Patients, Power & Politics

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.

PART I
THE INDIVIDUAL

2

PATIENTS

> Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of the other place.
>
> Susan Sontag, *Illness as Metaphor*, (1991)

Everyone of us is at some time or another a patient. Most of the time we look after our own health, perhaps seeking information or advice from family and friends, magazines, or the pharmacist. Sometimes we have to ask for medical help and, when we do, we are 'patients' for the short time we are in contact with health services. Even then it is not primarily how we see ourselves. We are playing a role: the role of patient.

This chapter considers the changing, and often contradictory, expectations that underlie the rights and responsibilities of patients and professionals. There are different models that have been used to describe this relationship. In the traditional model of paternalism, professionals are deemed to know best and patients are required to trust them. Consumerism goes to the other extreme: individuals are in charge of getting the 'best buy' for their own health care and they cannot take the trustworthiness of professionals for granted. The partnership model sees the giving and receiving of health care as a negotiation agreed between the parties. Finally, there is the model of autonomy that puts respect for the individual first and recognizes the different perspectives of patients and professionals. Each model has its strengths and weaknesses for both users and professionals.

Who are 'patients'?

'Patients' are just people with particular health problems who may be taking medicines or receiving treatment. Generalizing about 'patients' can be misleading and ignore the great diversity in individuals' attitudes to health and expectations of health care. Patients and carers want different things from health services. Relationships with, and expectations of, health professionals will also be different according to who you are – education, social class, income, ethnic origin and lifestyle will all have influence on an individual's perspective. Some people, often because of barriers of language, race or disability, have problems in using health services and may receive a poor service.

At each stage in life people have a different attitude to health and want different things from health care. Babies and young children can become seriously sick very quickly, and until recently many babies and young children died in their first year. Children, particularly toddlers, are prone to accidents, especially where they live in poor housing and do not have safe areas to play and explore. Parents are often anxious about their children's health and make demands on health services.

Adolescence is a time of change and growing into an adult body is often disturbing and stressful. Young people may be concerned about their relationships, their physical appearance, their weight, puberty, acne and their sexuality. They are also more likely to take risks – such as experimenting with drugs, cars and motor cycles. Young people may be reluctant to talk about personal matters to a doctor who knows their family or use a service where staff seem judgemental.

Women are major users of health services. Women visit their GPs almost twice as often as men, consume more drugs and medicines than men, occupy acute hospital beds slightly more than men and are admitted to psychiatric units more than men (Kane, 1991). Having a baby used to be a risky business but it is now safer, both for mother and for baby. However, there is conflict between midwives, obstetricians and women about the best place to have a baby and the best way to manage labour; in particular, a stormy debate centres around how far nature should be allowed to run its course and when and how far professionals should intervene. Some writers from a feminist perspective see the way health care is provided to women as a way in which they are controlled and exploited (P. Foster, 1995).

Men are likely to die earlier than women. They are less likely to ask for help and, when they do, they are likely to be more seriously ill. Howard (1996) found that, when young, men felt that it was not 'macho' to fuss about their health; however, when they got older they were still reluctant to go to the doctor. Men had a low level of knowledge about male cancers, found it difficult to talk about health problems and were embarrassed by intimate examinations.

Finally, people are living longer, but with more disabling conditions and with a poorer quality of life. The extra years of life that have been

achieved are extra years of disability, not of health (Dunnell, 1995).This puts demands on family and neighbours who look after older people. In old age people may live alone and be socially isolated; partners may have died and children moved away. Policies to develop primary health care and community care mean that people are now cared for in the community when before they would have been in hospital, whether as an in-patient after surgery or segregated in a large institution because of mental health problems.

At some point in our lives most of us are faced with the need to care for someone who is ill or disabled. Six million people in Britain take responsibility for the care of a friend or relative. Becoming a carer often leads to a reduction of income if you have to give up work. It may also mean being confined to the house if the person you look after cannot be left alone. The trend towards providing services in the community has meant that family and friends are under greater pressure to become carers. However, these pressures have coincided with other social trends such as more women working outside the home and having less time to care for elderly relatives, and more people living alone and choosing to do so.

