraged long-term planning, and could restrict activity. Limited resources meant choosing priorities. In particular, groups noted that involvement in policy had an opportunity cost in relation to membership activities.

4. Social Resources
HCGs facilitate networks of social relationships, 92.4% had some form of membership: including users, carers, relatives, other HCGs and professionals. 82.2% of groups had individual members. Most were small: 56.1% had a 1000 or less members, while only 5.5% had over 10,000. 40.7% of the groups included affiliated organisations. Almost half (49.2%) had a branch structure, thus linking national and local activity.

Although diverse, two common themes were identified in the accounts of HCG activities. First, importance was placed on interaction with their membership and the public. This was supported by helplines, the Internet, providing equipment, care and treatment and undertaking research. Groups communicated with members through newsletters, conferences and workshops in an interactive way. For the most part, these informal ways of facilitating participation ran alongside formal democratic processes such as annual general meetings and elections. They helped officials to maintain a dialogue with members and offset barriers to participation such as the condition itself. A few groups referred to the problems of attracting a cross section of the public, particularly ethnic minorities, into membership. Others mentioned internal conflicts within the organisation over priorities.

A second common theme referred to by all HCGs was their ‘expertise’. This was seen as a resource developed through interaction with the membership and the wider public-in-contact and disseminated through organisational activities. ‘Expertise’ had a number of dimensions consisting of:

- 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 patient / carer priorities and needs;
- information on the realities of service delivery;
- an understanding of the capacity for the self management of particular conditions;
- knowledge of networks of expertise;
- knowledge of the workings of the policy process.

Internally generated social resources related to expertise were translated into political resources when HCGs engaged with each other; with other interest groups and when they operated within the policy process.
5. Alliances between HCGs

We identified three levels of interaction between HCGs:
- within formal structures: the FAOs
- informal alliances: groups that had regular meetings and shared administrative support
- ad hoc links around particular policy issues

85.7% of groups claimed their organisation had links/alliances with other user/carer organisations, and 76% viewed this as a key facilitator in the policy process. Interviewees noted that alliances enabled them to share workloads, pool knowledge/expertise, and raise their organisation’s profile while strengthening their collective voice in the policy process. Groups worked together on a range of issues: raising awareness, research, and influencing policy. Inter-organisational links were particularly strong within the mental health and maternity and childbirth sectors, but were weaker among cancer and heart and circulatory disease groups. HCGs identified difficulties in joint working. They referred to difficulties in reaching consensus on policies, and to competition between groups for members and resources.

FAOs were seen as particularly important, not only by the HCGs but by other policy actors, including civil servants and MPs. They provided effective support to smaller organisations, including access to networks and information about policy developments. They could also present a more coherent voice to policy makers. This was especially true of larger FAOs which cut across condition areas. During the project, government plans to create a national patients’ organisation for the whole sector reached the agenda. Some interviewees raised arguments for and against this. Whilst it was believed that such an organisation could provide greater support for HCGs, for example, through training, and improve co-ordination, interviewees were concerned that bureaucracy would increase and that groups representing rare or stigmatised conditions might be marginalised.

6. Relationships with other interests

The majority of groups had links with other interest groups including medical research charities and general consumer organisations. Of particular interest was how they interacted with health professionals and the pharmaceutical industry.

6a. Health Professionals

Close links existed between the majority of HCGs and health professionals. 47.9% of HCGs had at least quarterly contact with doctors’ organisations. 68.3% of groups had individual professionals among their membership and 33.7%, professional associations as members. Formal relationships had grown through mutual membership of executive and advisory groups (48.2% of groups had doctors on their decision making body). The interviews showed that some HCGs are represented on various consumer fora established by professional bodies. Though most groups were positive about such links, a few distanced themselves from health professionals, fearing ‘capture’.

