Letters

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Debate on cot death

These deaths must be prevented without victimising parents

Editor—Green's article is obviously intended to stir up the cot death establishment.[1] When cot death was introduced as a registerable cause of death, largely under the influence of forensic pathologists Bernard Knight of Cardiff and Francis Camps of London, some of us working in paediatric pathology were not in favour of this as we knew that it had many different causes.

We have known from the outset that a proportion of the deaths were technically filicide. In the early 1980s, when we publicly gave the figure of 10%, our findings were fiercely contested, but they were confirmed recently.[2] The recent studies by Meadows and Southall et al showing parents deliberately and calculatingly harming their infants apply to only a small proportion of the group of cot deaths that could be classified as infanticide.[3 4] In our experience of hundreds of confidential inquiries into sudden unexpected deaths the most usual scenario for filicide is for the baby to have been suffocated by an exhausted parent (usually the mother) while trying to quieten his or her crying. These parents usually barely knew what they were doing and did not intend or want to kill their child.

We need to prevent these deaths, not victimise the parents.

Green's advice to "think dirty" needs to be considered against our experience with the care of next infant (CONI) programme. This programme, funded by the Foundation for the Study of Infant Deaths, provides support for families with children born after a cot death. Of 5000 babies from 4182 families in the programme, 44 died (8.8 per 1000 live births), 35 unexpectedly.[5] After confidential inquiries 20 were considered to be natural deaths, of which 12 were classified as inevitable because of congenital anomaly or specific diseases and eight as unexplained because there was minimal or no disease. Fourteen were classified as non-natural deaths, including four attributed to overlaying. Ten deaths were not fully investigated (in seven cases the family declined investigation, in two cases no histology was done, and in the last the mother could not be traced). Thus at least 20 of the second deaths in these families were due to natural causes.

We found that before the death that led to enrolment the 4182 families had had 6406 infants, of whom 112 died (17.5 per 1000 live births). The difference between the earlier mortality and that on the programme cannot be explained simply by falling infant mortality over the period.

What is needed are deeper non-critical confidential inquiries into all unexpected deaths that include interested paediatric pathologists and are followed by systematic support. We do not need to create a pool of parents to which a label of unproved homicide is publicly attached.

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5 Foundation for the Study of Infant Deaths. *Report on 5000 babies using CONI (care of next infant programme).* London: FSID, 1998.

Standard system for postmortem examination and certification needs to be agreed

Editor—Whether or not the term sudden infant death syndrome should be abandoned, the present system for categorising sudden deaths in infancy seems to be in a muddle.[1]

Analysis of 450 necropsies in the recent study of sudden unexpected deaths in infancy shows that the extent of investigation varies widely with the specialism of the pathologist, paediatric pathologists doing the most tests and forensic pathologists the least.[2] Furthermore, pathologists may not always agree in their interpretation of the same findings, especially whether or not they constitute an adequate cause for the death, and so whether it should be classified as due to the sudden infant death syndrome. The sudden unexpected deaths in infancy study, like the multicentre study 20 years ago,[3] found frequent discrepancies between the opinions of the original pathologist and the expert assessor.

Then the way in which pathologists report their conclusions may result in omissions from the totals given by the Office for National Statistics both for the sudden infant death syndrome and for sudden infant deaths in general. For example, if a pathologist thinks a death should be classified as due to the sudden infant death syndrome but also finds bronchitis, and both terms appear on the death certificate, the Office for National Statistics will allocate the death to bronchitis rather than the sudden infant death syndrome; this is because international guidelines require the selection of the more specific condition. Similarly, if a baby dies unexpectedly and a cause such as septicaemia is identified at necropsy the death will not be included in the generic total of sudden infant deaths if no allusion is made to its suddenness on the certificate. In addition, pathologists and coroners vary in their willingness to accept the sudden infant death syndrome as a designation for unexplained deaths.

In recent years, partly as a result of Green's advocacy, there has been an increasing tendency to categorise as unascertained those deaths in which there is any suspicion of maltreatment; infant deaths under the relevant code have risen from 18 in 1996 to 26 in 1997 and 46 in 1998. Similarly, about 10 deaths a year that might otherwise be categorised as due to the sudden infant death syndrome are coded under respiratory failure. Now that the total of sudden infant deaths has fallen these various anomalies

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have greater effect, distorting national and local figures and reducing the validity of comparisons. Agreement is needed on a standard system for postmortem examination and certification that all coroners and pathologists will follow.

