

novel treatments in children with acute life threatening disease might expect parents to agree to anything that might increase their child's chance of survival. Our experience shows that this is not true in all cases. Most local research ethics committees are now moving towards asking for reports of trials they have approved. It is rare, however, for them to ask about refusals to participate. Reports of trials to the committees and for publication should routinely state the proportion of people who refuse to participate and the reasons for this. This information may suggest whether patients are being properly informed, may help with study design, and might also be a means of detecting scientific fraud.

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1 Wager E, Tooley PJH, Emanuel MB, Wood SF. How to get patients' consent to enter clinical trials. *BMJ* 1995;311:734-7. (16 September.)

Information and consent forms should use short words and sentences

EDITOR.—In their article on how to get patients' consent to enter clinical trials Elizabeth Wager and colleagues mention the need for short sentences in forms that give information about consent.¹ They do not discuss the merits of using short words. The model consent form that they reproduce uses long words and phrases when short ones would easily do. It also begins by assuming literacy ("Have you read the information provided?") although many people cannot read English or speak little English and may not have been given a translated form. Forms with short words can aid oral explanations that make sense to people from a wide range of ages and abilities. Informed consent can depend as much on professionals' clear explanations as on patients' understanding.

The national forum Consumers for Ethics in Research publishes a booklet on preparing information for people who are asked to help with medical research; it suggests clear phrases to explain research concepts and techniques.²

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1 Wager E, Tooley PJH, Emanuel MB, Wood SJ. How to get patients' consent to enter trials. *BMJ* 1995;311:734-7. (16 September.)

2 Alderson P. *Spreading the word on research or patient information: how can we get it better?* London: Consumers for Ethics in Research (CERES), 1995.

Participants should be given feedback about the trial

EDITOR.—Elizabeth Wager and colleagues have set out extremely useful guidelines for gaining patients' consent to enter clinical trials.¹ I have undertaken an anonymous, retrospective postal survey of 90 patients who participated in five trials of treatment for rheumatoid arthritis and one for ankylosing spondylitis. Seventy patients returned questionnaires (78% response rate). Most (69) thought that they had received a full explanation of the study and (67) that they had not been put under any pressure to take part, and all thought that they had been given enough time to consider taking part. Nevertheless, a considerable number (11) said that at some time during the study they wished that they had decided not to take part.

Twenty one patients could not identify the particular drug trial in which they had taken part when they looked at the names of the six drugs that were investigated (one patient ticked three of the names). Two questions concerned only those patients who had withdrawn from the study because of side effects or lack of efficacy of the study drug. Of the 24 patients who answered these questions, 19 expressed satisfaction with the resolution of their problems and subsequent treatment.

Gaining informed consent is the start of participation in a clinical trial. Results of this survey show that those who obtain consent should audit patients' assimilation of the information given them at this time. It is also important to ensure that patients are satisfied with their treatment during the study. Of the 11 patients who said that at some point they wished that they had decided not to participate, six said that this was because of side effects but five gave no reason. This suggests that researchers should be diligent in recognising uncertainties and anxieties experienced by patients and a wish to withdraw from a clinical study during its progress. The concerns of patients are not always the same as those of researchers.

Patients also reported a strong desire to have feedback about the results of the study in which they were participating. It has been recommended that patients should receive written thanks for cooperating in a study.² A plea has also been made for patients to be the first people to hear the results of a study.³ Not everyone would agree with this, but it is surely right that patients are informed of the results by the investigator, preferably at the time of publication.

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1 Wager E, Tooley PJH, Emanuel MB, Wood SF. How to get patients' consent to enter clinical trials. *BMJ* 1995;311:734-7. (16 September.)

2 Royal College of Physicians. *Research involving patients*. London: RCP, 1990.

3 Goodacre H, Smith R. The rights of patients in research. *BMJ* 1995;310:1277-8.

Nurses could halve GP workload

EDITOR.—Keith Thompson complains that most of a general practitioner's workload consists of dealing with trivia and routine tasks (for example, cervical cytology and measurement of blood pressure).¹ I accept that general practitioners, as the public's first port of call, are likely to see many patients with minor and self limiting conditions. Patients attend the surgery because they are concerned or need advice about a problem, not to waste their general practitioner's time. What may seem to be minor or routine to the general practitioner may be of great importance to the patient. It is only general practitioners' training that enables them to recognise these minor or self limiting conditions and to reassure their patients. Furthermore, the importance of interpretation and counselling for even the most routine of procedures should not be minimised: they should be seen as a vital part of the general practitioner's workload.

The second issue arising from Thompson's letter concerns the use of nurses in general practice. The nursing profession has spent years trying to move away from performing single tasks on many patients to being involved in all the aspects of each patient's care. Nursing is a profession complementary to but separate from medicine. Nurses have different skills and should not be seen as underqualified doctors to be trained to do the tasks that general practitioners find too trivial and

menial to complete themselves. I fully support the concept of nurse practitioners, but they should be seen as professionals with their own specialised role, not as cheap medical labour.

General practitioners should not underestimate their importance in dealing with minor complaints and undertaking routine procedures. They should pass on the responsibility for these matters to nurse practitioners only when to do so will improve patients' care, and having regard to the nurses' professionalism. Nurse practitioners should be allowed to apply all their skills and not be used purely as technical assistants.

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1 Thompson K. Nurses could halve GP workload. *BMJ* 1995;311:808. (23 September.)

Training in substance abuse is lacking for GPs

EDITOR.—My practice looks after 45 patients who misuse opiates and amphetamines, for whom it has a prescribing programme.^{1,3} The local police drug squad has commented that the care given to these patients has decreased the availability of heroin on the streets of north Bedfordshire. Six months ago the practice looked after more than 60 patients, and the strain of this led to the breakdown of the health of one of the partners. None of us has any training in this aspect of medicine.

After a visit by the NHS Drug Advisory Service, Bedfordshire Health has made money available for training in counselling and for support services for this work. As the leading partner in this work, I contacted the regional adviser in general practice, several treatment programmes for drug misuse, and the Institute for the Study of Drug Dependence to ask about training courses for general practitioners. I was told that no intensive short courses existed. Records showed that only two one-hour sessions were available—one of them run by me. All that was available was a part time diploma course, requiring attendance in London half a day a week for a year. As I do not wish to become a specialist in treating drug misusers, however, I cannot justify spending a whole year studying this subject intensively. The practice has as many patients with epilepsy as with drug problems, and many more with diabetes and hypertension. I do not have diplomas in any of these aspects of medicine, but I do attend courses in them. Our local drug treatment centre provides a good standard of care for the patients registered with it, but it cares for fewer patients than our practice, there is little consultant input, and it does not provide training for general practitioners.

My partners and I wish to look after our patients who misuse drugs in the same way that we look after patients with other chronic problems. The government has specifically encouraged this course of action. At the moment, however, general practitioners who treat drug misusers are flying by the seat of their pants with little support. If any problems arise the media are very ready to criticise. It seems wrong that general practitioners are encouraged to get involved in a problematic aspect of medicine when no relevant training courses are available. The only thing that keeps us going is that, as well as having 45 current drug misusers on our list, we have 28 former drug misusers. These people can be helped.

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1 Martin E. Drug addiction in general practice. The reality behind the guidelines. A discussion paper. *J R Soc Med* 1987;80:305-7.