Compliance and patients' responsibilities

By tradition, doctors are expected to be experts, adhere to high ethical standards and not to make mistakes. In return for their expertise and ethical standards, patients are expected to trust them and comply with their advice. Sir Raymond Hoffenberg puts the case for clinical freedom and paternalism:

> My concern to preserve the central role of the doctor in clinical decisions, moral or otherwise, is not a reflexion of professional self-interest or a wish to perpetuate professional sovereignty. It is based on my belief that such decisions must rest on a proper knowledge of all the medical consequences of each option, physical and psychological, qualitative as well as quantitative; that they must be made with critical and professional detachment; and that they should be conveyed to and discussed with the patient and the family with compassion and sensitivity. (1987: 72)

However, often people do not follow the instructions they are given or take their medicines as instructed. One in five patients do not even get as far as the pharmacy to collect the medicines that have been prescribed for them. Half of patients who suffer from chronic diseases do not take their medication in fully therapeutic doses (Royal Pharmaceutical Society of Great Britain, 1997). Sometimes there are serious consequences if you do not take medicines as instructed. For example, one study showed that 18 per cent of renal transplant patients did not follow instructions in taking their medication. Ninety-one per cent of these patients experienced organ rejection or died, while only 18 per cent of patients who adhered to the

prescribed regimen experienced organ rejection or died (Rovelli et al., 1989). Non-compliance also means that side effects of drugs may be under-reported and research results may be based on inaccurate information.

From Compliance to Concordance, a report published in 1997 by the Royal Pharmaceutical Society of Great Britain, looked at how patients could be persuaded to take their medicines. It seemed to assume that patients had no rational reasons for non-compliance, but that their irrational reasons needed to be understood in order to deal with the problem:

> Researchers suggest . . . that the most salient and prevalent influences on medicine-taking are the beliefs that people hold about their medication and about medicine in general. These beliefs are often at variance with the best evidence from medical science and consequently receive scant, if any, attention from the prescriber. Yet they are firmly rooted in the personal and family and cultural experiences of us all. For the prescriber simply to reaffirm the views of medical science and to dismiss or ignore these beliefs, is to fail to prescribe effectively. (1997: 7)

The report was prepared by an advisory group of professionals, academics and representatives of a pharmaceutical company but had no representative of users or voluntary organizations.

However, there are many reasons why people do not take professional advice or look elsewhere for help and some of them are rational (Donovan and Blake, 1992). They may not admit that they are not following advice for fear of alienating professionals and being labelled as 'difficult'. Some people do not comply because of the nature of their illness, for example people with manic depression are most likely to stop taking medication as they move from depression to mania, which is when they need it. Some people may not collect medicines prescribed for them because they cannot afford the prescription charge or because they wanted some other kind of help when they went to the doctor.

Sometimes people do not take medicines because they perceive the cause of the problem and its solutions differently from professionals, such as people who are anxious and stressed but do not feel that drugs will help solve their problems. Some people who have received mental health care see themselves as passive recipients of coercive treatment and as survivors of the system, where intervention has created problems for them rather than helped them. A study found that mental health service users wanted a more active role in treatment and in planning services but that professionals found this threatening (Glenister, 1994). Many surveys have found that talking therapies, counselling and psychotherapy are rated more highly than other therapies. However, they were often not offered to people with severe conditions or to black and Asian people. People with mental health problems want more attention paid to helping them to manage their mental illness and to live with it. People find aromatherapy, art and creative therapies help them cope (Mental Health Foundation, 1997).

People may stop 'complying' when they find that orthodox medicine does not help them. Some people with chronic pain may feel like the 'failures' of modern medicine. They may see the whole range of specialists – orthopaedics, neurology, gynaecology, psychiatry and physical medicine – and receive many treatments, but still not get better. Orthodox services often only offer painkillers, which have side effects and become less and less effective over time. So people look for alternative ways of living with their pain. Some join self-help groups which provide opportunities to learn things from each other which can only be gained from people who have had the same or similar experiences.