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In 1994, 29% of suspicious deaths were officially recorded as due to sudden infant death syndrome

EDITOR—The debate between Green and Limerick about cot death is important.[1 2]

We recently completed a review of one year's submissions to the Department of Health of part 8 review reports, which primarily comprise reviews of cases in which maltreatment is known or suspected to have caused a child's death.[3] In the year to March 1994, 37 deaths in the United Kingdom had been confirmed at the time as caused by the child's caretaker(s), but in a further 14 cases we remained highly suspicious that the evidence available indicated a death related to abuse.

Four of these "suspicious" deaths had been officially recorded as due to the sudden infant death syndrome. The first concerned a 4 month old infant whose name was already entered on the child protection register: his parents had a violent relationship and misused drugs, the mother received no antenatal care during the pregnancy, and his needs were repeatedly ignored. In the second case the mother had used heroin throughout the pregnancy, so that the child was born with severe withdrawal symptoms, and she admitted having smoked crack cocaine on the night that the 10 week old child died in her bed while she was unconscious.

In the third case the baby had been unplanned. There were several observations of bruising to the baby, who died aged 5 months with postmortem evidence of non-accidental soft tissue injuries. The fourth case contained a history of failure to thrive in both the 3 month old child and his elder brother, who had been made the subject of a care order just two weeks before the baby died.

Misdiagnosis has wide-ranging importance, including for professionals' appreciation of the risk to future children. In another case in which the child's death was eventually confirmed as being the result of abuse, the death of the mother's first child had been diagnosed as due to the sudden infant death syndrome and most professional interventions and monitoring had been aimed at preventing the syndrome. When her next two children, aged 19 months and 5 months, were found dead the initial concern had been that they had both died of the syndrome—on the same day. The mother was later convicted of their murders.

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Childhood vulval lichen sclerosus and sexual abuse are not mutually exclusive diagnoses

EDITOR—In their lesson of the week Wood and Bevan point out that failure to recognise lichen sclerosus can lead to distressing allegations of abuse.[1] We agree: in a cohort of 72 girls with early onset lichen sclerosus that we studied, the possibility of sexual abuse had been raised by the general practitioner or within the family in over seven tenths of cases.

We would like to raise three further issues. Firstly, we have found that the increased anxiety and awareness of sexual abuse have led to increased and earlier referral of children to our paediatric vulval clinic in recent years; this has resulted in earlier diagnosis and treatment than even five years ago.

Secondly, it is important to remember that the two diagnoses are not mutually exclusive. Some authors have speculated that the trauma and increased infection related to sexual abuse may act as a trigger to developing lichen sclerosus,[2] related to Koebnerisation, which is known to occur in this disease. In view of this, diagnosing lichen sclerosus should not prevent further abuse investigations if these remain warranted.

Lastly, our retrospective and prospective studies on these children have shown that treatment initially with potent or very potent topical steroids as previously reported in adults[3] and children[1 4] causes few side effects. More importantly, it leads to faster resolution of symptoms, less likelihood of recurrence, and lower total use of steroid than if mild topical steroids (such as 1% hydrocortisone, as mentioned in the article) are used. Successful treatment regimens are described elsewhere.[5]

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1 Wood PL, Bevan T. Child sexual abuse inquiries and unrecognised vulval lichen sclerosus et atrophicus. *BMJ* 1999;319:899-900. (2 October.)
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5 Powell J, Wojnarowska F. Lichen sclerosus—a seminar. *Lancet* 1999;353:1777-83.

Antidepressant drugs have previously been shown to be ineffective in mild depression

EDITOR—Peveler et al confirm the inefficacy of antidepressant drugs in the treatment of mild depression.[1] I reviewed this subject when working as a medical assessor with responsibility for new product licences for the Committee on Safety of Medicines during 1979-81. The standard antidepressants imipramine and amitriptyline had been studied in randomised controlled trials in different types of depression. Both drugs had been tested against placebo in patients with mild depression, and both were found to be no better than placebo; in contrast, in studies with mixed categories of patients with depression and in hospital studies efficacy was clearly shown.

Despite this background, new antidepressants were granted licences without restrictions on the basis of studies with no specific evidence of efficacy in mild depression. Placebo studies with the newer antidepressants to determine valid criteria for treatment of depression in general practice are long overdue. As far as counselling against non-compliance is concerned, it would be best to restrict this to evidence based treatments. It is relevant in this context to recall the words of the late Sir George Pickering on the subject of non-compliance. He pointed out that patients may sometimes be wiser than their general practitioners.

