Letters

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Waiting times for patients with cancer

Waiting lists are putting patients' lives in jeopardy

EDITOR—Spurgeon et al's findings on waiting times in England for patients with cancer are worrying to say the least.[1] Nevertheless, the authors understate the problem because they take no account of delays before referrals by general practitioners.

In my experience the main cause of delay in patients with cancer receiving the treatment they need is delay in obtaining the necessary investigations, even when they are marked "urgent." For example, in my area, suspected cases of bowel cancer take about four months to investigate—a four week wait for a sigmoidoscopy and a 12 week wait for an "urgent" barium enema. If patients need a colonoscopy the wait is longer still. By contrast, once these cases are diagnosed, they are usually seen by general surgeons within two weeks and wait no more than another two weeks for surgery.

More worrying still are patients with cancer who present with apparently benign symptoms and physical signs and who have to wait many months because they go on the non-urgent waiting list for investigation. I can recall one patient who clinically seemed to have gall stones but who eventually proved to have a primary hepatoma, and another patient who had persistent heartburn while taking low dose aspirin who had carcinoma of the stomach.

The mere fact that a clinician requests an investigation usually implies a degree of diagnostic uncertainty. Therefore, it follows that it is unsafe to put patients on waiting lists for investigations until a definitive diagnosis has been made.

It is high time that our profession impressed on government that waiting lists for investigations are putting patients' lives in jeopardy. We should be aiming to abolish waiting lists for all investigations. I can think of no better way of spending the £2bn of extra funding that the government has promised the NHS.

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1 Spurgeon P, Barwell F, Kerr D. Waiting times for cancer patients in England after general practitioners' referrals: retrospective national survey. *BMJ* 2000;320:838-9. (25 March.)

Applying conclusions from a selected sample is dangerous

EDITOR—The government has acknowledged that cancer care in Britain needs substantial improvement. It has focused on removing delays in access to cancer specialists and says this will improve outcomes. Spurgeon et al's study reports on data collected from 98% of NHS trusts in England.[1] Yet the total number of patients detailed is less than half the number expected to present with cancer in a single month. Furthermore, the data indicate that the incidence of breast cancer is twice that of lung cancer. We are concerned that this is a selected sample and that applying any conclusions widely is dangerous.

Spurgeon et al show, but do not comment on, the far more important delay in the time to first definitive treatment. Solving this will require a far more radical overhaul of the cancer patient's journey through investigation and treatment. Substantial resources are clearly needed to bring our cancer services up to the standards of our European neighbours. We hope that the national cancer director puts appropriate emphasis on treating patients—knowing you have cancer will not cure you.

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1 Spurgeon P, Barwell F, Kerr D. Waiting times for cancer patients in England after general practitioners' referrals: retrospective national survey. *BMJ* 2000;320:838-9. (25 March.)

Meeting the two week target for breast cancer

EDITOR—Spurgeon et al's paper mentions the government's initiative to speed the time from referral to first appointment.[1] The initiative has been the subject of much criticism and debate. The reasons for setting these targets may be ultimately to affect mortality by early treatment. On our unit, however, we have maintained this practice for nearly three years. We have managed to see not only suspected cancers but also all new patients within two weeks of referral. More than 2000 new patients were seen in the past year.

My reasons for giving early appointments are mainly patient driven. General practitioners, under pressure from the patient, may prefer to refer rather than risk a missed diagnosis. Patients with symptoms are anxious and fear that they have cancer until reassured by a specialist. It is unreasonable to keep patients waiting 13 weeks before they are told that they have benign breast disease.

Our cancer unit is in a district general hospital but is situated in a designated area with mammography, scanning facilities, consulting rooms, a counselling room, a minor procedure room, and an appliance room all housed together to help patients. This is how I envisage all breast units will be in the future. To meet our objective we relied on innovation and on improving communication with general practitioners and patients. Liberal use of standard forms, patient history questionnaires that are filled in by patients themselves before arriving in clinic, a one stop diagnostic service, patient information leaflets on every conceivable breast condition, and same day communication to the GP has helped us achieve our unit targets.

We have achieved these results in a singlehanded surgical practice with a skeleton staff. Meticulous planning, hard work, and commitment by staff have made this possible without any help from the government or the trust. We have addressed the issue of quality using patient and GP surveys that assess satisfaction with the service. Patients and GPs both have a high degree of satisfaction.

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1 Spurgeon P, Barwell F, Kerr D Waiting times for cancer patients in England after general practitioners' referrals: retrospective national survey. *BMJ* 2000;320:838-9. (25 March.)

Women need to be educated about the risks of breast cancer

EDITOR—The introduction of the two week rule for the referral of patients with a possible diagnosis of cancer, introduced for breast cancer in April 1999, has had a considerable impact on clinics dealing with patients with symptoms.[1 2] The pick up rate of breast cancer in a clinic for patients with symptoms varies with the symptoms the patient is experiencing and the age of the patient. Overall it is well documented at 10%. When pain is the only symptom there is a 2% rate of cancer.

