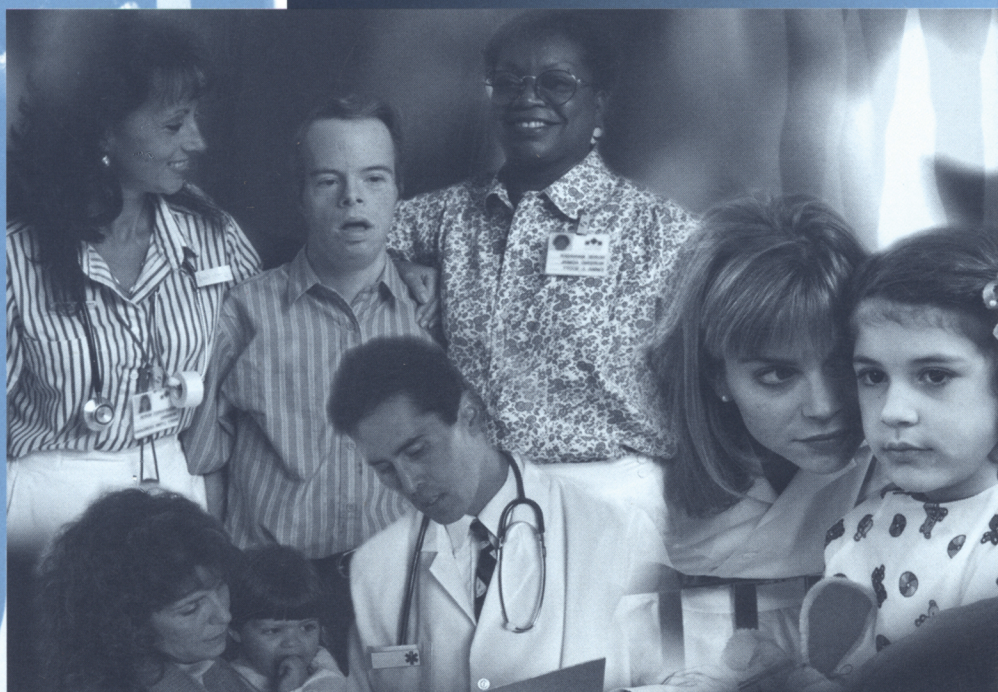


# Patients, Power & Politics

From Patients to Citizens



Christine Hogg

## PATIENTS, POWER & POLITICS



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*From Patients to Citizens*

CHRISTINE HOGG



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To my parents, who showed me the value of being  
a non-conformist





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## INTRODUCTION

Patients, of course, have roles assigned to them within the scripts of the modern medical drama. Depending on who is doing the analysis or the accountancy, patients appear as demand, costs and benefits, input or output, voters, clients or consumers of services, bearers of rights or pursuers of litigation, the 'tib' and fib' in bed 15, frozen sperm in the deep freeze, diseased bodies or clinical material, points on a graph or numbers crunched on a software programme.

Roy Porter, *Greatest Benefit to Mankind* (1997)

History is written by the victors. What we know about English history after 1066 relied on the versions written or sponsored by the French conquerors. Until recently the history of America, Australia and Africa was the history of the white settlers. There is an alternative story, generally suppressed: the story of the English under the Normans and of the native Americans, Australians and Africans.

Similarly, the analysis of current health issues is based on the experiences of people who are in a position to get their views heard: politicians, clinicians, managers, economists and drug companies. Political debates and decisions on health policy are based on their analyses of the problems and the negotiations, disputes and alliances between them. In 1997 the White Paper, *The New NHS – Modern, Dependable NHS*, stated: 'decisions about how to best use resources for patient care are best made by those who treat patients – and this principle is at the heart of the proposals' (Department of Health, 1997b: 7). Certainly, people who provide services need to be involved in making decisions, but so do the people affected by these decisions – health service users. The interests of the public and users of health care are evoked to support particular interests in these negotiations, sometimes by professionals, sometimes by managers and sometimes by the pharmaceutical companies. Health care professionals, managers and pharmaceutical companies appeal to the public to support them to achieve the health care system they are aiming for. Doctors argue for their clinical freedom to do their best for patients and for more resources for their services. Managers talk of rationalizing services based

on local needs, patient satisfaction and consulting with users – even of ‘controlling’ patient expectations. Meanwhile drug companies, who have for a long time targeted professionals to increase their sales, now target the public directly in order to raise their expectations and create consumer demand for their products. However, the public, as citizens or as users, have rarely been directly involved, except where their views coincide with those of the more powerful.

There are major upheavals going on in how health care is provided, and more and more is expected of health service users and those who represent their interests. Changes in the relative position of health service users have been rapid – after all, until the Medicines Act was passed in 1968 patients did not have the right to know the names of drugs prescribed for them. Not surprising then that there is confusion over the appropriate role for people who use health services. There is no word that everyone may comfortably use to describe the individual receiver of health or social care. Patient, client, customer, consumer and user are all used and each has different implications. The word ‘patient’ implies a compliance and passivity that reflects but also reinforces the unequal power between patient and professional; it also excludes carers, people who may use health services in the future and recipients of social care, normally called ‘clients’. ‘Consumer’ or ‘customer’ is often used as this fits in with the business ethos that has been introduced into health care, but people receiving health care do not see themselves as consumers or customers and rarely have the choice that this implies. ‘User’ is a wider term that can include patients, potential patients, clients and carers, but it does not reflect the intimacy of the relationship that often exists between the receiver and giver of care or the unequal power balance between them. In this book individuals receiving health care are called ‘patients’, while the term ‘user’ includes everyone who uses or may use services in future, either as patients or carers.

