Letters

Website: **bmj.com**
Email: **letters@bmj.com**

Stored tissue may be important for the future care of families

EDITOR—Obtaining informed consent for storing tissue is problematic. Which normal clinical practices need written consent and what material constitutes tissue? In how much detail should a practitioner obtain consent for a blood sample taken for a full blood count or for biochemical analysis, and what information can or should be given about the ultimate fate of samples such as tumours removed at surgery?

These are not trivial questions: their answers lie at the heart of good clinical practice. Clinical geneticists are familiar with the need for and the difficulty in ensuring that patients have given fully informed consent before blood is taken for DNA analysis. The pace of advance has blurred the boundaries between today's research and tomorrow's clinical practice.[1] Clinical geneticists are often asked why written consent is required for some clinical tests but not others. Unsurprisingly, many patients and doctors are still confused about the difference between clinical genetic tests and genetic research.

As the Human Genetics Commission asks whose hands are on our genes, the long and distinguished history of clinical genetics in the United Kingdom and the contribution of clinical geneticists to ethical debate should be remembered. In genetic disease ethical considerations must be seen in the context of a family and a multigenerational history. Tissue samples from dead members of a family are often needed to detect gene defects and enable accurate diagnosis. This tissue often comes from stored surgical blocks, whose lack would compromise the care of current and future generations. Similarly, when a couple have lost a child with a potentially inherited condition, analysis of tissue from the dead baby may be crucial for accurate genetic counselling and future prenatal testing.

If too much restriction is placed on storing tissue and if obtaining consent becomes too complex, patients may well be disadvantaged by the very mechanisms aimed at protecting them. Indeed, the future may show how inappropriate it was that samples were not kept for future generations to allow them to benefit from advances resulting from the human genome project.

Future problems with storing pathological material must be avoided. The medical profession must work with patients to enable a fully informed debate about informed consent. Public education is needed to ensure that people are aware of the full consequences of their decisions in giving or withholding consent for pathological examination and storage of tissues.

Neva Haites *professor in medical genetics*
n.haites@abdn.ac.uk

Z Miedzybrodzka *senior lecturer in clinical genetics*
John Dean *consultant clinical geneticist*
Department of Medical Genetics, University of Aberdeen, Aberdeen AB9 2ZD

1 Department of Health, Advisory Committee on Genetic Testing (ACGT). Advice to research ethics committees. Available at: www.doh.gov.uk/genetics/recrev3.htm; accessed 17 Apr 2001.

Advice to authors

We prefer to receive all responses electronically, sent either directly to our website or to the editorial office as email or on a disk. Processing your letter will be delayed unless it arrives in an electronic form.

We are now posting all direct submissions to our website within 24 hours of receipt and our intention is to post all other electronic submissions there as well. All responses will be eligible for publication in the paper journal.

Responses should be under 400 words and relate to articles published in the preceding month. They should include ≤5 references, in the Vancouver style, including one to the BMJ article to which they relate. We welcome illustrations.

Please supply each author's current appointment and full address, and a phone or fax number or email address for the corresponding author. We ask authors to declare any competing interest. Please send a stamped addressed envelope if you would like to know whether your letter has been accepted or rejected.

Letters will be edited and may be shortened.

bmj.com
letters@bmj.com

Genetics and insurance: a possible solution

EDITOR—The interaction between clinical genetics and insurance is controversial. The remit of the government's Genetics and Insurance Committee is to assess the clinical and actuarial relevance of DNA test results to insurance practice. Its first ruling was that the industry could continue to use the results of DNA tests for Huntington's disease in underwriting applications for life insurance.

One way of dispelling much of the controversy surrounding genetics and insurance would be to establish whether access to insurance is a basic right. If, as perceived and endorsed by the government, it is not regarded as a right, then mutual insurance mechanisms should work according to the usual principles. Underwriters would seek to use the results of tests that have already been performed and the industry and the person seeking cover would want the same information about the risk being insured. The committee's decisions would then be free of questions about equity and justice. If society rejects that view, access to solidarity style cover is required. No government in the United Kingdom is likely to extend the welfare state to such insurance provision, given that the Scottish Executive alone seems to want to implement fully the recommendations of the Royal Commission on Long Term Care.