We applaud the fact that information and health education have improved patients' awareness of the disease, but women grossly overestimate the risk of developing breast cancer.[3] This anxiety is real and is something that the primary care doctor finds hard to deal with. In many cases it is impossible to exclude breast cancer on the basis of a simple clinical episode in the general practitioner's surgery.

We have audited the impact of the two week rule on the referral pattern to our breast clinic for patients with symptoms over the six months May to October 1999. The

Impact of the two week rule on referral to breast clinic in South Cleveland Hospital, May-October 1999

Referral letters	No of patients	No (%) of patients with cancer
Sent by general practitioner*		
Request for urgent appointment	231	26 (38)
Request for routine appointment	969	42 (62)
Categorised by consultant		
Urgent (see within 5 working days)	174	51 (75)
Soon (see within 10 working days)	312	11 (17)
Routine (see within 15 working days)	729	6 (7)

*Includes 15 letters graded "two week rule must apply."

overall pick up rate for cancer has averaged 8% over the six months (table).

Of the 231 requests made by general practitioners for an urgent appointment, only 15 carried the specific annotation "two week rule must apply," which is supposed to give the primary care doctor rapid access to the hospital for patients with cancer. Of these 15 requests, only six patients actually had cancer. Substantially more referrals are made requesting urgent attention because of the patient's anxiety (table). In our clinic, consultants regrade the referral letters on receipt using the British Association of Surgical Oncologists guidelines. Substantially more cancers are diagnosed in the "urgent" and "soon" groups using these guidelines than using the two week rule. In the small percentage of breast cancers that pose a difficult diagnostic problem, referral under the two week rule does not speed up the diagnosis.

We would strongly advise appropriate health education for the public about the risk of breast cancer and education on the use of recommended British Association of Surgical Oncologists guidelines for doctors making referrals. Requests for urgent appointments on the basis of anxiety alone usurps finite resources, taking valuable quality time from patients with cancer.

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1 Spurgeon P, Barwell F, Kerr D. Waiting times for cancer patients in England after general practitioners' referrals: retrospective national survey. *BMJ* 2000;320:838-9. (25 March.)
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Prediction of survival for preterm births

Editor—We would like to clarify one or two issues raised in the correspondence about our recent paper in the *BMJ*.[1–4]

The data from Trent were presented not as being good or bad but simply to reflect what was actually happening. They will become less useful with time, but, having established the methodology, we hope to offer biennial updates. It would be possible to provide a more complex model of predicted outcome using additional factors, but we were aware that this would add little to the accuracy of prediction.

We do not agree with Ferriman et al that hospital based data are an acceptable alternative.[3] The small numbers make the predictions far less accurate, and the inevitable referral bias also has a marked effect on the results of each unit.[5] We are currently looking at the quality of the survival of preterm infants at discharge from neonatal care[4] in terms of respiratory and neurological morbidity. Although this may be of interest, what parents really want to know is the probable long term health status of their infant. Population based outcomes of this type for large numbers of preterm infants are, however, not currently available.

All three letters report survival rates higher than those from Trent. None provides data relating to the outcome of all babies, of the relevant gestation, alive at the onset of labour. This is essential if any comparison is going to compare like with like. Doyle et al comment: "The improving survival rates are reported to obstetricians, who decide whether a preterm infant will be born alive and whether the paediatric team will participate."[4] We accept that determining viability is a difficult area for parents and clinicians and that practice varies between centres in the United Kingdom with regard to the most preterm infants. Variation in how these infants are defined and treated will, however, affect survival rates for "liveborn infants." In units where all liveborn infants are not necessarily admitted to neonatal units or seen by a paediatrician, the sickest infants may not be classified as liveborn, and survival rates will seem more favourable. We have recently reported data supporting this concept.[5] This study showed that babies aged 28 weeks or less who had been transferred postnatally for intensive care had significantly better survival rates than predicted from scores for disease severity and better than infants whose whole course was in a tertiary centre. These seemed to be simply a selected group.

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1 Draper ES, Manktelow B, Field DJ, James DJ. Prediction of survival for preterm births by weight and gestational age: retrospective population based study. *BMJ* 1999;319: 1093-7.
2 Koh THHG, Harrison H, Casey A. Prediction of survival for preterm births. *BMJ* 2000;320:647. (4 March.)
3 Ferriman EL, Doulah MA, Simpson NAB. Prediction of survival for preterm births. *BMJ* 2000;320:647-8. (4 March.)
4 Doyle LW, Morley CJ, Halliday J. Prediction of survival for preterm births. *BMJ* 2000;320:648. (4 March.)
5 Field D, Draper ES. Survival and place of delivery following preterm birth: 1994-1996. *Arch Dis Child* 1999;80:F111-F113.