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1 Peveler R, George C, Kinmonth A-L, Campbell M, Thompson C. Effect of antidepressant drug counselling and information leaflets on adherence to drug treatment in primary care: randomised controlled trial. *BMJ* 1999;319:612-5. (4 September.)

Eradication of *Helicobacter pylori* infection in non-ulcer dyspepsia

Commentary did not inform or update general medical community

EDITOR—Thomson's commentary on the paper by Dominici et al on familial clustering of *Helicobacter pylori* was presumably intended to inform and update the general medical community.[1] In relation to the eradication of *H pylori* in non-ulcer dyspepsia he states that, "a recent prospective study strongly suggests that there is no basis for this."[2] For many years, however, this topic

has been keenly debated, and it continues to be so. It is therefore unfortunate that he does not mention the Medical Research Councils's dyspepsia trial from Glasgow[3] or a study from Ireland.[4] Both of these studies show a positive benefit of about 10% over placebo for one-off eradication treatment in non-ulcer dyspepsia. This degree of benefit is similar to that of any other chronic treatment such as proton pump inhibitors, previously studied in non-ulcer dyspepsia. Both of these studies were published before the study that Thomson quotes.[2] Furthermore, the other previously published trial that he did not mention[5] shows a positive trend at a similar level to the other two trials,[3 4] although it does not show a significant benefit at a power of 80% to show a 20% benefit over placebo.

The omission of these three trials, all published before the one quoted, suggests a lack of balance, a lack of acquaintance with the literature, or overly stringent editorial restrictions. At best, this commentary is therefore worthless in informing and updating the general medical community on the current evidence on managing non-ulcer dyspepsia. At worst, it is misleading.

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1 Dominici P, Bellentani S, Rita Di Biase A, Saccoccio G, Le Rose A, Masutti F, et al. Familial clustering of Helicobacter pylori infection: population based study [with commentary by M Thomson]. *BMJ* 1999;319:537-41. (28 August.)
2 Talley N, Janssens J, Lauritsen K Racz I, Bolling-Sternevald E. Eradication of Helicobacter pylori in functional dyspepsia: randomised double blind placebo controlled trial with 12 months' follow up. *BMJ* 1999;318:833-6.
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5 Blum AL, Talley NJ, O'Morain C, Veldhuysen Van Zanten S, Labenz J, Stolte M, et al. Lack of effect of treating Helicobacter pylori infection in patients with NUD. *N Engl J Med* 1998; 339: 1875-81.

Author's reply

EDITOR—I thank Gillen and McColl for their comments on a commentary that was, as they rightly perceive, editorially constrained by lack of space, reference culling being a feature of this. My commentary was not intended to be a wide ranging Cochrane style review but to inform, as succinctly as possible, the basics of knowledge to date on *Helicobacter pylori*. In such a contentious subject anyone can cite references to suit his or her position, as Gillen and McColl seem to have done, but because my commentary was constrained by space, preventing all-inclusiveness, I am guilty at most of an inadvertent bias.

Gillen and McColl cite a trend in the paper by Blum et al that is always interesting but not scientifically persuasive,[1] but they do not mention a much more recent paper showing no effect on non-ulcer dyspepsia of eradicating *H pylori* infection, which has at least one author in common with that of the paper by Blum et al.[2] Talley et al show no improvement in symptoms or quality of life or significant association between treatment success and histological improvement in chronic gastritis at one year.[2] This is, in addition, a randomised double blind controlled trial reaffirming the results of the study quoted in my commentary by Talley et al reported earlier in 1999.[3]

Clearly, this subject will remain a matter of debate. I am sure that a wider remit in future similar commentaries would allow a broader citing of references in all aspects of *H pylori*, the treatment of non-ulcer dyspepsia being only one of many that are hotly debated.

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Stable chronic obstructive pulmonary disease

Incomplete evidence based reviews may condemn by omission

EDITOR—The review by Kerstjens published in the *BMJ* on behalf of *Clinical Evidence* claims to be an evidence based account of treatment for stable chronic obstructive pulmonary disease.[1] Unfortunately, the author restricted his analysis to drug treatments and therefore omitted non-pharmacological treatments, which may be of great benefit to patients with the disease.

In particular, pulmonary rehabilitation provides benefits to patients in terms of exercise capacity and quality of life, outcomes that were clearly included in the aims of the review. The benefits of pulmonary rehabilitation have been validated in well designed and executed randomised controlled trials.[2 3] Indeed, the clinical efficacy of rehabilitation is greater than that of many drug treatments.[4] Evidence based guidelines for pulmonary rehabilitation have been published.[5]

Provision of pulmonary rehabilitation in the United Kingdom lags behind that in the United States and the rest of Europe. Incomplete evidence based reviews such as this may worsen the situation by giving the impression that treatments not included in its analysis are of no benefit.