A solution might be negotiable, given that governments generally want to privatise and that the insurance industry wants to sell cover at standard rates to as many people as possible. The British insurance industry recognised that many life insurance policies are bought as part of getting a mortgage, a step towards the fundamental human right of shelter, and agreed to disregard DNA test results for people arranging moderate cover (up to £100 000), with the mortgage for their main home. Income protection and insurance for critical illness and long term care are not big sellers. If the government gave tax relief on these premiums, companies might then offer standard rate policies to everyone who wanted moderate cover starting at the usual age, retaining the right to ask penetrating questions of people wanting large amounts of cover in unusual circumstances.

This solution would not only quell worries about fairness for people in families with inherited adult onset conditions but also give equity between them and others at high risk of claiming through no fault of their own. The subsidy from those at normal risk to both these groups would be overt, assuaging the majority's social conscience.

Virginia Warren *consultant in public health medicine*
BUPA (British United Provident Association), BUPA House, London WC1A 2BA
warrenv@bupa.com

Confidential inquiries should be funded in clinical genetics

EDITOR—The confidential inquiry into genetic counselling by non-geneticists (CEGEN) investigated free personal choice in consent for genetic screening, testing, or intervention in clinical records of non-directive genetic counselling. It audited 621 pregnancies affected by Down's syndrome in women over 34; 271 infants with neural tube defects; 46 infants with cystic fibrosis who had a full sibling with cystic fibrosis; 172 pregnancies affected by thalassaemia; and 212 people with multiple endocrine neoplasia type II. Adverse events were sought when cases lacked documentation of informed choice.

Clinical records were unacceptably poor, rarely showing whether genetic counselling had been offered or stating the reasons for accepting or rejecting an abortion. Less than half of cases known in advance to be at high genetic risk were referred to a clinical geneticist. Most couples with undetected thalassaemia were British Pakistanis; their records assumed that they would decline genetic abortion for religious reasons, but over 70% of British Pakistanis accept prenatal diagnosis offered in the first trimester.[1]

National guidelines, standardised antenatal records, and local written policies, with specific recommendations for Down's syndrome, neural tube defects, cystic fibrosis, β thalassaemia, and multiple endocrine neoplasia type II, are needed.[2] Audit of antenatal units found little awareness of the confidential inquiry or its recommendations, an apparent failure of interdisciplinary communication, and a lack of written policies. Policies varied widely in quality and important groups (community midwives) were often excluded from their drafting.[3]

Primary healthcare teams need to guide an informed public through genetic issues (confidentiality, testing of children, insurance). They require better genetic education and computerised records for disease registers and family history taking, as well as prompts for screening and interventions. Progress is impeded by inadequate Read coding for genetics, a deficiency becoming more urgent as disease is reclassified by genotype.

National standardised antenatal protocols must include genetic screening and testing sensitive to population ethnic profile and the realities of local secondary care provision. Referral protocols for patients with a family history of cancer will ensure effective use of resources (many are at low or population risk). Explanation of risk factors and preventive options must be provided by primary care.

An ethics driven genetic service must show that information and counselling facilitates unpressurised decision making. Confidential inquiry is an appropriate form of audit and should be recognised and funded as such. Its recommendations should be adopted by the National Institute for Clinical Excellence (NICE) so that everyone is familiar with acceptable standards.

Kirsty Challen *research assistant*
kirstychallen@hotmail.com

Hilary J Harris *research associate*
Rodney Harris *emeritus professor (medical genetics)*
Genetic Enquiry Centre, St Mary's Hospital, Manchester M13 0JH

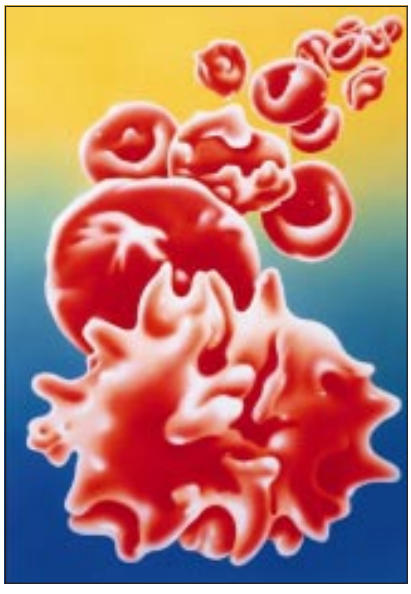
Bernadette Modell *emeritus professor (community genetics)*
Department of Primary Care and Population Sciences, Royal Free and University College London Medical School, London N19 5NF