Sleep apnoea and hypertension

Findings cannot be applied to general public

Editor—The study by Lavie et al is the first to provide evidence that sleep apnoea is an independent risk factor for hypertension.[1] We think, however, that the clinical implications put forward are limited by the chosen population and study design.

The findings of this study cannot be applied to the general population for the following reasons. Firstly, all the study population consists of patients referred to a sleep clinic and is therefore highly selected. Furthermore, we believe that patients' risk of comorbidity is significantly greater than that of the general population; for example, 22.8% of the control group were hypertensive. Associations in highly selected populations are open to bias,[2] a factor not addressed by the authors.

We question whether patients should have been diagnosed as hypertensive on the basis of readings taken over a 24 hour period. Standard practice is to make a diagnosis on the basis of measurements taken on three separate occasions, eliminating influencing factors, in particular environmental stresses.

We agree with Locke that many of these problems could be overcome by adopting a new study design.[3] We think, however, that a prospective cohort study is more suitable. Non-apnoeic patients from the general population would be matched and compared with patients with varying degrees of sleep apnoea and followed up over an appreciable time. This approach would further support a causal relationship between apnoea and hypertension.

Upon closer examination of the paper, we noticed some fundamental discrepancies in the data. The text reported that diastolic blood pressure was increased by 0.04 mm Hg per apnoeic event, while table 3 states 0.07 mm Hg. Neither of these figures gives the result of a 4.7 mm Hg blood pressure increase in severe apnoea as shown in the text. Furthermore, initially severe apnoea was described by an apnoea-hypopnoea index of >50, but subsequent calculations use an index of >60.

We concur with Lavie et al that this study is both relevant and important. Further research is required, however, before it can be concluded that sleep apnoea is an independent risk factor for hypertension in the general population.

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1 Lavie P, Herer P, Hoffstein V. Obstructive sleep apnoea syndrome as a risk factor for hypertension: population study. *BMJ* 2000;320:479-82. (19 February.)
2 Berkson J. Limitations of the application of fourfold table analysis to hospital data. *Biometrics Bull* 1946; 2:47-53.
3 Locke KA. Not a population study. Electronic response to obstructive sleep apnoea syndrome as a risk factor for hypertension: population study. bmj.com 2000;320 (www.bmj.com/cgi/eletters/320/7233/479#EL1; accessed 26 June.)

Author's reply

EDITOR—Harrison et al raise the issue of the adequacy of our selected population to the general question of sleep apnoea and hypertension. We agree that the title of the article should have been more specific. Unfortunately, the editor shortened our proposed title, "Obstructive sleep apnoea syndrome as a risk factor for hypertension: a sleep clinic population," which more accurately described our study population. We would like to direct the correspondents to a study by Young et al, who studied the relation between breathing disorders in sleep and hypertension in a randomly selected cohort of state employees in Wisconsin.[1] They also reported a significant relation independent of all other important risk factors.

We think that the importance of our study lies in our ability to investigate a very large population of patients with sleep apnoea and to control for all possible confounding variables by statistical methodology. We agree with Harrison et al that a longitudinal investigation of people with sleep apnoea and matched controls may yield important insight into the causal relationship between sleep apnoea and hypertension. Such a study is yet to be undertaken.

Finally, we are indebted to the third year medical students, whose sharp eyes caught discrepancies between the text and the table in our data. The data reported in table 3 of an increase of 0.07 mm Hg in diastolic blood pressure per apnoeic event is the correct value, and not 0.04 mm Hg as stated in the text. This estimate gives an increase in blood pressure of 4.2 mm Hg in the patients with severe sleep apnoea, and not 4.7 mm Hg as indicated in the text. We apologise for these errors. Harrison et al did not realise, however, that we took an apnoea-hypopnoea index of 60 as an example, and assumed we meant 50 because this was the apparent starting point of the "severe apnoea" group (we used >50). In any case, they should be congratulated for their constructive criticism of our paper.

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1 Young T, Peppard P, Palta M, Hla KM, Finn L, Morgan B, et al. Population-based study of sleep-disordered breathing as a risk factor for hypertension *Arch Intern Med* 1997;157:1746-52.

Active approach to detection of obstructive sleep apnoea is imperative

EDITOR—The study reported by Lavie et al shows that 43% of middle aged and elderly people, mostly men, with obstructive sleep apnoea (defined as an apnoea-hypopnoea index of >10) have hypertension.[1] Since 30-50% of people with essential hypertension have obstructive sleep apnoea[2] this could mean that obstructive sleep apnoea is a major contributor to the production of this disease.

Lavie et al show that apnoea is an independent risk factor for hypertension, consistent with most, but not all, studies.[2] That it may actually be the cause of the hypertension is also suggested by the fact that in most intervention studies, treatment of obstructive sleep apnoea reduces the blood pressure,[2] and by animal studies that show that apnoea causes hypertension and that cessation of its stimulus returns the blood pressure to normal.[3] All these data might influence hypertension experts at least to include obstructive sleep apnoea in the differential diagnosis of hypertension, but this is not the case.