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1 Kerstjens HAM. Clinical evidence: Stable chronic obstructive pulmonary disease. *BMJ* 1999;319:495-500. (21 August.)
2 Goldstein RS, Gort EH, Stubbing D, Avendano MA, Guyatt GH. Randomised controlled trial of respiratory rehabilitation [see comments]. *Lancet* 1994;344:1394-7.
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5 Pulmonary rehabilitation. Joint ACCP/AACVPR evidence-based guidelines. *Chest* 1997;112:1363-96.

Published correction for one of studies must be borne in mind

EDITOR—Kerstjens's clinical review on stable chronic obstructive pulmonary disease[1] cited our systematic review on the effect of mucolytics on exacerbations of chronic bronchitis.[2] As noted in the article, we found that treatment with mucolytics led to a significant reduction in the frequency of exacerbations and to a reduction in the days of disability. There was, however, an error in our review, as published in the Cochrane Library, which we would like to point out. As stated in the article, the effect size for the change in forced expiratory volume in one second was 57 ml; for the vital capacity it was 40 ml, but the change was in the opposite direction. In other words, treatment with mucolytics led to a small increase in lung function, not a decrease.

We think that this finding should be interpreted with caution because it was based on only three trials that reported forced expiratory volume in one second and four that reported vital capacity and there was considerable heterogeneity in the studies. Furthermore, these changes are small and fall within the coefficient of variation for spirometry. Nevertheless, on the basis of these studies we cannot conclude that mucolytics have a deleterious effect. This error will be corrected in the next update of the Cochrane Library.

We would also like to point out one other error in the article. It says that we did not find any effect on antibiotic use, but this is not the case. The review reported a significant difference in the number of days for which the patients were taking antibiotics. The weighted mean difference was a reduction in 0.68 days of treatment with antibiotics for each month of treatment with mucolytics (95% confidence interval -0.71 to -0.64, $P<0.001$).

Our review was not able to address the effect of mucolytics on long term decline in lung function, but we await with interest studies that will do this.

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1 Kerstjens HA. Clinical evidence: Stable chronic obstructive pulmonary disease. *BMJ* 1999;319:495-500. (21 August.)
2 Poole PJ, Black PN. Do mucolytics reduce the frequency of exacerbations in chronic bronchitis? (Cochrane review). In: *Cochrane library*. Issue 4. Oxford: Update Software, 1998.

Author's reply

EDITOR—The review in the *BMJ* is taken from issue 1 of *Clinical Evidence*, a new information resource for clinicians.[1] Steiner et al have noticed correctly that only maintenance drugs were covered, and not rehabilitation. Unfortunately, the first line of the review in *Clinical Evidence*, which underlined the fact that only maintenance drug treatment was covered, was not included in the review in the *BMJ*.

Many other interventions were not covered—among them the most important one in the disease (smoking cessation) but also nutrition. Additionally, interventions during acute exacerbations were not discussed. Clearly no inference about (lack of) benefit should be drawn from topics not covered in the review. The compendium will be updated and expanded every six months, and rehabilitation will certainly need to be added, together with several other topics.

I gratefully acknowledge the corrections of errors by Poole and Black. As stated in the review, the effect of N-acetylcysteine on long term decline in lung function is currently the subject of a large European multicentre study, and the results are eagerly awaited.

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Young people should be included as partners

EDITOR—The position of young people (between the ages of 13 and 18) as partners is not discussed in the *BMJ* issue of 18 September "Embracing patient partnership." Dixon-Woods et al's article on partnerships with children begins with a reference to a 15 year old woman but focuses on important issues relevant to professionals working with children.[1]

Young people are, in political, economic, and social terms, a marginalised group almost always represented by adults. Young women and young men are included in the general invitation to communities to participate in health partnerships without discussion of the inequalities they experience because of their age, including poor access to health services.[2] Partnership with young people, on their terms, can be valuable to them (because of the skills, knowledge, and confidence they gain), as well as an investment in the quality of services. There are examples of successful pilot partnerships between young people and professionals, with young women and young men defining their health agenda.[3] There is great potential for the development of key services, such as sexual health and mental health, in partnership with groups of young people who are rarely supported to participate—for example, young people who have been excluded from school and those who have serious problems around alcohol and illegal drugs.

