

Patient partnership is not a magic formula

EDITOR—Partnership with patients in sharing medical decisions is an idea of paramount civil importance for modern health systems, as raised in correspondence in the *eBMJ*.¹ Partnership stems, on the one hand, from the reasons underlying the right to informed consent to medical practices and the humanisation of the approach to patients and, on the other, from the development of advocacy in health promotion and self determination of civil rights. Such a profound innovation increases the complexity of and turbulence in organisations and has cost implications.

Firstly, the medical profession needs to be trained in this aspect. Education should not be restricted to questioning current medical practices to improve human contact with patients but should embrace specific epidemiological knowledge on risks and outcomes as well as evidence based medicine. These disciplines should, despite their limits, play a pivotal part since they hold the information everyone needs to formulate an opinion.

Secondly, all services will clearly become more costly since doctors will require more time for each patient. In some cases time will increase only minimally; in others it will increase considerably. The time devoted to patients will in no case fall.

Thirdly, the breakdown of barriers between patients and doctors will remove inhibition and increase the possibility of legal wrangling.

Fourthly, increased interplay between the roles of doctor and patient will probably unveil the limits of medicine, revealing that it is not an exact science as believed by most of the general population. The crude impact of predictive medicine may drive more people towards alternative or supernatural practices.

Fifthly, boundaries, including legal limits, need to be outlined for the role of patients' relatives. Special attention should be paid to patients who are unable to communicate competently, who are medical or surgical emergencies, and who are psychiatric cases.

Lastly, as outlined above, cultural change, fostered by health and political institutions through complex educational strategies, is required.

Balancing the interactions between doctors and patients is a noble and pressing idea. But partnership is not a magic formula. The ground is not quite ready. Massive long term financial and cultural investment is required to realise this opportunity fully—

but on the understanding that all patients have the right to delegate decisions to their doctor when this is the most comfortable solution for them.

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¹ Web extra. Patients as partners? *eBMJ* 1999;318 www.bmj.com/cgi/content/full/318/7186DC1 (accessed 1 September 1999).

Patient participation cannot guarantee empowerment

EDITOR—Much has been written about the importance of participation in community health projects and the benefits of participatory processes for patients and the local population generally. Becoming an equal partner in the decisions that affect the health of individual people and communities is the ideal constantly trumpeted by many professionals in health and social care, as well as being raised in the *eBMJ*.¹ But how much of this is simply utopianism?

Being a partner must mean sharing in the power to make decisions. But how many health professionals are willing or able to share their knowledge and skills, let alone enable a person to decide the next course of action? Regardless of the genuine intention to help and empower people, the reality of the participatory processes is often contradictory to the empowering principle. At times, middle class values are imposed and utopian dreams of progress associated with the idea of equality for all are promoted. Participation is often openly encouraged, but the ladder of participation has several rungs and people are frequently on the lowest—consultation only.

Being a partner may mean your voice is heard, but is it heeded? Does the credibility and legitimacy afforded to healthcare professionals (those in power) encourage people to acquiesce and so in effect perpetuate the imbalance of power? The bureaucracy of the health service forms a strong barrier to effective participation, and the needs and career aspirations of many professionals tend to prevent the shift in power needed if patients and the general public are to take some control over their health care and become true partners.

Notions of participation are socially constructed and can mean anything from

the giving of information to a complete shift in power. I believe that a complete shift in power is almost impossible in today's society, which places great emphasis on professionalism, progress, and universal moral principles and has the capacity to enforce the status quo through its structures. These structures are both produced and reproduced by the people.

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¹ Web extra. Patients as partners? *eBMJ* 1999;318 www.bmj.com/cgi/content/full/318/7186DC1 (accessed 1 September 1999).

Patient-partners may be political correctness gone too far

EDITOR—A partner is “one who shares equally with another,” according to the New Collins dictionary.

To have a patient-partner is a bit of an oxymoron and perhaps a case of political correctness gone too far.¹

My feeling is that this is not what doctors or most patients wish in general practice. If I visit my lawyer or dentist I trust his or her knowledge and experience as being superior to mine and take their considered advice.

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Undoubtedly our roles as doctors are changing. This is through increasing patient knowledge (though the significance of the internet is probably exaggerated), increasing expectations, and also the increasing likelihood of litigation.

If patients have an illness, whether self limiting or serious, or are recovering from surgery I sign a medical certificate (when appropriate). I discuss with patients when I would expect them to return to work. Clearly there are individual differences, but patients almost consistently prefer a definitive suggestion to a debate.