The 1999 guidelines for detection and treatment of hypertension of the Joint Committee of the World Health Organization and the International Society of Hypertension fail to mention even a single word about this entity.[4] Most people with apnoea go undiagnosed, simply because the condition is not looked for.[5] Yet when doctors actively seek out the condition by asking the hypertensive patients (and indeed all patients) and their family members only three questions, they increase the number of cases diagnosed and treated in their practices by 800%.[5] These three questions concern the frequency and loudness of snoring, the presence of excessive daytime sleepiness, tiredness, or fatigue, and whether the bed partner or other family members have witnessed episodes of gasping, choking, or apnoea during sleep.

The diagnosis and treatment of obstructive sleep apnoea will lead to a big improvement in the quality of sleep and therefore improve alertness and cognitive function, reduce the chances of these people falling asleep during driving and having an accident, and improve the quality of their lives and the lives of those around them. All these benefits, as well as a lower blood pressure, can come from the three simple questions that astute, aware, and awake doctors should routinely ask all patients. An active approach to detection of obstructive sleep apnoea, as Lavie et al state, is imperative.

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1 Lavie P, Herer P, Hoffstein V. Obstructive sleep apnoea syndrome as a risk factor for hypertension: population study. *BMJ* 2000;320:479-82. (19 February.)
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4 WHO Guidelines Committee. 1999 World Health Organization-International Society of Hypertension guidelines for the management of hypertension. *J Hypertension* 1999;11:151-83.
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Funding long term care for older people

Funding is to do with politics, not health care

EDITOR—What on earth has induced the presidents of the three royal colleges and the British Geriatric Society to involve themselves in the dispute over the funding of long term care, which is not a healthcare issue at all but a wholly political one?[1]

The issue concerns those people in possession of financial and property assets valued in excess of £10 000 who by reason of illness and infirmity become unable to sustain themselves in their homes, which they usually own, and are therefore obliged to enter residential or nursing care. They lose the benefit and enjoyment of their homes and assets because of their illness and infirmity, and this distress cannot be alleviated no matter who pays for their care.

Let us be clear about this: were the state (or taxpayer) to succumb to this orchestrated campaign to fund care costs, there would be no particular gain to the infirm people themselves (they would still lose their homes and assets). Those who stand to gain most are the beneficiaries of their estates. Most of these beneficiaries will be middle aged, financially secure, and in no particular need of additional support from the state. The wealthier the estate involved, the greater the potential gain to the beneficiaries. Were this proposal to be enacted it would represent yet another regressive system of subsidy to people who are already well off, with no general social benefit. Moreover, since the system would probably be subsumed into the healthcare budget, it would further constrain the ability of the healthcare system to attempt to ameliorate the health disadvantage of poverty by state funded provision.

It is greatly to be regretted that the four presidents have been naive enough to lend their support to this politically motivated campaign to favour the wealthy at the expense of taxpayers in general and the poor in particular.

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1 Petrie J, MacKay C, Alberti G, Williams B. Funding of long term care for older people needs to be publicly debated. *BMJ* 2000;320:936. (1 April.)

Elderly people are taxed by mode of dying

EDITOR—The letter from four presidents is welcome.[1] They are right to deplore the lack of equity in the present system, with its variable local interpretations of the rules. There is another fundamental inequity. Usually, taxation is progressive and predictable: the better off pay more, and people know the rules and what to expect. Taxation of substantial inheritance probably nowadays commands near universal assent. By contrast, in regard to long term care there is in effect an unpredictable capital levy before death, operating far below the level at which

inheritance tax begins, and imposed solely on certain types of final protracted illness: taxation by mode of dying.

People who work with frail and dependent old people, whether those people are in long stay care or in equivalent substantial care at home, constantly witness their grief and anxiety as they see their survival consuming what they expected to be able to leave for their family—most often their house. This not ignoble expectation can be a main consolation and source of self esteem in the time of their dependency. Often they have been personally frugal all their lives—hence their savings. The inequity is hardly lessened, indeed perhaps is compounded, by the fact that many other elderly people are unaware, because of dementia, that their savings are disappearing at the last moment.

It is to be hoped that there is truth in suggestions that the government is likely to respond favourably to the Royal Commission's recommendations.

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The situation is a disgrace

EDITOR—The letter about the funding of long term care for older people was pertinent.[1] I am a retired general practitioner, and I look after my wife, who has Huntington's disease. The situation is indeed a disgrace and has been imposed on us by stealth. My wife's mother, who naturally also had the illness (never mentioned in that generation), died well cared for in an NHS hospital. The cost of long term care is £30 000-60 000 a year and is an important factor in my continuing to struggle to care for my wife at home.