For some patients, compliance with orthodoxy is the price they may have to pay for acceptance by professionals. If physical causes cannot be found for symptoms, the illness may be labelled 'psychosomatic' and the person transferred from mainstream medicine to psychiatry. People resent this if they feel that there is a physical cause for their illness. Some people may be considered to have adopted the 'sick role'. The 'sick role' is a concept developed by sociologist Talcott Parsons (1970). People occupying the sick role are not held responsible for their incapacity and are exempted from their usual obligations. However, in return, they must want to get well and seek and follow medical advice. If they do not behave in this way, they may lose the right to be thought of as sick. If they reject medical advice – based on their experience of what helps them – they may be dismissed as not really being as ill as they say they are. This can be very alienating and humiliating for people who do not fit easily into conventional diagnostic categories.

Though the language may change from 'compliance' to 'concordance', the pressures on patients may remain. Incentives for patients are generally seen as giving them better information and communicating with them better so that they understand the importance of following instructions. Sharing information may increase compliance but also, at times, may increase dissent. If people are aware of the risks they may not wish to take them, as, for example, seems to be the case in childhood immunization programmes (Chapter 3). Sometimes information is not enough and other incentives may be used where compliance is in the public interest. For example, if patients with tuberculosis (TB) do not comply with their medical treatment, they may pass the infection on to other people. In New York payment is made to encourage homeless people with TB to come for weekly treatments. Financial incentives are most likely to be effective for TB, antenatal and post-natal care, treatment for alcohol and drug abuse, and anti-rejection therapy and weight loss (Togerson and Giuffrida, 1997). There is, however, always the risk that people will take up the activity in order to qualify for the incentive to give it up; apparently some Russian prisoners deliberately infected themselves with TB in order to get into hospitals with better food and conditions.

Consent to treatment

When people seek medical help, this does not mean that they want to pass over all the responsibility to professionals, though they may want to share the responsibility. In all events, patients take the risks and have to live with the consequences of decisions about treatment. For many conditions diagnosis is often uncertain or the effects of treatment unpredictable. McPherson (1990) has argued that where this is the case, such as for prostate cancer, patients' preferences are very important in determining what treatment is given.

However, there is still some resistance to providing information to patients. In the past, when doctors had few effective medicines or treatments, they built up patients' confidence in their skills through magic. The power of magic depends on the audience not understanding how the effect is achieved: the audience does not need to know how the rabbit appears from the 'empty' hat. Clinicians relied on the placebo effect – that is, people's positive responses, at least initially, to almost any treatment as long as they believe in the treatment and trust the professional. The benefit may have nothing to do with the treatment itself and almost any treatment is as likely to be effective. When doctors relied on 'magic' for results, patients did not need information. From the mid-1950s doctors came to be seen more as scientists or technicians. For technical solutions, you also do not need to know how the part in your body (or your car) is repaired. You just need to know that it can be repaired. And so the resistance to sharing information has continued, though this is changing.

In 1991 the Patient's Charter gave people the right to have any proposed treatment, including any risks involved in that treatment and any alternatives, clearly explained to them before they decided whether to agree to it (Department of Health, 1991a). Consent has two different functions. One function is legal – without consent clinicians may be committing assault or trespass when they touch their patient. The idea that a person's bodily integrity should be protected from unauthorized touching or invasion has been part of English law since the Middle Ages. The second function is clinical and aims to secure the patient's trust and co-operation (Montgomery, 1997).

In spite of this, English law does not require that consent be fully informed. In general, the courts do not define patients' rights by what is adequate information to make a decision but by whether other reputable practitioners would have done the same. This was established in 1985 after Anne Sidaway was left partially paralysed as a result of an operation on her spine. This was not negligence but she sued because she was not told that the operation had a one to two per cent chance of causing paralysis. She lost the case because expert witnesses testified that some neurosurgeons would not have mentioned the risk of paralysis under similar circumstances. However, in the late 1990s the Senate of Surgery of

Great Britain and Ireland (1997) called for surgeons to go beyond what was legally required and give the information that a reasonable person would want to know.