Most HCGs valued the expertise of the professionals and used it to support their membership. Similarly health professional organisations valued the expertise of HCGs and in particular their ability to represent a broader perspective than would be provided by individual patients. A further impetus was that government expected them to involve the ‘lay perspective’. However, the professional organisations were careful to avoid ‘unproductive’ relationships, appointing representatives with whom they could work. Most HCG/professional activity was geared to promoting mutual understanding and developing treatment standards. There were few examples of joint working to influence government. One instance was concern over rising caesarean-section rates. Different interest groups, including HCGs, obstetricians and midwives, were working together to present evidence to government.
6b. The Pharmaceutical Industry

Although, in the questionnaire, most HCGs reported some contact with the pharmaceutical industry, 37.5% stated that they had never had any contact. Involvement with the industry occurred on issues such as: the sponsorship of publications, meetings and conferences; awareness raising; research. In interview, we found only two examples of joint activity to influence government. HCGs were cautious about their relations with industry. They wanted to be seen to maintain their independence, and a number had established rules of good practice. A few refused to work with the industry, and in two cases were in direct conflict over adverse drug reactions. The industry’s trade association said they valued the expertise of HCGs and that their main reasons for working with them were to share information and develop mutual understanding.

7. Media

Most HCGs acknowledged the importance of the media’s portrayal of policy issues. 49% of groups had monthly contact. In interview, HCGs said that they worked with a wide range of media: press (newspapers and magazines), broadcast media (radio and TV, factual and drama), as well as advertising. The main reasons for using the media were to highlight problems and issues, and to raise awareness of an organisation or condition. A minority of groups used the media to raise funds, promote their services, and to challenge stereotypes. HCGs had a keen sense of what was newsworthy. Some groups (notably mental health groups and those representing ethnic minorities) referred to difficulties in attracting favourable coverage. Several groups identified ways in which media coverage could be damaging, for example, focusing on stereotypes, highlighting atypical cases, or presenting problems as ‘crises’.

8. HCGs and Government

75% of HCGs had been in contact with central government on policy issues within the past three years. 62.4% believed opportunities for participation had increased over this period. Although contact was made with other departments, most was with the Department of Health (DOH). 47.9% of HCGs were in at least quarterly contact with DOH civil servants and 29.8% with Ministers. The questionnaire data showed that a greater proportion of FAOs and PBGs had contact with central government compared to CBGs. There was also some variation by condition area, with cancer and maternity and childbirth groups more likely to report contact with central government.

HCGs described constructive relationships with civil servants, who were regarded as informative and valued for their role in building networks and briefing ministers. Groups approached ministers in order ‘to make things happen’ where an issue had stagnated. Although the strategic importance of the core executive (including the PM’s office) was acknowledged, only a few groups attempted to influence it directly. HCGs were involved in a range of official advisory committees; in interview, fourteen groups referred to National Service Framework (NSF) committees, and individuals from five groups were involved in NHS Modernisation Actions Teams.

By highlighting patient and carer perspectives, HCGs argued that they could improve the quality of policy making. They believed their experiential knowledge was valued by government and that they offered innovative solutions to policy issues. However, HCGs commented on various barriers: poor communication and feedback; lack of co-ordination within the DOH and between departments; the financial costs of involvement and the reluctance of government to fund this; insufficient time given to consultation and barriers to consulting with their constituency, particularly where there were confidentiality requirements. HCGs didn’t feel the ‘rules of engagement’ were sufficiently explicit.
Civil servants acknowledged that HCGs could represent patient/carer interests, and said they valued their expertise. They identified political and pragmatic reasons for involving HCGs. Participation could improve policy outputs and help create a consensus about what was possible. Involving groups could also provide support for the government’s reform agenda and minimise overt criticism. Civil servants expected HCGs to recognise the constraints imposed by the policy process, as well as issues of timing, confidentiality, priorities and scarce resources. From the civil servants’ perspective, the credibility of groups depended on active engagement with their constituency.

9. Parliament
44.9% of HCGs had at least quarterly contact with MPs/Peers. Groups found Parliament useful for building networks, acquiring/disseminating information and raising issues. They believed that Parliament could put pressure on government and thus have an impact on policy, most visibly in relation to legislative change. HCGs said they had little difficulty in establishing these relationships. MPs found HCGs a valuable source of information. Contacts with Parliament were made through: written communication, briefings, meetings, the appointment of MPs/Peers as trustees, and through Parliamentary committees. Select Committee inquiries were seen as a way of raising issues, while All Party Groups were viewed as useful for exchanging information and co-ordinating activities.

Mental health groups, followed by cancer groups, were the most active in Parliament and gave priority to co-ordinating these activities. FAOs and PBGs were more frequently in contact with Parliament than CBGs.