It is difficult not to be bitter. When she was younger my wife contributed a lot to the community in a variety of unpaid jobs (justice of the peace, prison board member, and district councillor). In addition, the familial nature of the condition means that getting insurance for long term disability is a non-starter.

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1 Petrie J, MacKay C, Alberti G, Williams B. Funding of long term care for older people needs to be publicly debated. *BMJ* 2000;320:936. (1 April.)

Alternatives to evidence based medicine

Propaganda based medicine is an alternative …

EDITOR—Isaacs and Fitzgerald's short paper on alternatives to evidence based medicine seems to establish a new classification in the art of medicine.[1] I would like to make a small but practical nosological contribution.

Eminence based, eloquence based, and confidence based medicine could be grouped into the single entity narrative based medicine (a term borrowed from Carlo Favaretti). Notwithstanding the fact that each of these individual disciplines has a longstanding tradition, their strong chat based rather than fact based component makes them similar enough to justify the suggested aggregation.

Although the authors skilfully depict the consensus and decision making processes that are adopted in practice, I believe, however, that they have ignored a commonly used eighth alternative—namely, propaganda based medicine.

If doctors have only a limited amount of time for scientific training, if they swallow anything they are told, or if they find themselves in any other unmentionable circumstance they may fall prey to pharmaceutical representatives with the best strategies for physician-changing behaviour. In clinical practice the markers for the two types of propaganda based medicine are (*a*) gullibility and (*b*) unexplainable variation in the prescription of drugs. For the first type, for example, the measuring devices are reactions to test questions such as "How would you react if you had a 40 000-legged spider on your back?" and the unit of measurement is the rate of frightened responses.

I fear that the only reason why propaganda based medicine has not been included, particularly the gullible variety, is that the term does not rhyme with "ence."

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1 Isaacs D, Fitzgerald D. Seven alternatives to evidence based medicine. *BMJ* 1999;319:1618. (18-25 December.)

… as is arrogance based medicine

EDITOR—I enjoyed reading the alternatives to evidence based medicine[1] and the various responses from other readers.[2] I wish to add arrogance based medicine to the list, although I recognise that it overlaps with eminence based medicine and eloquence based medicine. It is particularly relevant in teaching hospitals, where opinions are given out as fact and no explanations are needed. The measuring device is phrase count; the unit of measurement is the phrase "because I said so."

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1 Isaacs D, Fitzgerald D. Seven alternatives to evidence based medicine. *BMJ* 1999;319:1618. (18-25 December.)
2 Electronic responses. Seven alternatives to evidence based medicine. bmj.com 1999;319 (www.bmj.com/cgi/content/full/319/7225/1618#responses; accessed 12 May 2000).

Different rating scale could be used

EDITOR—I am a sceptical proponent of evidence based medicine. But to Isaacs and Fitzgerald's short paper on alternatives to evidence based medicine[1] I would add the definition that it is a system of belief that requires prospectively collected objective evidence of everything except its own utility. I suggest the adoption of the following as a realistic evidence based rating scale:

Class 0: Things I believe

Class 0a: Things I believe despite the available data

Class 1: Randomised controlled clinical trials that agree with what I believe

Class 2: Other prospectively collected data

Class 3: Expert opinion

Class 4: Randomised controlled clinical trials that don't agree with what I believe

Class 5: What you believe that I don't.

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1 Isaacs D, Fitzgerald D. Seven alternatives to evidence based medicine. *BMJ* 1999;319:1618. (18-25 December.)

Summary of rapid responses

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EDITOR—This paper gave rise to 13 electronic responses altogether.[1] Bebe Loff, from Australia, pointed out that until women begin to suffer from balding they "cannot achieve the 'halo' effect, presumably reserved for those most eminent." She had "no competing interests other than female status."

Frank O'Brien, also from Australia, said that the authors had omitted effervescence based medicine. "This is practised by physicians who have taken too much bubbly at the hospital Christmas party and is marked by slurred speech and ataxia."

Steven Ross thought that an additional alternative was "annoyance based medicine, or avoidance based medicine. This occurs when a patient … or other practitioners become so annoying in their demands for a specific course of care that the physician gives in."

Gunther Eysenbach, from Germany, thought that "profit based medicine (also known as opulence based medicine)" was particularly prevalent in systems based on private practice and fee for service. He defined it as "the conscientious, explicit, and judicious use of the most profitable and lucrative interventions when making decisions about patients' care."

Bruce Slater, from the United States, says that "Webidence is scientific (type 1) and pseudo-scientific (type 2) medical advice and opinion posted on a website. The marker … is 'sticky eyeballs,' the measuring device is the web hit counter, and the unit is the unique hit and repeat visit count. Unfortunately, no reputable authority exists for separating types 1 and 2."