The principle of informed consent recognizes that patients have the right to give their consent to treatment on the basis of full information. This was recognized as important in relation to research as part of the judgement at the Nuremberg trials after the Second World War and was later extended to clinical practice. Caroline Faulder (1985) has outlined five principles that underlie informed consent:

1 Autonomy – the individual's freedom to decide his or her own goals and to act according to those goals. This demands a respect for individuals even if the clinician disagrees with their views or actions.
2 Veracity – trust in doctors by patients must be based on truth and honesty.
3 Justice – both parties have a duty to treat each other justly, whether the doctor–patient relationship is seen as a contract, covenant or a partnership.
4 No harm – the doctor has a duty to do no harm.
5 Best interests – the doctor has a duty to act in the best interests of the patient.

The last two principles are used to justify refusing patients the right to give their informed consent. Each doctor has the duty to do what he or she sees to be in the best interests of the patient, even if the patient disagrees.

Overriding informed consent

Sometimes consent may be overridden. For example, the interests of research or teaching were at one time seen to override the right of patients to give informed consent, particularly where professionals do not see any harm in the procedure and consent might be refused. An example of this was allowing medical students to carry out internal vaginal examinations on women who were anaesthetized for an unrelated condition. The public were first made aware of this practice in November 1983 and were outraged. The practice was defended by medical schools as it was argued that this was the only way that medical students could get experience of internal examinations. This was, however, assault; and the implication was that the unconscious patient has less rights than a conscious person: if you are not aware that your rights have been infringed, it does not matter.

Some professionals are reluctant to accept the patient's right to refuse treatment because they believe that they know best. The doctor's duty to do 'good' is seen as more important than a patient's autonomy and rights over their own body. In the 1980s there were increasing numbers of interventions in maternity care ordered by the courts in the USA and, since 1992, in the UK. High Court hearings in obstetric cases do not always

follow due process or comply with the principles of natural justice. Hearings are held in an emergency, and the women concerned are often not represented and may even be sedated at the time of the hearing. Even if they are represented, they may not have adequate opportunity to brief their advocate or obtain alternative clinical advice. The court is expected to make difficult judgements about the likely clinical outcome of an intervention, without adequate notice, in a clinical area where clinicians disagree about when intervention is necessary. In 1992 a High Court ruled that a woman should have a Caesarean section in order to protect the life of the foetus, though she had refused this on religious grounds. This was a curious ruling since it put the interests of the foetus before those of the woman, even though the foetus has no legal rights until it is born alive. In this case the Caesarean was performed but the baby died (Rock, 1995). In 1997 a Court of Appeal considered an emergency case of a woman with a needle phobia. After initially agreeing to a Caesarean, she changed her mind and refused when staff tried to give her an injection. She lost her case on the grounds that her needle phobia made her temporarily incompetent. However, the ruling upheld the woman's right to refuse intervention:

> The law is, in our judgement, clear that a competent woman who has the capacity to decide, may for religious reasons, other reasons, or for no reasons at all choose not to have medical intervention, even though, as we have already stated, the consequence may be the death or serious handicap of the child she bears or her own death. (Beech, 1997)

It remains to be seen if this is the last word.

Compliance with clinical treatment is seen as important for pregnant women to protect the health of the foetus. In some US states the foetus has rights; in other countries, as in the UK, the foetus only has rights when it is born alive. In the USA there are increasing numbers of prosecutions against women who have used drugs or alcohol during pregnancy which can result in babies being born addicted and needing to be withdrawn from drugs. Such attitudes may mean that some women try to avoid the health system, whereas, in fact, they need more antenatal care not less for their own and their baby's health. If drinking and using drugs in pregnancy are criminalized, what about damage caused by smoking or eating inadequate or inappropriate food? Criminalizing women with problems may deal with public anger, but it does not help the woman or baby.

In 1992 a 16-year-old girl with anorexia nervosa was made a ward of the court so that she could be force-fed to keep her alive. The High Court ruled that 16- and 17-year-olds have the right to consent to treatment, but not to refuse treatment, undermining established medical practice and the rights of young people. However, she could have been compulsorily treated under a section of the Mental Health Act 1983 (Hodgkin, 1993). In