Bruce Ponder *professor*
CRC Human Cancer Genetics Research Group, Box 238, Level 3, Laboratories Block, Addenbrooke's Hospital, Cambridge CB2 2QQ

Charles Rodeck *professor*
Department of Obstetrics and Gynaecology, University College London Medical School, London WC1E 6HX

The confidential inquiry into genetic counselling by non-geneticists (CEGEN) was funded by the Department of Health.

1 Modell B, Harris R, Lane B, Khan M, Darlison M, Petrou M, et al. Informed choice in genetic screening for thalassaemia during pregnancy: audit from a national confidential enquiry. *BMJ* 2000;320:337-41.
2 Harris R, Lane B, Harris HJ, Williamson P, Dodge J, Modell B, et al. National Confidential Enquiry into Counselling for Genetic Disorders by Non-geneticists: general recommendations and specific standards for improving care. *J Roy Coll Obstet Gynaecol* 1999;106:658-63.
3 Lane B, Challen K, Harris HJ, Harris R, Williamson P, Dodge J, et al. Existence and quality of written antenatal screening policies in the UK: a postal survey. *BMJ* 2001;322:32-3.



JOHN BAVOSI/SPL

Distorted red blood cells of thalassaemia: many patients are not offered genetic counselling

Screening for familial hypercholesterolaemia

Funding is difficult to obtain but screening can be international

EDITOR—Bhatnagar et al highlighted the cost effective approach of screening family members of probands with the dominant condition of familial hypercholesterolaemia to identify affected relatives at high risk for atheromatous vascular disease.[1] We would like to raise three additional points.

Firstly, patients with clinical features of familial hypercholesterolaemia are often not given an accurate diagnosis unless they come to the attention of a physician interested in lipid disorders. Examination of the Achilles tendons for xanthoma is often overlooked during the routine physical examination, even in patients with very high plasma concentrations of cholesterol and obvious xanthelasmata or prominent premature corneal arcus, so that the precise clinical diagnosis of familial hypercholesterolaemia, with the implications for family screening, may not be made.

Even cardiologists who have a direct interest in the consequences of the disease may not diagnose it because of a preoccupation with the acute events, intervention procedures, and rapid transfer or discharge of patients before plasma concentrations of cholesterol are available.[2] All doctors should therefore be aware of the familial nature of this condition so that probands can be identified and referred to specialist lipid clinics or other facilities that can undertake family screening.

Secondly, although this type of screening is cost effective, it remains difficult to obtain funding.[3] In Hong Kong we screened more than 300 family members of probands for a postgraduate degree study without any specific funding except for a research grant for genetic studies in a subgroup of these patients.[4] Funding for such activities should be available from government health services as this saves costs in the long term, but many health service providers may not regard this as a priority, especially as the treatment of affected subjects will result in an increase in short term expenditure on drug budgets.

Lastly, the screening of family members does not have to be restricted by national boundaries in these days of rapid easy communication. About half of the families we screened had members living in other countries, and members of an extended family in Hong Kong and Singapore have been identified with the same mutation. This approach to the identification of subjects with genetic disease was championed by the late Professor Roger Williams, who initiated the MEDPED (make early diagnosis, prevent early deaths) organisation.[5] Currently more than 28 countries have enrolled over 25 000 patients with familial hypercholesterolaemia in a major international collaboration funded by various international healthcare agencies and pharmaceutical companies to identify subjects with this serious but treatable genetic condition.