Luiz Claudio da Silva, from Brazil, says that in his country "many physicians have found out a specially safe way to practise medicine: … rheumatism based medicine." Tests show blood rheumatism, lupus, rheumatoid arthritis, rheumatic fever, nervous rheumatism, or bone rheumatism. "The prognosis is bad because there's no cure.… While a few rheumatologists fight against the quackery, many 'rheumatismologists' take advantage of this mine of gold."

Carl Hauser, from the United States, reports a new form of scholarly writing, "the case report and review of the email. . . . We should be aware that as we enter the information age many worthy scholarly efforts will continue to go unrecognised while others will continue to be not worth the paper they're written on."

From Italy, Gensini writes that in a paper in the *International Journal of Epidemiology* (1996;25:704-12) Schulzer and Mancini talked of adding "us" ("unqualified success") and "uf" ("unmitigated failure") to the number needed to treat (NNT) and number needed to harm (NNH) respectively. These calculations are "interesting in their potential relevance."

Finally, Rod McClymont, writing from Tasmania, points out that one of the authors of the paper (Isaacs) has previously written about clinical acumen. "Evidence based clinical practice is all very well in principle," McClymont says, "but when applied without acumen it frequently becomes just more vehemence based or even eminence based medicine."

1 Electronic responses. Seven alternatives to evidence based medicine. bmj.com 1999;319 (www.bmj.com/cgi/content/full/319/7225/1618#responses; accessed 12 May 2000).

Consumer health information needs to be rigorous, complete, and relevant

EDITOR—Barker and Gilbert emphasise the importance of evidence being relevant to those who may use it.[1] Their example is patient involvement in decision making in health care. As members of a working group for the Centre for Health Information Quality (www.hfht.org/chiq/), we considered what "evidence based" means for consumer health information about treatment effects.[2] We suggest that three dimensions need to be considered: rigour, relevance, and completeness.

All health information, including that for consumers, needs rigour or the information is inaccurate: it tells you something that isn't true. Searches that maximise rigour are well developed. But the content of what is found is important: its relevance to patients' concerns and its completeness.

If information is irrelevant it tells you something you didn't want to know—for example, about treatments unavailable locally or not reimbursed by your health system. If information is incomplete it doesn't tell you all you wanted to know. For instance, women often don't take iron pills in pregnancy because they get constipated and assume that this is the effect of the iron. At present the Cochrane review of iron supplementation doesn't mention constipation,[3] and the review of methods to prevent or treat constipation doesn't mention iron[4]; women's concerns may be addressed by a review currently under way.[5]

We think that it is helpful here to think in terms of the performance of diagnostic tests. Relevance means that what you find when searching is within the scope of the topic you wish to cover. High relevance is therefore equivalent to positive predictive value in a diagnostic test—a/(a + b) in the table. Completeness means that what you find covers as much of the scope of the topic you have to cover as possible. High completeness is therefore equivalent to sensitivity—a/(a + c).

Table of completeness and relevance

	Information found is within scope of topic	
	Yes	**No**
Evidence found:		
Yes	a	b
No	c	d

An important issue for busy people preparing consumer health information is the ease with which rigorous, relevant, and complete information can be found. In searching for the evidence on which to base consumer health information the question remains whether it is possible to draw on the information from related systematic reviews (therefore maximising rigour) found by careful searching (maximising relevance) and covering a wide enough area (maximising completeness). Only if all three possibilities are pursued can patient information be evidence based.

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Management of chronic skin diseases is important

EDITOR—In its preoccupation with cancer, heart disease, and mental health, the Department of Health has begun to lose sight of the quality of life issues surrounding long term illness. Although the *BMJ* special issue on chronic diseases addressed the importance of considering the needs of people with chronic conditions, I was disappointed not to see any examples from dermatology in the papers presented.[1] Unlike many other chronic conditions, skin diseases are often stigmatising to a greater extent even than depression, but there is little understanding among health professionals or the public of the impact they can have on people's quality of life.

In the report on its inquiry into the training of healthcare professionals who come into contact with patients with skin diseases the All Party Parliamentary Group on Skin called for funding to be made available for skin disease management clinics in primary care comparable to the funds already provided for asthma and diabetes.[2] Since then, we have been working with the NHS Executive to acquire the evidence needed to secure such funding. Skin diseases can be notoriously difficult to diagnose, and diagnosis must therefore be undertaken at an appropriate level in the healthcare system. Thereafter, though, many conditions could most effectively be managed in primary care clinics (probably nurse led), improving compliance and patient satisfaction and reducing the burden on the NHS.

There would, of course, be a cost associated with the establishment of clinics of this sort. At present, and as the report of the All Party Parliamentary Group on Skin showed, dermatology training for nurses and general practitioners ranges from negligible to nil.[2] That would have to change, but given that skin diseases occupy some 15% of the average general practitioner's caseload, it ought to be changing anyway.