When prescribing in depressive illness I emphasise the need to take drug treatment consistently for at least six months, the need for regular reviews, the possibility of modifications, and the need not to stop treatment when the patient feels better. Patients often expect such criteria (but not given in a condescending or patronising fashion). No offence is taken when I suggest that the patient may not be the best judge of when to stop such treatment.

It is believed that patients recall only about a third of what was said by their doctor in a consultation. When views are not expressed clearly, particularly in a condensed appointment of 7-10 minutes, patients have little chance of gaining much from the consultation.

Personal views in the *BMJ* are often about sick doctors and the treatment they or their families received. The treating doctor is often at pains to include such patients in their own management but to a detrimental extent. The conclusion is frequently that the authors wish that they had not declared their profession and had remained an "ordinary patient."

People go to their doctors for advice. They may reject it, as is clearly their right, but if the ball is thrown back into their court time and time again ultimately respect is lost and we all lose out in the end.

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1 Web extra. Patients as partners? *eBMJ* 1999;318
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Doctors should help patients to communicate better with them

EDITOR—When was the last time that you visited a doctor? Did you think that you were given all of the information you sought? Did you come away feeling there were still questions you wanted to ask but didn't for whatever reason? Did you feel vulnerable?

If you felt somewhat disempowered on considering your answers to these questions you are not unusual. If you went into your consultation armed with medical knowledge and still came away feeling less than satisfied consider how much worse this would be for somebody without medical knowledge.

The concept of patients as partners is far from political correctness gone too far¹: it is essential for efficient doctor-patient consulta-

tions, in which mutual understanding leads to rapid diagnosis and negotiated treatment options that are thus more likely to be adhered to. A more fundamental issue, beyond providing information about diseases and therapeutics, is how we as doctors can enable patients to communicate more effectively with us. Often we are ignorant of the power we are perceived as having by some of our patients and about how this might inhibit them from communicating effectively with us. When patients are in the vulnerable position of feeling unwell our power is amplified.

I have explored some of these questions with patients who, importantly, are not my patients to see what makes patients feel inhibited in their communication with healthcare professionals and what ideas they have to improve matters. Some initial comments and suggestions were embarrassingly simple.

Patients commonly thought that doctors did not provide an environment in which they would feel free to ask questions because they could tell that the doctor's time was obviously limited: the clinic was crowded, the doctor did not look them in the eye, or the doctor interrupted frequently when they were trying to speak. Patients also said that if they were confident that they could ask questions or seek clarification they would do so. Their suggestions for improvement included posters for waiting rooms that explicitly gave patients permission to ask questions, and checklists of credit card size that they could refer to during consultations as prompts.

It is wrong to assume that doctors letting go of some of their power and encouraging patients to be partners will be more time consuming. It should lead to much faster shared understanding, greater patient satisfaction, and improved health outcomes, as has been shown in diabetes.²

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1 Web extra. Patients as partners? *eBMJ* 1999;318
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2 Greenfield S, Kaplan S, Ware JE, Yano EM, Frank HJL. Patients' participation in medical care: effects on blood sugar control and quality of life in diabetes. *J Gen Intern Med* 1988;3:448-57.

Cultural diversity matters

EDITOR—To investigate whether patients are partners¹ in Russia we recently conducted a small study of patients in hospitals of a provincial town. Although half of the patients knew their right to participate in decisions and to give consent, only a third wanted to know all the details about the course of their disease and their prospects of treatment.

Only a third had read about their chronic conditions in medical or lay texts, and half had only the information that they had been given by their physician or nurse. About a quarter wanted their physician to take responsibility for all the decisions. Income, age, and education of patients did not influence these proportions significantly.

I think that cultural differences enormously affect patients' acceptance of the partnership relationship. Cultural diversity may occur in many national or religious groups in every country. Russia is a special example: orthodox paternalistic style is still alive in Russian medicine despite legislation regulating health care since 1993. This is understandable because the state has been all powerful here since 1917. I believe that people must be treated in the way that suits them best.

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1 Web extra. Patients as partners. *eBMJ* 1999;318
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Whether patients should be partners depends on the patient

EDITOR—I have worked as a general practitioner in India for a couple of years and have encountered many types of patients. Most are more eager to know about their underlying problem—whether it is serious or small, curable or potentially fatal—than about the molecular biology or pathology. When health awareness is high and patients have easy access to information about their illness and, more importantly, can understand the disease and its implications, it may be wise to include them as partners.¹ It may improve the outcome, lower the cost, and make patients happy.