Change in response to young women and young men developing a sense of joint ownership of local services can be uncomfortable for adult health professionals. Perhaps partnership with young people is left out of the debate because of the effort entailed in a shift to working equitably with a group that is viewed as less powerful. If the challenge is not met, through opening up and debating the issues around partnerships with young people, we (adult workers) will not have to give up any of our power, but we will close down exciting opportunities.

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2 Benzeval M, Judge K, Whitehead M, eds. *Tackling inequalities in health: agenda for action*. London: King's Fund, 1995.
3 Thompson E, Job D, Pringle L, Archbold A, Cooke J. Not just a phase we're going through. . . . *Youth Action* 1999; spring:12-13.

Moving the research agenda

Primary care research needs extending, not moving

EDITOR—Kernick et al assert that it's time to rattle the cage of academic general practice.[1] This is essentially a revisiting of the age old complaint that academics are distanced from practice and hence do not produce "relevant" research. Would the authors really contend that research into the appropriate use of antibiotics for upper respiratory tract infections,[2] for example, was irrelevant?

This editorial ignores the contribution of academic practice to developing the methods of measuring change and complexity at the level of the general practitioner-patient interaction. That we can apply complex models, health services research, and qualitative methods is largely due to the growth of multidisciplinary academic primary care based in universities in the United Kingdom.

Kernick et al's biggest mistake is to consider primary care academics as general practitioner academics; this is patently not the case. At the 1999 annual meeting of the Association of University Departments of General Practice one could discover that most of the association's members are not general practitioners (they are a diverse mix of statisticians, epidemiologists, social scientists, nurses, etc). At the meeting the editor of the *BMJ* commended the discipline for bringing new methods and the health services research agenda into medical research. It is precisely because of the growth of academic primary care that we can now even consider pragmatic approaches to the evaluation of quality in service delivery. Without the academic base that has been created over the past 25 years these approaches would be impossible.[3]

General practitioner academics continue to practise, with many (if not most) working in challenging inner city environments. They play a part in developing new methods of service delivery in local personal medical services pilots and primary care groups. The additional role for academics is in ensuring the highest quality of research to support the development and practice of primary care. Without the protected time and university based career pathway to ensure both wide training in appropriate methodologies and membership of a multidisciplinary research team, primary care research would lack rigour. We would turn the clock back 40 years to when research was conducted exclusively by specialists; general practitioners then were concerned only with service delivery, with little regard to the quality of service delivered.

The primary care research agenda needs both controlled generalisable research, such as primary care based randomised controlled trials, and assessments of service delivery with a strong focus on local ownership and relevance. It doesn't need moving: it needs extending.

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2 Little PS, Williamson I, Warner G, Gould C, Gantley M, Kinmonth AL. An open randomised trial of prescribing strategies for sore throat. *BMJ* 1997;314:722-7.
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Academic GPs can get research ideas from their experiences in practice

EDITOR—Kernick et al's editorial on the research agenda in primary care was thought provoking, and I am sure it will have rattled several academic departmental cage.[1] Many of the criticisms of the old system that informed the authors' ideas, however, are based on anecdote rather than evidence. For example, the authors assert that "funding spirals, assessment exercises, and internal politics often divorce research practitioners from their service commitments." They also suggest that research questions are "often irrelevant to everyday practice." The reality, based on the responses to a postal questionnaire sent to all 121 eligible junior academic general practitioners in the academic departments of general practice in the United Kingdom and Dublin (response rate 89%) shows a very different picture.[2]

Most (47%) of the respondents were profit sharing partners, and a further 20% were salaried partners. The mean number of academic sessions a week was 4.5 (SD 2.3; range 1-10). In other words, most of the general practitioners were still firmly committed to day to day general practice. The

main attraction of academic practice—mentioned by 29% of the respondents—was the opportunity to pursue research ideas generated from their day to day experiences in primary care and therefore as likely to be relevant as those generated by an initiative led by a primary care group.

The authors suggest that national structures would need to be developed to support and facilitate their new approach, ignoring the real gains made in recent years in the development of a supportive infrastructure for primary care research.[3] They also ignore the value of the cross cultural fertilisation of ideas that often accompanies multidisciplinary and interdepartmental university based research.

The authors recognise the evolution of research practice networks that foster "bottom-up research." Similarly, they note that healthcare issues are "complex, multidimensional, and grounded in individual experience." I would propose that only when healthcare providers establish a symbiotic relation with academic departments, staffed by experienced researchers and with established links to the many different disciplines that are involved in research of relevance to primary care (statistics, epidemiology, health economics, psychology, linguistics), can quality research be performed cost effectively.

