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DRAFT

User Involvement in Health – values and conflicts in national policy 1974- 2004.

3,540 words

1 Brief description

The research will document developments in national policy in user involvement in healthcare from 1974-2004, in particular the values and tensions that underlie them. It will examine the rise of health consumer groups and the events that led to the abolition of community health councils (CHCs) and setting up of the Commission for Patient and Public Involvement in Health (CPPIH) by reviewing documentation and interviewing key actors in the events under examination.

The study develops further the research of the principal investigator, who has been a major player in the field of user involvement in health care as a practitioner and researcher. It will contribute to our understanding of theories and practice of community participation, in particular, the relationships of local involvement and national policy and decision-making.

2 Background

Since 1974 the UK has had a statutory arrangement for patient and public involvement in the NHS, with CHCs made up of local lay people commenting on service and planning issues and assisting individuals. The NHS was the first public service to introduce a formal local structure for participation. This indicated a reconstruction of the representation of the patient from passive beneficiary to an active agent.

The development of patient and public involvement was considered important in the 1970s for three reasons.

Counterbalancing professional interests -In the traditional view of the politics of health care, professional interests are seen to be dominant (Coulter 2002, Alford 1975). CHCs were set up in 1974 following scandals in long stay hospitals where the medical profession had failed to protect patients (Hogg 1999).

Mitigating the democratic deficit -Patient and public involvement was seen as a counter to the perceived democratic deficit in the NHS (Cooper et al, 1995). CHCs were set up at the same time as responsibility for managing community health services was transferred from local authorities to health authorities that were not democratically accountable. Theories of deliberative or participatory democracy also imply that if ordinary citizens are actively involved in decision-making, the quality of democracy will improve (Macpherson, 1973).

Decentralising decision-making – As costs were perceived to be escalating, decentralising decision making was seen as a way of sharing and legitimising decisions about which services should be provided and who should receive them (Kitzhaber, 1993). Local participation may shift public attention away from national responsibility for resource allocation. Different approaches were developed in the 1990s, such as citizen's juries, to enable citizen engagement particularly around choosing priorities or 'rationing' (Stewart et al, 1994)

The reasons outlined for setting up CHCs in 1974 are the reasons why patient and public involvement is still a major component of health policy. With the increasing salience of market mechanisms in health care, policy has supported regulation and emphasis on the individual consumer rather than collective approaches towards dealing with dominant professional interests. Setting up national audit and inspection bodies, such as the Audit Commission, Mental Health Act Commission and more recently the Healthcare Commission and National Patient Safety Agency, supported a managerial approach to clinical issues.

Initiatives have sought to strengthen individual patients within the NHS, such as the Patients Charter (DoH, 1991); training patients to become 'expert patients' (DoH, 2001) and giving them easier access to their records and copies of letters written by health professionals about them (DoH, 2003). 'Choice' is seen as a way of decentralising decision making. By giving people choice of hospital, NHS or private, it is thought that services will become more patient focussed.

During the 1990s there was a growth of health consumer groups (Hogg, 1999; Baggott et al, 2004). With market-based reforms, the voluntary sector took on a role in providing health and social care under contracts. However, as contracts are likely to be available only for activities that support government policy (Baggott et al, 2004), it potentially threatens the independence of the voluntary sector and undermines their traditional advocacy role. Other social movements developed among users, in particular users of mental health services (Barnes & Bowl, 2001).

Local Voices, published by the Department of Health in 1992, recommended community involvement to help the NHS '*establish priorities, develop service specifications and monitor services'*. This initiative of the Conservative Government brought community activists, feminists and socialists together. There was agreement about forms of democracy that used the language of empowerment and acknowledged group membership and thereby gave considerable scope to communities organising themselves, for example, ethnic minority groups. It gave opportunities for activists within the voluntary sector to see themselves as important stakeholders. It also encouraged the development of community development approaches to local participation as a way of reaching marginalized groups (O'Keefe & Hogg, 1999) and in building in new ways of involving communities in health impact assessment (O'Keefe & Scott-Samuel, 2002).

From 1974 until abolition in 2003 the role and powers of CHCs remained almost unchanged. There were criticisms of how they interpreted their role and the variations in the activities and quality of services they provided (Hogg, 1994). However, there has been little primary research on CHCs at local or national levels since the 1970s or independent evaluation of their effectiveness. By the 1990s there was support within CHCs themselves for reform (Hogg, 1996; Hutton, 2000; Gerrard, 2005).