But what about people who are unaware of their health problems and cannot understand the importance of maintaining good health and hygiene? I have encountered many patients whose beliefs are so strong and deep seated that they are practically impossible to dispel and have the effect of jeopardising health. The harder a doctor tries to make such patients understand the quicker they consult another doctor. They refuse to follow, let alone participate in, what is being said. How do we include this set of patients as our partners in decision making?

How do we balance beneficence with beliefs? I agree that patients have to be informed about the risks and advantages and should be given the options and outcomes of treatment. Whether they should be included as partners should be decided individually. Many factors such as their degree of comprehension and capacity for judgment should be taken into account. We as doctors with a good conscience should strive to do what is best for our patients and hence not generalise. Our patients are as varied and as different as the number of diseases, and decisions should be tailored accordingly.

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Health library in India works to empower patients

EDITOR—The main reason patients have not been treated as partners¹ in India is that traditionally it has always been the doctor who has had all the information about medical problems: the patient simply followed the doctor's orders. However, today we know that if we empower patients with information about their medical problems, they can become educated partners in their own medical care.²

Thus, the Health Education Library for People (HELP) in Bombay was launched in May 1996. This is India's first consumer health library, and it has grown to become one of the world's largest.³ HELP is a free public library which aims to empower people by providing them with the information they need to protect their health and to prevent and treat medical problems while working in partnership with their doctor. The library is run by a registered charitable trust, the Community Health Research Program, which finances its activities. The library provides air conditioned reading rooms that can accommodate up to 25 people; an up to date collection of over 5000 consumer health books, 10 000 pamphlets, and many magazines and newsletters; audiovisual educational media, including over 500 videotapes which can be viewed in privacy in the library; computer software, including over 30 CD Roms on health and medical topics; and photocopying facilities. The library has four staff members (including librarians) to help readers find the information that they need.

We believe that a consumer health library can act as a catalyst in empowering patients with information.⁴ Doctors who visit the library adapt its educational materials for their own practices and customise them to improve the clinical care that they provide.

HELP has become a prototype of the modern digital library, and our website (at www.healthlibrary.com) allows us to extend our outreach services by providing consumer health information to internet users from all over the world.

We are trying to encourage hospitals all over India to open similar libraries for patient education. Hospitals, after all, have a captive population of patients' relatives who often have thousands of unanswered queries. These in-hospital libraries could help hospitals improve the medical care they provide⁵; they could be as simple as a single room with a computer providing access to the internet, or they could grow to become as large as ours. As with any new idea, we expect it will take time to gain acceptance but we do hope it will soon become routine for every hospital to have a resource centre for patient education.

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Patients can educate doctors about long term disease

EDITOR—Two fifths of both men and women reported having a longstanding illness.¹ The role of patients² in chronic disease is different from that of patients in acute disease. Patients with acute disease are usually happy to do what they are told and are generally cured and able to continue with their business. In chronic illness, however, the onset of the illness and subsequent diagnosis is often much slower. After diagnosis, treatment options are soon exhausted. With access to up to date information and research through the internet, patients are often better informed than their general practitioner about their condition.

People with a long term illness may at times conclude that the health service can no longer help. This naturally leads to frustration for everyone: doctors because they cannot do more and patients because they have to come to terms with living with reduced social and economic function. Part of the problem is that patients do not know how to make effective use of consultation time.

It does not need to be like this, however. If patients can attend courses that teach them the skills to deal with their symptoms through cognitive and behavioural exercises and learn the value of effective communication, including accurate self reporting of symptoms to their healthcare team, then a partnership can be formed which is both constructive and rewarding to both parties.

As someone who runs courses in the self management of chronic disease I have seen that those who attend courses wish for more of a partnership with their doctor and are often frustrated at the entrenched attitudes they encounter. Given the chance, patients are capable of managing their illness in partnership with their doctor. After all, it is they who wake up with it every morning.

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2 Web extra. Patients as partners? *eBMJ* 1999;318 www.bmj.com/cgi/content/full/318/7186/DC1 (accessed 1 September 1999).