Brian Tomlinson *professor*
btomlinson@cuhk.edu.hk

Irene Wei Lan *research assistant*
Division of Clinical Pharmacology, Department of Medicine and Therapeutics, Chinese University of Hong Kong, Prince of Wales Hospital, Shatin, Hong Kong Special Administrative Region, China

Ian Hamilton-Craig *chairman, MEDPED (Asia-Pacific)*
North Adelaide, South Australia 5006, Australia

The MEDPED Australia website is www.medped-aust.com

1 Bhatnagar D, Morgan J, Siddiq S, Mackness MI, Miller JP, Durrington PN. Outcome of case finding among relatives of patients with known heterozygous familial hypercholesterolaemia. *BMJ* 2000;321:1497-500. (16 December.)
2 Dorsch MF, Lawrance RA, Durham NP, Hall AS. Familial hypercholesterolaemia is underdiagnosed after AMI. *BMJ* 2001;322:111. (13 January.)
3 Neil HAW, Hammond T, Huxley R, Matthews DR, Humphries SE. Extent of underdiagnosis of familial hypercholesterolaemia in routine practice: prospective registry study. *BMJ* 2000;321:148.
4 Mak YT, Pang CP, Tomlinson B, Zhang J, Chan YS, Mak TW, et al. Mutations in the low-density lipoprotein receptor gene in Chinese familial hypercholesterolemia patients. *Arterioscl Throm Vas* 1998;18:1600-5.
5 Williams RR, Schumacher MC, Barlow GK, Hunt SC, Ware JL, Pratt M, Latham BD. Documented need for more effective diagnosis and treatment of familial hypercholesterolemia according to data from 502 heterozygotes in Utah. *Am J Cardiol* 1993;72:18D-24D.

Early identification and treatment of patients is important

EDITOR—Familial hypercholesterolaemia is the commonest single gene disorder, thought to affect about one in 500 of the population in the United Kingdom. It is treatable with statins. As Bhatnagar et al point out in their study,[1] the risk of developing cardiovascular disease in affected people is far higher than the Framingham data would suggest. For affected men aged 30-50, the risk is almost 100-fold compared with unaffected men.[2] Early identification and treatment of such patients is important, and their subsequent treatment is likely to be efficient in preventing early onset coronary heart disease and thus highly cost effective. The best place to start is in already defined family groups.

In our study of 38 families with definite familial hypercholesterolaemia (tendon xanthomata present in at least one person) and 120 families with probable familial hypercholesterolaemia (no tendon xanthomata recorded but all the other features of familial hypercholesterolaemia), we identified the responsible mutation in 30 (79%) and 22 (18%), respectively.[2,3] Since then the proportion in families with definite familial hypercholesterolaemia has increased to 90% with the description of cryptic splice defects in the intron region of the low density lipoprotein receptor gene.[4]

Using these results, we have also adopted the approach of nurse led family screening. A specialist part time nurse visits the families in their own home, seeing as many relatives as possible (not just first degree relatives). The degree of compliance is high; almost every family group approached has been keen to avail themselves of this facility. Although we and others initially considered possible psychological upset, this does not seem to have been a problem in practice.

Screening for defined mutations is more specific than measuring cholesterol concentrations, and wherever possible it should be used to confirm the clinical diagnosis. This will permit accurate identification of affected persons at a young age and will distinguish the presence of familial hypercholesterolaemia from coincidental polygenic hypercholesterolaemia occurring in the same kindred. Using cholesterol alone can result in overlap between affected and unaffected people, which could lead to conflicting advice.[5] This does, however, raise the question whether the risk of cardiovascular disease is related to the mutation itself or to the degree of cholesterol elevation. The answers to these and other questions, such as response to treatment with different mutations, are likely to be found in longer term studies of the genotype:phenotype correlation.

We support the approach of the Manchester group and the setting up of a national database of patients with familial hypercholesterolaemia to complement the work of the Simon Broome Trust.

Paul Nicholls *consultant physician*
Royal Group of Hospitals and Dental Health and Social Services Trust, Royal Victoria Hospital, Belfast BT12 6BA
dp.nicholls@royalhospitals.n-i.nhs.uk

Ian Young *professor of medical biochemistry*
Royal Victoria Hospital, Belfast BT12 6BA

Kelly Lyttle *specialist nurse*
Colin Graham *consultant in molecular genetics*
Department of Medical Genetics, City Hospital, Belfast BT9 7AB