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Tensions in implementing the new genetics

General practitioners in south Wales are unconvinced of their role in genetics services

EDITOR—Kumar and Gantley's work opens a necessary debate about the role of general practitioners in providing genetic services.[1] Specialists suggest that many aspects of genetics services should be offered in primary care. This is argued on the basis of familiarity with families and their dynamics, access to a life long clinical record, in the NHS at least, and the provision of potentially continuous care. But there are large doubts about the capacity of general practice to shoulder this new work.[2]

Our early analysis of research work conducted with general practitioners in south Wales over the last six months of 1999 confirms the lack of detailed knowledge about genetics in general and cancer genetics in particular. More importantly perhaps, genetics does not seem to be considered a relevant priority compared with other

pressures faced by general practitioners. The call of Watson et al for an increase in educational activity in this discipline may be misguided.[3] We found that general practitioners were reluctant to undertake the detailed family histories required during consultations and to acquire the data and skills needed to explain risk to patients, although they acknowledged that this could guide the appropriateness of referrals to a newly established all-Wales cancer genetics service. However, their hesitancy was based entirely on the practical problems of matching time to demand. They simply could not perceive a generalist service oriented towards the need to satisfy the detailed exchange of information required in a genetic counselling exercise, and they rejected the idea that this could ever be assisted by computer assisted decision aids, given the current constraints.

The establishment of an all-Wales cancer genetics service earlier last year was generally welcomed, yet there was some unease about the requirement to adhere to referral guidelines to prevent the service being overwhelmed by patients at low risk.[4] The service, however, is keen to discharge all patients at low risk with breast, ovarian, and colorectal cancer back to primary care for support and counselling. Striking the balance between these two thresholds while meeting the rising expectations of both patients and policymakers will be difficult. The tension and anxiety we have witnessed seem to question the reasoning for a generalist service. If it is not structured or funded to provide what patients want—a reasonable conduit of information and advice about a new, if controversial, service—where should people turn?

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Genetic counsellors could be based in genetic centres but be formally linked to general practices

Editor—Kumar and Gantley's interesting and thoughtful paper describes general practitioners' concerns about raising the issue of genetic risk with patients.[1] We appreciate the practical constraints but would challenge the notion of ethical constraint described as the therapeutic gap. It is naive to believe that people do not worry about their family histories. Families at risk of mendelian disorders develop their own lay constructs of inheritance; this is borne out in studies in the general population.[2] Professionals were initially wary of offering presymptomatic testing for Huntington's disease and inherited breast cancer, but such testing has been sought by many people at risk.[3] Matters may be different for people who do not consider their family history to be clinically significant, but we would caution against prejudging their anxieties.

Information and counselling can be treatment in themselves. Women with a family history of breast cancer and those in the general population consistently overestimate their risk of breast cancer before genetic risk assessment and counselling, a process which improves knowledge without causing negative impact on mental health.[4] Failure to identify clinically significant family histories denies patients access to a specialist service which addresses the needs of people who are at risk or affected.

In highlighting tensions between the views of general practitioners and policymakers, Kumar and Gantley concentrated on the roles of doctors (general practitioners and clinical geneticists), but we believe there is a third way involving other professions. Regional genetic services are multidisciplinary; clinical geneticists work with genetic counsellors, members of an emerging profession whose training and competencies are currently being formalised.[5] They have a background in nursing or science and training in genetics through studying for a master of science degree or in service. They have skills in communicating genetic facts and provide support and psychological counselling around genetic diagnosis and testing. We envisage a model in which genetic counsellors are based in genetic centres but have formal links with primary care practices. For families at low or medium risk, information could be given to enable the general practitioner or practice nurse to inform and reassure the patient. For those at more substantial risk a genetic counselling session could be arranged either in the practice or in central or outreach genetic clinics.

We believe the time is right to initiate research into this integrated model, to investigate whether this would be a practical and acceptable approach for patients and their primary and secondary care providers.

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General practitioners need not view new genetics as catastrophe

Editor—Kumar and Gantley's paper on genetics services in primary care raises several important issues.[1]

It highlights a tension existing between general practice and policymakers in implementing genetic advances. Genetics is seen as being rare and having little relevance to general practice. We disagree with this. The bread and butter of general practice is managing and prescribing for chronic disease. General practitioners will need an understanding of genetics to continue this activity as common diseases become subclassified according to their molecular biology, leading to different management options for the same condition.[2] Moreover, pharmacogenetics (using genetics to predict the metabolism of drugs, including their effectiveness and side effects) is likely to expand the role of the generalist, not marginalise it, by changing the way general practitioners prescribe.