Dying patients need a good relationship with their doctor

EDITOR—The common complaints of patients' relatives about the undignified cir-

cumstances of death and lack of medical care of dying patients reveal an explosive situation and the need for doctor-patient partnership.¹ The development and specialisation of medical knowledge and the methods of diagnosis have led to partial delegation of diagnosis and treatment to machines. This has resulted in an appalling loss of the human element in medicine and a consequent increase in the suffering of patients. The yearning of patients for treatment that considers the whole person is therefore justified from a human as well as a medical point of view. The more ill the patient the more horrifying the dilemma between the overpowering treatment and the psychological oppression. The certainty of death renders all technical data superfluous. Dying patients and their friends and relatives are confronted with simple needs that require fulfilment. However, when doctors cannot help their patients any longer they often withdraw treatment and seriously ill patients lose their attention.

A profound change of attitude is necessary in which psychological counselling is considered to be part of a doctor's profession. Seriously ill patients and their doctors willingly or unwillingly have a close, unequal, and difficult relationship. Doctors have more power because they have knowledge, are healthier, and have the role of helper, and patients are dependent on them. Thus doctors are responsible for shaping the relationship with their patients. To shoulder this responsibility competently must be a goal of medical education.

Rightly, doctors are today accused of evading this responsibility. Though they treat the disease, they neglect the patient. Doctors can and do separate the mind from the body and treat them separately. Patients cannot do that. The total and effective treatment of patients with serious illness or who are dying demands competence in communication, an understanding by doctors of their own emotions and prejudices, and an ethical attitude. That means it demands a thorough training.

The knowledge required to treat a dying person competently is available but not within reach. No university in Germany has a chair of palliative medicine, and this subject is not included in the curriculum.

Individuality and cultural background affect the needs of patients. Doctors should learn to ask precise questions, listen accurately, and make plain that no subject is taboo. They should be ready to discuss any subject their patients are worrying about. Doctors should realise how they betray their patients psychologically by totally denying death and dying.

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People with learning disabilities should be partners too

EDITOR—Often arguments around the patient-doctor relationship—as for patient as partners raised in the *eBMJ*¹—assume that patients can understand and communicate effectively. This is not always the case for people with learning disabilities.

Any discussion on patients' decisions that affect their health should include people with learning disabilities and their carers. People with learning disability make up around 2% of the population, and, as a group, they have added health needs, many of which remain undetected for several reasons. One reason why they receive inadequate primary health care is poor understanding between them, their carers, and their family doctors. Many general practitioners have expressed their worries about consultations with and treatment of patients with learning disabilities, and appropriate training is required for all medical professionals.

Many conditions warranting medical intervention can be addressed through regular health checks. Regular reviews of any prescribed psychotropic drug are recommended, and health checks need to include published recommendations.² Improvements in communication between doctors, people with learning disabilities, carers, and local specialist health and social services can significantly improve health status, as well as serving to update the skills of the practitioner. Patient-doctor partnership in this sense is imperative.

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2 London: Royal College of General Practitioners, 1990. (Occasional paper 47.)

Patient information is often misleading

EDITOR—Sharing decisions with patients so that they may become partners¹ implies sufficient and appropriate information—that is, detailed discussion about the condition, the treatment options, and the likely outcomes with or without treatment. Assessing people's information needs is the first and most important step but is difficult because patients' desires are underestimated, consultation times are short, and clinicians often lack knowledge about treatment options and outcomes. Many other factors should be taken into account, such as the patient's degree of comprehension and capacity for judgment and the clinician's way of communicating.

I have found that patients' information on health care is often misleading and from sources such as tabloid newspapers, television, and their kith and kin. Much of the information currently available to patients is inaccurate or misleading. These low quality

sources cover common and uncommon clinical problems and are hard to oppose. Other problems such as drugs rationing and bureaucracy trouble the clinician-patient relationship. They are all obstacles to providing correct information to patients. Without honest, unbiased, up to date information about their illness, patients cannot express informed choices.

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Reorganisations often benefit administrators rather than patients

EDITOR—As part of the reorganisation of hospitals, health authorities have been issuing consultation documents and proposing merging, relocating, or closing services. They claim that it is not a matter of reducing costs while emphasising that no change is not an option. Consultation is regarded as a necessary evil. Some consultations are a sham in which the public is asked to endorse a single item, without any indication of what will happen if it is rejected.

We are not medically qualified but represent residents' associations on Community Voice, a body with over 40 member groups, which looks after the interests of patients. After observing the infighting between various groups we needed to dissect and challenge every detail of the proposals before us. Many are more concerned with their own positions than with benefits to patients.