This book looks at health care and public health from the perspective of users and citizens. ‘Patients’ have traditionally been expected to rely on experts for advice and be ‘compliant’. However, the imbalance in the relationship between the patient and clinician raises basic ethical issues. Professionals have used incentives and sanctions to encourage people to comply with treatment, when they consider it to be in their ‘best interests’ or those of society. There have been changes, with patients being encouraged to see themselves as consumers with rights and, more recently, as ‘partners’ with responsibilities as well. However, there are still tensions and contradictions in the professional–patient relationship between paternalism and the individual’s right to autonomy. There are problems in gaining access to independent information which would enable people to exercise their rights and responsibilities (Chapter 2).

The boundaries between health and illness are constantly shifting. Conditions previously seen as normal – such as being short, going through the menopause or even having a baby – have been redefined as

'problems' for medical science for which there are bio-medical solutions. In immunization and screening programmes, people are persuaded to use health services for which they may not see the need, either for their own good or for the public good. We cannot assume that we are healthy because we do not feel ill. Again there are tensions and conflicts between the individual's right to autonomy, the belief that the 'doctor knows best', and the good of society (Chapter 3).

Medicine is always looking forward hopefully, in search of better treatments and cures. Research policy is of great interest to the public since today's research determines the sort of treatments and services that will be available tomorrow. However, research is increasingly funded by pharmaceutical companies to meet their commercial needs. One result of this trend may be that studies provide evidence for the benefits but not the disadvantages of drugs and there will be little research into the effectiveness of other therapeutic approaches. Although research is carried out for the benefit of patients, they are generally excluded except as the subjects of research. Excluding users from research policy and design has meant that much health research is of poor quality and irrelevant to the experiences of patients and carers (Chapter 4).

While helping to strengthen the position of the individual user is important, there are many issues that can only be tackled by people as part of local communities and as citizens. Here again there is confusion about how users and citizens can contribute to health policy. At a local level, there is no democratic accountability in the health service. Though managers are expected to consult the public, it is up to individual managers how much notice they take of their views. However, there are some examples that show how even disadvantaged communities may be involved, using methods that empower them (Chapter 5).

Citizens elect governments which make policies that affect health. However, it is not generally possible to use votes to support particular health policies – they come with other policies as a job lot. Professionals, commercial interests and users each have different interests that sometimes conflict and sometimes overlap. Though there may be alliances between all those interest groups, professional and commercial interests are in a better position to influence government since it needs their co-operation to implement policies. Voluntary organizations are, in comparison, poorly funded and unco-ordinated. Often funding depends on the alliances they make with professional and commercial interests and the support they give to government policies. Voluntary organizations are increasingly accepting sponsorship from commercial interests which may compromise their independence and ability to speak on behalf of users (Chapter 6).

National lobbying is no longer enough. More and more policies that affect health and the way that health services are organized are made by international bodies, such as the European Union, the World Health Organization, the World Bank and the World Trade Organization. Often

decisions that affect health are made as part of negotiations about trade and tariffs, where health is a minor consideration. Commercial interests operate on a transnational level and it is important that there is a strong independent public interest and consumer movement to counterbalance commercial interests and to monitor their activities (Chapter 7).

In the midst of the upheavals in health services and public health, there is no clear vision of what we are trying to achieve. Current debates about rationing, scientific developments, regulation, audit, effectiveness and consumerism sometimes appear to be dominated by assumptions that need to be questioned. For example, people tend to assume that medicine is based in science and that any new technique or drug will be an improvement. In reality most health care is about chronic conditions that people live with for many years, and, in spite of greater scientific knowledge, diagnoses are uncertain and treatments unpredictable. Then there are newer assumptions that originate from an economist's view of health care: that demand for health care is infinite and that patients are consumers. In fact, 'demand' is created by professional and commercial interests as well as by patients. Furthermore, patients do not have the choice or information that is required to be true 'consumers' or even 'partners' (Chapter 8).

Developing health policy and health services that are user-centred requires action to strengthen the relative position of users and citizens at all levels. A user-centred health service would recognize that when people have health problems they do not just have clinical needs, but emotional, psychological, social and financial needs. The relationship between professionals and users would be rooted in respect for the autonomy of the individual. To achieve this, users need additional rights and responsibilities in the context of their position as citizens. They need access to independent information as well as advice to help them use this information effectively. Investment needs to be made to enable groups who represent users to participate as equals at national and international levels (Chapter 9).

In 1997 the government announced a ten-year plan for the NHS, emphasizing the importance of building partnerships with users, improving clinical effectiveness and governance, and addressing accountability. The test for this commitment will be whether users are allowed to speak for themselves in these changes or whether others will continue to speak for them.