1 Bhatnagar D, Morgan J, Siddiq S, Mackness MI, Miller JP, Durrington PN. Outcome of case finding among relatives of patients with known heterozygous familial hypercholesterolaemia. *BMJ* 2000;321:1497-500. (16 December.)
2 Steering Committee, Simon Broome Register Group. Risk of fatal coronary heart disease in familial hypercholesterolaemia. *BMJ* 1991;303:893-6.
3 Graham CA, McClean E, Ward AJM, Beattie ED, Martin S, O'Kane M, et al. Mutation screening and genotype:phenotype correlation in familial hypercholesterolaemia. *Atherosclerosis* 1999;147:309-16.
4 Kirk CW, Graham CA, Lyttle K, Beattie ED, Nicholls DP. A cryptic splice mutation (ivs 12 + 11 c > g) in the ldlr gene in five families with familial hypercholesterolaemia. *J Med Genet* 2000;37(suppl 1):S73.
5 Ward AJ, O'Kane M, Nicholls DP, Young IS, Nevin NC, Graham CA. A novel single base deletion in the LDLR gene (211delG): effect on serum lipid profiles and the influence of other genetic polymorphisms in the ACE, APOE and APOB genes. *Atherosclerosis* 1996;120:83-91.

Screening for medium chain acyl-CoA dehydrogenase deficiency is being evaluated

EDITOR—Tanner et al write that the effectiveness of screening neonates for medium chain acyl-CoA dehydrogenase deficiency has still not been completely evaluated.[1] Evaluation of population based screening is a two part process. Firstly, the likely benefits and costs are assessed before the screening is introduced; and, secondly, an investigation is subsequently done into whether these calculations are borne out in practice.

The United Kingdom's health technology assessment process has undertaken the first step of its evaluation process to assess the likely benefits and costs. Two systematic reviews concluded that medium chain acyl-CoA dehydrogenase deficiency fulfils all[2] or most[3] of the criteria for a screening programme. The one criterion not clearly satisfied is that the natural course of the disorder is well defined. Yet the only practical way to gather the population data needed to calculate the long term benefits of screening for this disorder is through population screening that uses tandem mass spectrometry.[3,4]

The first of the health technology assessment reviews called for a large pilot study using tandem mass spectrometry.[2] It would establish technical robustness, screening and diagnostic criteria, and general practicability, as well as document the effectiveness of neonatal screening using tandem mass spectrometry for a range of conditions, not just medium chain acyl-CoA dehydrogenase deficiency.

Several screening programmes of newborn infants in the United States and other countries have introduced tandem mass spectrometry on a pilot basis in limited geographic areas. Tanner et al object, saying that this is tantamount to tandem mass spectrometry being "introduced without trials."[1] A pilot study is not the same as a randomised trial. The purpose of a randomised controlled trial is to establish clinical efficacy. In contrast, a pilot study is intended to work out logistical and practical issues under routine programme conditions before the programme is implemented on a larger scale, and to compile data on outcomes in a defined population.

Massachusetts has introduced tandem mass spectrometry on an investigational basis, with screening for medium chain acyl-CoA dehydrogenase deficiency conducted on the same basis as that for established conditions, while screening for other conditions detectable through tandem mass spectrometry is performed on an investigational basis.[5] The data being collected in Massachusetts and elsewhere should satisfy most of the specific aims for the pilot study of screening recommended by the health technology assessment review.[2]

Scott Grosse *health economist*
Office of Planning, Evaluation, and Legislation, National Center for Environmental Health, US Centers for Disease Control and Prevention, Mail Stop F-29, Atlanta, GA 30341, USA
sgrosse@cdc.gov

1 Tanner S, Sharrard M, Cleary M, Walter J, Wraith E, Lee P, et al. Screening for medium chain acyl-CoA dehydrogenase deficiency has still not been evaluated. *BMJ* 2001;322:112. (13 January.)
2 Pollitt RJ, Green A, McCabe CJ, Booth A, Cooper NJ, Leonard JV, et al. Neonatal screening for inborn errors of metabolism: cost, yield and outcome. *Health Technol Assess* 1997;1(7):1-202.
3 Seymour CA, Thomason MJ, Chalmers RA, Addison MJ, Bain MD, Cockburn F, et al. Neonatal screening for inborn errors of metabolism: a systematic review. *Health Technol Assess* 1997;1(11):1-95.
4 Wang SS, Fernhoff PM, Hannon WH, Khoury MJ. Medium chain acyl-coA dehydrogenase deficiency (MCADD). *Genet Med* 1999;1:332-9.
5 Atkinson K, Zuckerman B, Sharfstein JM, Levin D, Blatt RM, Koh HK. A public health response to emerging technology: expansion of the Massachusetts newborn screening program. *Public Health Rep* (in press).