Last year's consultation proposed that two specialist units (highly regarded throughout the world) be moved to west London. Part of the pre-eminence of the units is due to their association with another outstanding unit and a well funded research unit. The sole emphasis of the consultation was on consolidation.

The reason given for the moves was that in the absence of a paediatrics service or an accident and emergency department (which had been closed previously), royal colleges cannot give accreditation for training. This is reorganisation for the convenience of administrators rather than patients.

Two health authorities supported the proposal to move the units. Community Voice, local residents, and hospital staff objected. A petition organised by Community Voice collected over 80 000 signatures. An expert advisory group was set up to reconsider the matter. We believe that this was the first experiment in participatory democracy in the NHS. The expert advisory group confirmed the decision to move the units but rejected the location as inaccessible and inappropriate. What would have happened had Community Voice not acted? Will the third major unit on the original site survive when common services disappear?

Common to all the proposals that we have seen is the recommendation for larger hospitals and centralisation, lending support to the idea that no change is not an option.

There is an apparent conflict between what the different parties deem essential. The argument about accreditation shows little originality of thought. Providing training by making difficulties for patients damages the image of a caring profession. Other specialties have similar requirements and, unlike medicine, some others also demand evidence of continuing education.

We support improvement and essential reorganisation. However, the needs of all parties involved—government, medical professionals, administrative personnel, and patients—must be considered. Major rethinking is needed in the NHS, at national, regional, local, and administrative levels, and within the corridors of power of the medical establishment.

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Media have key role in shaping use of health services

EDITOR—Information in the mass media is commonly thought to negatively shape the demand for health services, raising false hopes and generating emotional reactions and irrational behaviours. Oversight and misinterpretation of research information are indeed common ingredients of messages from the lay media, often leading to conflicts and tensions between health services and consumers and to public expectations that are bound to remain largely unmet.

Nevertheless, empirical research shows that the mass media may also positively affect the use of health services, promoting the use of effective interventions and discouraging the adoption of those of unproved or questionable effectiveness.¹ When research information is properly reported, the mass media can be instrumental in producing a more rational demand for health services.² Thus, current efforts are justified whose aim is to assure that what is reported in the lay media accurately represents the best knowledge on the effectiveness of healthcare interventions.

However, the mass media should not be regarded only as conveyors of research information. They may also have a role in representing societal views and identifying important needs that would otherwise remain unknown. Priority setting, organising health services, and choosing among different ways of managing healthcare problems call for enhanced participation from both the public and patients to deal adequately with choices that are often a matter of conflicting values. The mass media may fruitfully act at the interface between research and health services, promoting participation, fostering wider debates, and representing opinions and

values often overlooked within the research community. However, if the mass media are to bridge the gap between research and society and between health services and the public, ways are needed to achieve continuous communication between journalists and health professionals.

Both parties need to become more familiar with each other's language and rules and more conscious of the responsibility they share in assuring that patients' and the public's values are properly and fairly represented in the delivery and organisation of health care.

A good starting point would be that health professionals stop uncritically blaming the media whenever tensions with the public occur. As recently shown by the Di Bella affair in Italy,³ conflicts in health care are more likely to emerge and spread when communication between health services and patients is lacking, when clinical policies are not transparent, and when the medical profession falls short in its accountability for setting up standards of good quality care and validating them.^{4,5}

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Taking medicines: concordance is not compliance

EDITOR—Consultations between patients and doctors most often involve two contrasting sets of health beliefs. Concordance recognises that the health beliefs of the patient, although different from those of the doctor, nurse, or pharmacist, are no less cogent or important when making decisions about the best approach to the treatment of the individual.

In October 1998 the Concordance Coordinating Group, chaired by Marshall Marinker, was formed to take forward the programme of work outlined in a 1997 report.¹ The group comprises general practitioners, pharmacists, academic researchers, consumer representatives, and members of the pharmaceutical industry. The group's website (www.concordance.org) explains our activities. But misconceptions remain about what concordance means.

"Concordance is a new approach to the prescribing and taking of medicines. It is an agreement reached after negotiation between a patient and a healthcare professional that respects the beliefs and wishes of the patient in determining whether, when, and how medicines are to be taken."

The concordance initiative aims to help patients and prescribers to make choices that are as well informed as possible about diagnosis and treatment, and benefits and risks, and to help them to collaborate fully in a balanced therapeutic alliance and so optimise the potential benefits of medical care.