In 2000 the decision to abolish community health councils was announced in the NHS Plan with no warning (Gerrard, 2005). The stated policy objective was to strengthen and mainstream patient and public involvement (Cm 4818, 2000). There was opposition to the proposal to abolish rather than reform

CHCs, in particular from the voluntary sector. Consultation and transparency are the key features for effective patient and public involvement and many had difficulty understanding why decisions were made without consultation. The Health and Social Care Act 2002 set up patient forums and the Commission for Patient and Public Involvement (CPPIH) as well as Overview and Scrutiny Committees within local authorities to scrutinise NHS services. It imposed a duty to consult on NHS bodies (Section 11 Health and Social Care Act 2002).

The initial intention was to have a transition from CHCs to the new forums and a Transition Advisory Board was set up with major stakeholders represented. However, in spite of this there were no arrangements for transition for CHC members, staff or other resources and a fresh start was made by the CPPIH.

There were no plans initially to replace the national association of CHCs. A report funded by the Department of Health argued that a national infrastructure was needed to support local arrangements and avoid the inconsistencies of CHCs (Hogg and Graham, 2001). This was accepted by the Government with the decision to set up the Commission for Patient and Public Involvement in Health. However, after 18 months the Government announced the abolition of the CPPIH as part of the review of arms length bodies. Again this decision was made without consultation with patient or public interest groups or patients forums.

No evaluation or review has been undertaken of CPPIH or Forums. The stated reason for the decision to abolish CPPIH after 18 months was to transfer more resources to patient and public involvement forums at local level. There was no public outcry as there had been for CHCs. National stakeholders were angered by the decision, but felt that there were major flaws in the legislation and how it had been implemented (Hogg, 2004). There were concerns about the capacity and effectiveness of the Forums (Lewis, 2005).

The opportunity to bring NHS arrangements into wider involvement arrangements was not taken. While the Government was considering arrangements to replace CHCs, some urged that patient and public involvement should be seen as part of the wider citizenship.

3 Reasons for undertaking the research

The arrangements for patient and public involvement are at a crossroads and this study may help an understanding of the issues and enable lessons to be learnt. Throughout the history of CHCs and public involvement in the NHS there have been tensions and a lack of clarity about the values underpinning Government policies and what involvement should achieve. Behind these policy trends there are implicit but often conflicting values between politicians, civil servants, voluntary organisations and community activists. These need to be explored in order to understand better how user involvement impacts on the effectiveness and equity of outcomes for patients and communities.

Tensions and conflicts include the following:

- The relationship of local and national 'voices' for patients and public. There has been government support for local involvement, but

ambivalence about a 'voice' at national level. Patient and Public Involvement Forums have no mechanism for presenting their experiences and findings at national level. Hogg has argued that a national infrastructure is needed in order to support local voluntary groups and enable them to take part in policy discussions (Hogg and Graham, 2001; Hogg, 1999).

- The role of lay knowledge and the value given to contributions of the patient as consumer and collective/ proxy representations through voluntary groups. There is increasing acceptance that the nature and significance of lay knowledge is important to provide an understanding of contemporary health problems (Popay and Williams, 1996). Elliot and Williams (2003) have explored the complex relationship between expert evidence, political judgement and decision making. Public involvement can involve critical questioning of a kind that can challenge experts' claims to privileged understanding.

- The relationship between patient and public involvement in the NHS with other public services. Debates about arrangements for the NHS are largely carried out outside the wider debates on citizenship and community engagement. At the same time that the NHS is looking towards individual rather than collective voices, in other parts of government, such as the Home Office's Active Communities Unit, there is interest in citizenship and a more holistic approach to involvement and community empowerment by promoting 'social capital', encouraging social cohesion in communities to facilitate coordination and cooperation for mutual benefit (Health Development Agency, 2004).

This research is timely for three reasons:

- With increased interest in civil society and active communities, it is important to understand the processes that have facilitated and blocked the development of social capital and enhance the democratic process.

- Since 2002 expenditure on patient and public involvement in the NHS has increased. Significant resources have been and continue to be put into patient and public involvement over the last 30 years. However, there are serious doubts about whether this is leading to more patient focussed health services.

- With the abolition of CPPIH there is uncertainty about the future of Forums. It is important to learn from the experiences of CHCs and the years of transition to enable those involved at policy and practitioner level to learn and promote effective interventions.

4 Aims and objectives of the research

The research aims to better understand the interrelationships of patient and public involvement in public policy at national and local levels. It will look at events at national level that led to the abolition of community health councils and the implications for local patient and public engagement.

The objectives are to:

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- Document the events that led to the abolition of CHCs and its national body, the Association of CHCS for England and Wales (ACHCEW).

- Document the transitional arrangements leading up to the abolition and setting up of the CPPIH.

- Identify the debates around the relationships of national and local arrangements for public policy.

- Provide empirical evidence about the inter-relationships of patient and public involvement at national and local levels.

- Analyse these findings within the framework of theories of public participation and community engagement.