10. Impact of HCGs within the Policy Process
HCGs have become more engaged in the policy process in recent years. This is a consequence both of a push by them to become more involved and a willingness by government to increase their participation. HCGs have developed skills and knowledge of policy advocacy and have constructed useful networks. They have formed alliances, both formal and informal - to build support, and pool resources, knowledge and skills. Coalitions have formed in relation to specific developments, such as the 1999 Health Act. HCGs have also been active in raising awareness, articulating problems, agenda-setting, policy formation and implementation. Other policy actors, including government, recognised their potential contribution and have drawn on their knowledge and their ability to speak for a particular constituency.

Participation has been promoted by central government, with the DOH developing specific policies. Meanwhile, the NSFs and National Plan have included representatives from HCGs on advisory bodies, working alongside other interests. The selection of health service priorities (cancer, coronary heart disease and stroke, and mental health) have encouraged engagement with groups in these particular condition areas.

HCGs believed their main contribution was to highlight issues previously ignored, downplayed or even opposed by established participants. Examples included issues concerning quality of life, carers’ needs, and the psycho-social aspects of health. In terms of actual impact on policy, two thirds of groups interviewed identified cases where they believed they had been influential. Our analysis showed that insider groups (those that were regularly consulted by government and represented on official committees) were the most influential. Even so, groups willing to engage with government, Parliament and the media (Whiteley/Winyard’s ‘open’ strategy) were more likely to report influence than those relying exclusively on contacts with government (Whiteley/Winyard’s ‘focused’ strategy). However, HCGs, civil servants and MPs still perceived professionals, research charities and commercial interests as dominating agendas and decision making in this field.
Among HCGs, there was a strong belief that influence varied according to their condition area. The mental health groups believed that despite its status as government priority, a lack of public understanding made it difficult for them to advance their policy objectives. Groups in the arthritis and maternity and childbirth sectors claimed that their impact was limited because these were not government priorities. Although these observations were confirmed by other participants, our analysis did not find a link between condition areas and self-reported influence. Similarly, there was a belief among participants that FAOs were more influential than other groups, though this was not confirmed by the interview data on self-reported influence.

The contribution of groups to policy was limited by their structure and capacity. There are many small HCGs that struggle to survive, due to limited human and financial resources. Groups felt they should receive more support for their participation and suggested recompense for involvement, improved systems of consultation and more explicit rules of engagement.

Among HCGs, there was considerable uncertainty about issues of representation (who should represent users/carers). Moreover a small network of individuals considered to be key players were frequently approached to participate. This brought problems of overload and accusations of elitism and self-selection.

11. Theoretical Perspectives
Our findings have implications for the theories outlined earlier. The most significant are:

1. The Alford model requires revision. As representatives of the community interest, HCGs are not ‘repressed’. They are included in discussions within the policy process, alongside professional and other interests, and the latter are being challenged to some extent by new agendas and issues that reflect a user/carer perspective. This observation is also consistent with Baumgartner and Jones’ model of policy dynamics. HCGs now have greater opportunities to participate in new institutional processes, and have increased their capacity for involvement, through, for example, FAOs and other alliances. Although, government and other established interests continue to act as institutional ‘gatekeepers’ regulating access to decision making fora, they appear to be influenced by broader perspectives which justify the involvement of HCGs, supporting arguments about the role of ‘ideas’ as change agents in policy networks (Richardson, 2000).

2. Our research had implications for theories of the democratic process. Although HCGs now participate alongside other interests, claims that this represents a move towards ‘discursive democracy’ are undermined because the government regulates access to, and shapes the agendas of, many decision making fora. Furthermore, in relation to ‘participatory governance’, Schmitter’s conditions have not been fully realised. There is still an imbalance of power between different interests and uncertainty about the ‘rules of the game’ among HCGs. Finally, our study of HCGs sheds light on their contribution as associations to the democratic process. HCGs generate social and political resources, and providing they are seen to actively engage with their members/clients, they are accepted as credible representatives. However, the capacity of many groups was limited due to a lack of resources and, especially at the national policy level, there were problems of overload and accusations of elitism. We argue that these are impediments to the development of associative democracy in this field.

3. Finally, our findings (see p.7-8) gave some support to theories that relate group characteristics and strategies to their policy influence (for example, Whiteley/Winyard and Grant). However, the former model was difficult to operationalise, more work is needed to improve ways of measuring these characteristics.
References
DOH (1998) A first class service quality in the new NHS. Wetherby: DOH.