Concordance, however, is not a replacement for compliance. Some professionals use the word concordance as a synonym for compliance and talk about improved patient concordance. The problem with the word compliance is that it implies that a patient takes orders from a health professional.

Concordance is not a one way communication. Concordance requires the agreement of two parties. It is not possible to impose concordance. Patients should be able to express their concerns about drug treatment and be encouraged to make decisions about their drug treatment. Some patients will not wish to be involved in this partnership; their wishes need also to be respected.

Concordance is not a recipe for a comfortable life. If concordance is successful some patients will decide not to take their medicine and some may decide to alter their treatment, and the outcome may not be what the clinician thinks is best.

Concordance is not a wholly new concept. Many doctors, nurses, and pharmacists have been practising concordance for years. And many patients have worked with their practitioners, explaining their concerns and working towards true partnership in treatment.

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- 1 Marinker M, ed. *From compliance to concordance: achieving shared goals in medicine taking*. London: Royal Pharmaceutical Society; Merck, Sharp, and Dohme, 1997.

Patients are important links in the healthcare chain

EDITOR—In Italy at the end of 1997 a new law was approved which streamlined the processes involved in obtaining external breast prostheses for women who have had a mastectomy. The new law was the direct result of action taken by the Italian Forum of Europa Donna, an umbrella organisation of consumer groups.

In January 1997, the forum collected evidence on the difficulties faced by women seeking breast prostheses through the national healthcare service. The forum collected evidence from 30 different organisations throughout Italy. What the forum discovered was that the process was lengthy (involving several trips to various offices to obtain the necessary certificates and authorisation for the prosthesis) and emotionally draining. The forum also found that different procedures were followed in different parts of the country. In May 1997 the evidence was presented to the Senate, and the new law was passed in December.

This result emphasises the idea that patients, or consumers, must play an important and fundamental part in the debate over public health because the incentive for valuable change may come from them. Patients face the problems of their illness daily and so have an excellent overview of where the system may be failing them. Consumers and their organisations are links in a complex chain of health care; the different parties must promote initiatives that allow patients to maintain their own identities and enable them to take part in their care, and services must be developed and offered in a coordinated manner.

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Encouraging HIV positive people to participate in clinical trials

EDITOR—Although many HIV positive patients play an active part in their treatment, it is proving increasingly difficult to recruit patients for clinical trials in the United Kingdom. There are reasons for this.

There is only a limited supply of "treatment naive" patients. Also, people living with HIV who are already taking antiretroviral drugs are seeing their lives improve. For those beginning treatment there are many drugs available. Combination therapy is working and patients' health is improving. So why participate in a clinical trial? Perhaps if the highly effective antiretroviral treatment begins to fail, we may see an increase in recruitment for clinical trials.

To better attract participants, trials need to be topical and to fit in with a potential participant's current drug regimen. People living with HIV need good, clear explanations of proposed trials. Detailed information about the uncertainties of the treatment, about the research that has prompted the trial, and about the potential risks and benefits of joining the trial need to be supplied to potential participants. Similarly, clear information about the progress of the trial must be provided regularly to participants, together with information on the final conclusions showing what has been learnt.

All this is essential, because many people living with HIV are well educated about the disease and may well be self taught in HIV medicine to a considerable degree. Many people living with HIV are better versed in using the internet to find information about HIV and new treatments than are their clinicians. Convincing such people—who may be influential in the community—of the necessity of a proposed clinical trial is a challenge for health service providers.

Only a small group of people living with HIV participate in clinical trials. However, because the disease is so new, all those living with the virus are actually participating in

trials. This is in marked contrast to people living with other serious, chronic illnesses. All HIV positive people are answering important clinical questions. To motivate and encourage people living with HIV to participate in clinical trials, clinicians should emphasise the advantages of participation.

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Cochrane Collaboration welcomes patient participation

EDITOR—The Cochrane Collaboration is an international non-profit organisation. It aims to help people make well informed decisions about health care by preparing, maintaining, and promoting the accessibility of systematic reviews on the effects of healthcare interventions. One of the groups contributing to this task is the Cochrane Consumers and Communication Review Group, which is based in Australia and has an international editorial group.

This review group undertakes systematic reviews of interventions (particularly those that focus on information and communication) which affect consumers' interactions with healthcare professionals, services, and researchers. The interventions may relate to the individual's use of healthcare services (for example, communication between consumers and health professionals during consultations and throughout episodes of care) or to consumer participation in healthcare planning, policy, and research.