Such collaborative partnerships are, I would suggest, a more productive option than confrontation and sabre rattling.

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2 Lester HE, Carter YH, Dassu D, Hobbs FDR. Survey of research activity, training needs, departmental support, and career intentions of junior academic general practitioners. *Br J Gen Pract* 1998;48:1322-6.
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RCGP is encouraging improvements in primary care research

Editor—The need for the development and expansion of the research base in primary care in the United Kingdom is now widely accepted, and Kernick et al's editorial goes some way in suggesting how we might better approach this.[1] In particular the authors emphasise the need for a cultural change to ensure that research is firmly at the heart of everyday practice, and they suggest that the Royal College of General Practitioners' scheme for the accreditation of research practices could be a key component in achieving such a shift.[2]

The infrastructure of primary care research has been changing over recent years, with United Kingdom governments proposing to double the proportion of research money spent on primary care.[3] These moves reflect the increased importance of primary care as outlined by the Mant report[4] and the Medical Research Council's topic review.[5] Kernick et al identified research practices as key to sustaining such changes. The first research practice was appointed by the Royal College of General Practitioners in 1994 and given limited financial support to cover infrastructure costs. Since then we have seen similar developments through regional research and development offices and nationally through the first round of Culyer awards.

Recent policy documents have emphasised the need for development of the primary care research and development capacity, including the development of a national framework of accredited research practices. The primary care topic review was part of the 1999 NHS research and development strategic review led by Professor Michael Clarke and has made recommendations on how research should be prioritised in the future. This should inform the next big round of bids in 2000.

The Royal College of General Practitioners' scheme is currently in the pilot phase, involving practices in the South West region and East London and Essex. Relevant dimensions for assessment include education and training, organisation and management, and research ethics, as well as research output. The scheme also recognises the need for research practices to feed into the primary care agenda through, for example, standards relating to the involvement of patients in research.

Strategically, the development of the scheme into a national system for accreditation will allow research practices to have an achievable high standard to aim for and provide a "quality marker" that may be useful to both patients and funding bodies.

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Patient surveys identify needs

Editor—Cleary is right to exhort us to undertake patient surveys to improve the quality of care provided.[1] Surveys are particularly important with regard to ethnic minority populations since, because of different languages, they may find it difficult to communicate their experiences or may be generally less forthcoming than others.

We undertook surveys of the provision of hospital services in Middlesbrough to ascertain the needs of Asian people. As a result, appropriate services were made available and satisfaction levels were improved.[2] A further survey highlighted the need for continuous monitoring, since some aspects—for example, provision of interpreting services—had not been fully implemented.[3]

The second survey was extended to ascertain views on and use of a range of clinical services, including family planning, cervical smear and breast examination tests, and other settings including primary care.[3 4] An interesting finding was the high level of satisfaction with many aspects of healthcare provision—for example, over 90% of Pakistani people were very satisfied or satisfied with the care received in inpatient and outpatient departments and from their general practitioners.

In conclusion, therefore, patient surveys can, and should, be undertaken. They can not only identify needs and help in the planning of better services but also dispel some myths: the feedback is not always negative. The surveys are most beneficial if they are part of the continuous quality improvement programme.

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Patients need more than written prompts for communication to be successful

Editor—We were interested in Slowie's suggestions on helping patients to communicate better with them[1] as we recently carried out a randomised controlled trial to test a written prompt to aid doctor-patient communication in an outpatient setting.[2] We sent a letter and help card to a random sample of patients at home before their appointment to encourage them to prepare and prioritise questions to ask the doctor at the consultation. The letter (explaining that questions would be expected but were not obligatory) was designed to give patients permission to ask questions.

The help card was pocket sized and included suggested generic questions (for example, about diagnosis, cause, prognosis, tests, treatment alternatives) and also had space for patients to list their own questions. After their consultation patients were sent a postal questionnaire to complete at home. Analysis of the questionnaires provided quantitative and qualitative data about patients' information requirements and whether they were fulfilled.

Half the patients who were sent a help card said that they had got more out of their consultation as a result, yet few significant

differences were found between the group sent a help card and the control group. Our results highlight the difficulties that outpatients have in asking questions and discussing topics fully at their initial consultation, even when they have thought of questions in advance. Some of the patients still did not feel able to refer to their cards during the consultation, perhaps because of a fear of being labelled difficult.[3]

A written prompt may help new patients to focus on their appointment and think of questions beforehand, and this may help them to get more out of their consultation. Patients also, however, need help and encouragement from staff during the consultation if communication is to be successful.