Kumar and Gantley mention a paucity of training in genetics. We agree with this. In our survey general practitioners in Nottingham said that they lacked postgraduate experience in genetics. However, unlike those in Kumar and Gantley's study, they saw genetics (in particular collecting family history information) as extending the "extraordinary preventable potential of the consultation."[3]

We agree that there is a threat from genetic determinism in the form of a shift from psychosocial and holistic family medicine to genetic testing and individualised treatment. But we need not see this as a catastrophe. General practitioners already measure blood pressure and cholesterol concentrations and screen a full blood count to counsel patients about the future risk of strokes and myocardial infarctions and the reproductive risk of fetal thalassaemia. This not so new process of counselling first, doing what is effectively a genetic screening test, and subsequently advising on risk modification is familiar to them and, indeed, something they all do every day.

General practitioners in the study of Kumar and Gantley emphasised the need to build on current practice. The psychosocial aspects of the family history and the role of genetics in current practice, such as registration medicals, have been described previously.[4 5]

General practitioners identified ethical dilemmas associated with the therapeutic gap between current genetic knowledge and effective interventions. The opportunity provided by this temporary gap should be used to increase awareness of genetics in

primary care. General practitioners need to be ready when the interventions arrive. If not, who else will provide a generalist, predictive, and preventive health service?

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Authors' reply

EDITOR—Our research described how informed general practitioners identified practical, educational, clinical, and ethical constraints in providing genetic counselling for common cancers. The study was designed to describe and understand general practitioners' responses to the new genetics. Our conclusions fell into two parts—genetics in the generalist context and the implications of genetics for the generalist identity—and identified tensions between generalists and the policymakers in implementing the new genetics. We note that all of the commentators on our paper have concentrated on aspects of the first part of our data, genetics in the generalist context, and have sought to prescribe what a generalist's role should be. In so doing, they reinforce our view of the tensions we describe.

The study of Elwyn et al in south Wales supports our position that general practitioners are unlikely to be convinced of their role in genetic counselling through educational activity alone. We too have evidence that computer based support for decisions needs to be sensitive to the generalist's clinical context.

Donnai et al misinterpret our concept of the therapeutic gap. It is not a dismissal of patients' anxieties about their family history. Indeed, we suggest that "it was in the context of established genetic diseases that general practitioners saw a clear role for themselves." Donnai et al dismiss evidence of general practitioners' legitimate ethical concern.[1] Informed general practitioners were neither prejudging nor dismissing patients' anxieties by raising ethical concerns; those who were knowledgeable about genetic advances were discriminating in implementing new technologies that do not yet fully fulfil Junger and Wilson's criteria.[2] Donnai et al do not address the issue of general practitioners as mediators between biological and holistic models of illness[3] and the importance of this role in view of concerns about biological determinism and geneticisation.[4] Patients' genetic risks need to be managed with an understanding of the broader social and psychological context, to which—as we argue in the paper—generalists bring the key skills. We welcome the suggestion of a new profession of genetic counsellors to support general practitioners in assessing genetic risk; this was favoured by many of the general practitioners interviewed given the potential of such role to accommodate their own priorities. Counsellors providing specific genetic risk assessment would fulfil a role complementary to that of the generalist.

We agree with Hapgood et al that the rhetoric of catastrophe—and, indeed, revolution—must be regarded with scepticism, and we have avoided adopting such positions. We refer them to an accompanying paper that challenges such reactions.[5]

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Revalidation won't be cheap

EDITOR—The debate on revalidation is important,[1] but only in Furness's letter is the question of paying for revalidation raised.[2] Even the General Medical Council's revalidation web page is vague on the financial aspects.[3] The American Board of Medical Specialities charges between $533 (£355) and $1255 (£837) to sit the written examinations and up to $10 500 (£7000) for on site visits.[4] The Dutch scheme of professional visits costs over £60m a year (relative populations: Netherlands 15m, United Kingdom 55.5m in 1992).[5] Where will the money come from?

It could come from several sources.

Firstly, it might come from the clinical budget, but, like so many moves designed to improve patients' care, this might actually reduce the quality of the service.

Secondly, it might come from a revised General Medical Council levy. This year the council's annual retention fee is leaping from £80 to £135; could this be the first of many increases, mirroring escalating defence subscriptions of a decade ago—a case of the profession putting its own house in order and the many paying for a few bad eggs? Depending on the council's registration fees to fund revalidation is an option only if the council can simultaneously regain public confidence in its integrity and offer doctors a comprehensive package for their reaccreditation.

Thirdly, it might come from direct billing: clinicians would have to pay for their own reaccreditation or lose their registration. This sounds like a non-starter. Those in secondary care would probably expect their employing authority to pay. It would be hugely unpopular for those in primary care, who would see themselves as paying for a government popularity exercise, unless some allowance for it was built into their remuneration (that is, it comes out of the clinical budget again).

Fourthly, it might come from funds for education. This seems the most promising option. Fulfilling the requirements for individual reaccreditation would become an outcome of continuing professional development, managed by directors of postgraduate medical education and funded by the primary care groups/primary care trusts (which, through the clinical governance agenda, are responsible for the quality of health care delivered to their populations).

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