Outcomes that the group is interested in reviewing include effects on people's knowledge and decision making, their use of health care, their experience of health care, health and wellbeing, and healthcare systems. (Additional information about our protocols and about reviews that are in progress is available from www.dhs.vic.gov.au/ahs/quality/cochrane.htm.)

The review group welcomes contributions. There are a number of ways in which both consumers and professionals can become involved including hand searching journals, participating in a team preparing a review, by providing information and relevant literature in a subject area of interest, and by being willing to be consulted or act as a referee.

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Educating patients helps the NHS

EDITOR—They say timing is everything. In my former life as a casualty officer, I was yanked out of a deep sleep to tend to a patient: "Doctor, I have had this annoying

boil on my neck for two weeks." I groggily asked him why he had not gone to see his GP and he replied, "Well, I was driving home from the pub and thought it would be quicker just to drop into casualty and get it fixed up. After all what else do you docs have to do during the nightshift?"

As an inner city GP, I know that many of my patients do not understand when to go to their GP, to casualty, or to see the local pharmacist. The public lack the confidence needed to take care of their own health and need confirmation that they are doing the right thing by taking simple remedies such as paracetamol. Many young mothers don't have relatives around who they can ask for advice, so it makes sense that they would go to ask their GP instead.

The Doctor Patient Partnership was born out of the belief that if the public was made aware of how to use the NHS more effectively and efficiently it would help curb the growing demands on the health service. The partnership is unique in being the only initiative aimed at demand management rather than at the supply side of the NHS.

The partnership works with patients' groups, voluntary organisations, and health professionals to develop public education campaigns on issues as varied as childhood immunisation, teenage suicide, and the social isolation of the elderly. To date, the partnership has produced over 5 million posters, leaflets, and other educational materials for patients. The demand seems almost insatiable.

The partnership, along with the NHS Executive, the Patients' Association, and the National Pharmaceutical Association (representing the Pharmaceutical Alliance) has been charged by Alan Langlands, chief executive of the NHS Executive, to manage the communication for the executive's winter planning project. A national advertising campaign has been developed, and materials will be distributed to health authorities, doctors' surgeries, and pharmacies. Even brewers will be involved.

It appears that the partnership's philosophy—that demand should be managed by empowering the public to make appropriate choices rather than by rationing—has struck a chord. This should benefit healthcare workers, the government, and especially the public.

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Government wants patient partnership to be integral part of NHS

EDITOR—I am delighted that this edition of the *BMJ* focuses on the issues of patient and public participation in health care. This government is strongly committed to the principles of partnership between the NHS, its patients, their carers, and the public. Its policies will be clearly stated this month in a

new document *Patient and Public Involvement in the New NHS*.

This new document sets out the action which the NHS Executive is taking to ensure that patient partnership is central to its work, and what the government expects the NHS and other bodies to do to make working in partnership a reality. It builds on the well established themes of the patient partnership strategy to:

- Promote patients' participation in their own care as active partners with professionals
- Enable patients to become informed about their treatment and care and to make informed decisions and choices about it if they wish
- Involve patients and carers in improving service quality, and
- Involve the public as citizens in health and health service decision making processes.¹

The document will be followed up in the autumn by publication of plans for a new NHS charter, which will have effective partnership working as a key theme.

People's expectations of the NHS are changing. It is now no longer enough for clinicians to decide which course of treatment is best for patients and provide care accordingly. Increasingly, patients want to know more about their illness or condition and the different treatment options available so that they can make informed choices about their own care.

These principles of involving patients as individuals and citizens are important not just from the point of view of openness and accountability. Working effectively in partnership has major potential benefits for health and health care, including:

- Reductions in health inequality
- Better outcomes of individual care and better health for the population
- Better quality and more locally responsive services
- Greater local ownership of health services
- A better understanding by all concerned of why and how local services need to be changed and developed.

The government wants to see patient partnership become integral to the work of every part of the NHS—health authorities, NHS trusts, primary care groups and trusts, and general practices—and also within the NHS Executive centrally. Responding positively to this ambition and involving patients as equal partners are undoubtedly key challenges facing the professions and indeed the NHS as a whole as we move into the new millennium.

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¹ NHS Executive. *Patient partnership: building a collaborative strategy*. Leeds: NHS Executive, 1996.

Rapid responses

Correspondence submitted electronically is available on our website www.bmj.com