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Risk assessment is open to public interpretation

Editor—Sarah Darby says that the media should work harder to convey clear information on risks to the public, and that psychologists should work to identify why people worry about risks that seem statistically small.[1] Although she endorses public debate, the main role of the public seems to be to receive scientific wisdom, on the basis of which it is assumed that a rational decision will be made. Her focus on clear information is welcome, but the overall position is limited.

Risk assessment entails the scientific assessment of the size and nature of a risk, followed by the decision on whether or not to accept the risk. The second stage is a sociopolitical process, rather than a scientific one. The public uses a broader set of factors when assessing risk than are usually considered by scientists.[2] Factors such as voluntariness, immediacy, dread, and revulsion influence people's assessment of the risk from a particular process or activity. These elements of risk assessment are difficult to quantify and modify. Although greater technical knowledge and understanding about a particular risk are often associated with greater acceptance of the risk, this relationship is not seen in every situation.

The political dimension of risk communication has been considered by several authors.[3] Science is not a value free pursuit, and the interpretation and dissemination of scientific data on risk is inevitably influenced by the vested interests of the risk communicator. Even in the absence of conflicts of interest, scientists and doctors can reach different conclusions from the same evidence. In the past, the public has depended on risk assessment communicated through intermediaries, including scientists, politicians, and expert groups. Diminishing public confidence in institutions, and in the prestige of professional groups generally, is eroding public acceptance of the information and recommendations offered by such intermediaries.[4] Public confidence is further diminished by the failure of institutions to pursue consistent, rational policies towards health risks.

We agree with Darby that provision of clear information is important, but we should also be prepared to debate the interpretation and value of the information available and not assume that the public will accept the risk assessment of institutions and professional bodies. Even when the size of the risk can be agreed on, the general public or parts of a local community may decide that the nature of the risk makes it unacceptable at any level.

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Medical ethicists do not conform to stereotypes in *ER*

Editor—Having worked in an American hospital for seven years as an ethicist, I find Macnair's assertions in her article on medical ethics to be inaccurate.[1]

She states: "US ethicists lurk around the hospital armed with a bleeper waiting to be called whenever an ethical dilemma crops up."

We neither lurk in the corridors nor tout for business. Macnair implies that we rush furtively from one potential crisis to another, trying to drum up business like a car salesman. Nothing could be further from the truth. As medical ethics is a fairly new discipline, we are aware of the damage that can be done by a "lone ranger" and work hard to dispel such a stereotype. In fact, patients, families, or members of the clinical team who are in conflict or distressed about a case usually initiate case consultations.

Additionally, Macnair asserts, without a supporting reference, that medical ethicists "may be given as little as 15 minutes to provide the definitive ethical answers on problems."

We do not purport to know or provide definitive ethical answers, should such things exist. The function of an ethicist is to work with ethics committees or the case consultation team to gather relevant information, discuss the issues or principles that may be in conflict, and help those concerned (patients, families, and clinical team members) to reach the best possible decision to meet their needs. Such a process cannot usually be completed in 15 minutes.

It has been my practice and that of my colleagues to foster an environment in which patients, families, and staff are able to ask for guidance on ethical matters. It is both positive and reassuring for those facing ethical dilemmas to know that help and support are available.

Clearly, Macnair has had limited exposure to the role of the healthcare ethicist in America and I would caution her not to overgeneralise. Although some people will always practise on the fringe of any profession, I would encourage Macnair to avoid the stereotypes portrayed in *Chicago Hope* and *ER*; they are both inaccurate and demeaning.

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Quality at general practice consultations

Time may not lead to quality

Editor—Howie et al claim from their study that the outcome of a consultation in general practice is better if more time is given and if the patient knows the doctor well.[1] This conclusion is based on the use of an enablement questionnaire, a high score after a consultation meaning a successful consultation. The authors claim that this is a measure of quality of care, assuming that the degree of enablement predicts outcome. If this assumption is false, then what has been measured in this study? It is simply the degree of doctor as drug.

The study then shows that patients who are given more time in a consultation feel more enabled. The authors conclude that therefore there should be incentives to persuade more doctors to give longer consultations. This study does not show that patients feel more enabled when doctors who generally give quick consultations swap to giving longer ones. The sort of doctor who decides to give longer consultations may simply be the sort that patients feel better with.