5 Potential impacts of the research

The research will contribute to current policy and provide an evidence base for the development of patient and public involvement that will be relevant to policy makers and practitioners involved in the NHS, as well as patients and the public. The research will:

- Identify barriers to enabling local views to be heard at national level

- Explore the conceptual terrain that underlies debate, struggle and conflict about patient and public involvement.

- Explore the complexity of bringing about change in health organisations (McNulty and Ferlie, 2002).

6 Methods

6.1 Literature review

A scoping review will be undertaken on the conceptual framework and value based framework and value based debates underpinning the research, from the 1990s to date. Literature and publications on involvement at national level will be reviewed, in particular on community health councils and the work of ACHCEW. This will take account of the work, inter alia, of Baggott, Allsop and Jones on health consumer groups and the policy process.

6.2 Data Collection

Documentation

This will include looking at files and documents from

- The archives of the ACHCEW, held at Oxford Brookes University, the Wellcome Trust and London Metropolitan University.

- Documents from the Department of Health, Transition Advisory Board and the CPPIH.

Most of these documents are publicly available, but access will be requested where necessary for other files under the Freedom of Information Act. The research will have access to tapes of interviews undertaken with politicians and civil servants from 1974 –2000 for a history of CHCs written by Gerrard (2005).

Interviews

Interviews will be undertaken with key figures in the transition. Up to 15 interviews will be undertaken. Informants will include:

- Department of Health 2-3 civil servants and ex civil servants involved in the key periods.
- Two or three key members of the Transition Advisory Board
- Two or three individuals from national voluntary organisations.
- Three former directors of ACHCEW covering the period of the 2000-2003.
- Two or three 'opinion' leaders, not directly involved but observing the process

The interviews will be based on questionnaires looking at the chronology of events and informants' views on the developments. It is envisaged that the interviews will last ¾ -1 hour. The interviews will be recorded (with consent) and detailed notes taken at the interview. Notes will be written up and a copy sent to the informant to check for accuracy. Theory based themes will be identified within each category of stakeholder to provide a basis for coding and analysis.

While access is not guaranteed, the research proposals have been discussed with many of the informants and it is expected that they will agree to be interviewed. The Principal Investigator is aware how important it is to ensure that this does not inhibit or influence what the informants report.

6.3   Data analysis

The information will be collated and analysed. The interviews will be recorded and extensive notes taken and provided to the informant to ensure that they reflect their recollections accurately. These will be analysed for content and common themes.

Following the analysis of the interviews and literature review, additional interviews may be undertaken to provide a check on the interpretation of the data (triangulation).

7 Ethical issues

No ethical issues have been identified. Information will not be attributed to individual informants, except with explicit written consent. The research ethics committee at the London Metropolitan University will be consulted and if necessary, ethical approval obtained.

8 The Researchers

The Principal Investigator, Christine Hogg, has worked in the area of user involvement and community development for 30 years. She has written extensively about community health councils and was project manager of the Transition Advisory Board set up by the DoH to advise on the transition form CHCs to the CPPIH. She has made major contributions to the field, including

the development of a typology for characterising individuals who take part in involvement activities and collective input where individuals become involved in single issue pressure groups or public interest groups (Hogg, 1999). This work has been widely used by other researchers including Baggott et al (2004).

Christine Hogg was a member of the Advisory Group for the Department of Health's research programme, Health in Partnership (HIP). A summary of the results of the research was published in 2004 (Patient and Public Involvement in Health – The evidence for Policy Implementation. She was also on the project advisory group for the research undertaken by de Montfort University on Health Consumer Groups and the Policy Process (ESRC grant number R000237888).

Eileen O'Keefe's research includes a focus on user involvement in the management of community health services, participatory strategies in health impact assessment and community development-based research methods in health and social care needs assessments with African migrant communities in the UK

9 Time table

The research project will spread over two years. This is to enable access to be obtained under the Freedom of Information Act if necessary.

Preparation and design - Months 1 - 3

Literature review, design of questionnaires, identifying informants and setting up interviews

Documentation collection and interviews – Months 3-14

Reading documentation and archives, applications for access to information under the Access to Information Act.

Carrying out and writing up interviews

Analysis – Months 12-18

Writing up the findings – Months 17 –24

10   Dissemination

The research will be disseminated in the following ways:

- The research will be published as a report. Copies of the report and executive summary will be circulated to key policy makers and practitioners at national and local level.

- Papers will be submitted for publication in peer-reviewed journals, such as Social Science and Medicine.

- Articles will be produced for wider practitioner and public understanding such as the Health Service Journal and Health Matters. – drawing out the lessons for strengthening patient and public involvement.

- A seminar with respondents and stakeholders will be held at the London Metropolitan University to present the findings and discuss their implications.

11   User engagement

The proposal was discussed during the design with several key actors involved in the events that will be studied.

An advisory group comprising academics, people involved in patient and public involvement, will be set up to comment on and help steer the direction of the research.

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