The study shows that patients who expect a prescription but do not get one feel

less enabled. Howie et al do not conclude from this that there should be incentives to increase prescribing and that more prescribing produces higher quality—and rightly so, for the study only gives vaguely supportive evidence for this. The authors seem to have drawn only the conclusions they wanted. The rewards should be given for better rather than more prescribing. In the same way, the rewards should be given to those who give better rather than longer consultations.

The conclusion in the abstract should simply be that more study is needed on this subject, and I hope that no health service managers impose an expensive incentive scheme on general practice before there is more evidence.

I agree that short routine consultations are not good, but only because I believe that these may tempt doctors to make dangerous clinical short cuts.

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Authors' reply

EDITOR—We are glad that Kremer agrees with us that short routine consultations are to be discouraged as a preferred general consulting style. Not only do they tempt doctors to take short cuts but they reduce the likelihood that the comorbidity that patients would like to discuss (whether physical or psychosocial) will be either recognised or dealt with.[1 2]

Doctors who generally take more time are significantly more likely to be those who enable patients more and who enable more of their patients (we regard enablement as a desirable outcome in its own right—not simply as a measure of satisfaction, although it is related to it).[3] It is true that we do not yet know all the determinants of enablement, but it is indeed likely, as Kremer suggests, to include the interpersonal and communication skills that are still—for want of a better term—summarised as reflecting the doctor as drug.

Whether prescriptions are issued is interesting but not a major part of the complete picture. Doctors who enable their patients highly do not prescribe at 23% of consultations for acute illnesses in which patients would have liked a prescription; in comparison, doctors who enable their patients less do not prescribe at 31% of such consultations.

We are happy to agree that more work on defining better consultations and their determinants is needed. This includes trying to define which interventions will lead to improvement. A starting point would be to organise surgeries so that doctors do not end sessions with a batch of quick consultations to catch up with running late because of overbooking.

We are rather at a loss to see why Kremer is against the idea of rewarding doctors who make more of their patients feel better. Present reward systems seem loaded in favour of doctors who have the most outside commitments or the largest lists—both of which are opportunity costs for the longer consulting patterns we all agree seem desirable.

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Is germ cell harvest and storage justified in minors treated for cancer?

EDITOR—Experiments in ewes[1] and autologous ovarian grafting in an oophorectomised woman have focused research attention[2] on harvesting germ cells from female patients before they undergo sterilising cancer treatments—much as "sperm banking" has long been used for men. Epididymal aspiration and testicular biopsy are established methods of obtaining the "single" sperm necessary for intracytoplasmic sperm injection and successful reversal of male infertility due to azoospermia.[3]

Such technical advances have led to consideration of their application in children undergoing similar treatments causing sterility. Given that efficacy and safety are unproved, that there is no immediate therapeutic benefit for the child, and that fertility is a quality of life rather than quantity of life issue, we question whether such experimentation in minors with cancer is ethically justified by the science so far, which, though promising, remains young.[4]

A complicating factor is that the protection the Human Fertilisation and Embryology Act 1990 affords to (haploid) gametes of adults does not directly apply to (diploid) germ cells of prepubertal children.[5] Is consent to gamete storage under the act truly informed and freely given in minors who are pubertal and "Gillick" competent (deemed "of sufficient understanding and intelligence to comprehend," as ruled in the Gillick *v* Department of Health case in 1986).[4 5] In small, sick children, harvesting may carry greater operative risks and delay lifesaving treatment, whereas techniques for prolonged storage, future in vitro steps to maturation, and prolonged survival of any future autograft[1] have not been tried. Hence any research must fulfil ethical and legal criteria in establishing voluntary and valid informed consent.

Paediatric practice is underpinned by a professional requirement to act in the child's best interests. We urge caution in the application of new experimental assisted reproductive technologies in children, given the lack of a defined risk-benefit assessment, the advent of new, changing therapeutic regimens with differing gonadotoxicity, and more efficient assisted reproductive technologies such as intracytoplasmic sperm injection (and ovum donation), which necessarily reduce the certainty of future infertility.

A voluntary code of practice is urgently needed to ensure safety in this area. To this aim, we convened a multidisciplinary conference to consider specifically:

- Which groups of minors should be offered opportunities for fertility protection, and which groups should not
- Which harvest and storage methods are most appropriate
- How valid informed consent is best obtained
- The possible role of the Human Fertilisation and Embryology Authority in regulating this activity.

The report produced will be circulated for consultation and a working party will be convened to produce guidelines of best clinical practice in this (and other) indications where fertility of minors may be significantly compromised.

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