Collusion in doctor-patient communication

Patients rarely regret optimism

EDITOR—Imminent death is not the inevitable consequence of a diagnosis of small cell lung cancer, as The et al say in their paper.[1] They are wrong in saying that life expectancy is a maximum of two years. A recent

analysis of patients on the National Cancer Institute's database showed a five year survival of 12.2% in patients with limited stage disease.[2] Remission and prolonged survival can be achieved only by active treatment with chemotherapy and radiation, and yet The et al report that patients familiar with the plight of incurable cancer refused treatment. This will certainly have compromised the survival of those patients, and yet it seems that The et al are advocating that all patients should be similarly persuaded of the hopelessness of their situation.

It remains true, however, that most patients will die of their disease within two years, but we believe that the false optimism that is reported is not a problem that needs to be overcome. It is a common coping strategy adopted by patients who, as The et al describe, often do know but cope by putting on the appearance of not knowing their prognosis. This allows them to lead their lives as fully as possible. It is not helpful and certainly not compassionate to insist that patients openly acknowledge their poor outlook. The et al describe a consultation in which the patient has to resort to pleading, "Please doctor, will you stop it?"

The et al conclude that most patients regret maintaining optimism. They quote only one anecdote to support this. Our experience suggests the opposite: that patients and their families rarely regret their period of optimism as this allows them to go on holiday and make plans, which they would not be motivated to do if they were waiting to die. For any patient faced with life threatening disease, it is hope and the triumph of optimism over reality which makes life bearable. It is wrong to suggest that this optimism needs to be taken away from patients for their own good.

Noelle O'Rourke *consultant in clinical oncology*
norourke@tinyworld.co.uk

Ann Barrett *professor of radiation oncology*
Richard Jones *consultant in clinical oncology*
Carrie Featherstone *registrar in clinical oncology*
Vivienne Hughes *registrar in clinical oncology*
Beatson Oncology Centre, Western Infirmary, Glasgow G11 6NT

1 The A-M, Hak T, Koeter G, van der Wal G. Collusion in doctor-patient communication about imminent death: an ethnographic study. *BMJ* 2000;321:1376-81. (2 December.)
2 Janne PA, Freidlin B, Saxman S, Johnson BE. The survival of patients treated for limited stage small cell lung cancer has increased during the past 20 years. *Lung Cancer* 2000 29(S1):314.

Specialist palliative care staff could act as treatment brokers

EDITOR—The et al in their paper describe the generation of false optimism about recovery and its ultimate cost to patients with small cell lung cancer and their relatives in terms of regrets and unfinished business.[1] The stories told in this study will be familiar to all those concerned with caring for patients with advanced cancer, whether in hospital or in the community.[2] Breaking the cycle of collusion is difficult, because , as The et al acknowledge, awareness cannot be forced on the patient: it can only be supported. They suggest a solution to the problem may be the involvement of "treatment brokers" acting outside the doctor-patient relationship.

In the United Kingdom members of specialist palliative teams can act as such brokers if they are involved at any early stage in the illness. Oncologists may be perceived as activists, and patients may collude with them to confine discussion to treatment plans. The participation of specialist palliative care doctors or nurses in joint consultations with oncologists would give patients an opportunity to pause and assimilate the seriousness of the bad news, and a chance to come to terms with the reality of their situation. They would thus be better equipped to make informed decisions about their future care.

David Jeffrey *Macmillan lead consultant palliative care*
Three Counties Cancer Centre, Cheltenham General Hospital, Cheltenham GL53 7AN
david@todairy.freeserve.co.uk

1 The A-M, Hak T, Koeter G, van der Wal G. Collusion in doctor-patient communication about imminent death: an ethnographic study. *BMJ* 2000;321:1376-81. (2 December.)
2 Jeffrey D. *Cancer, from cure to care.* Manchester: Hochland and Hochland, 2000.

Knowing is not always best

EDITOR—The study by The et al of approaches to death is an important advance, but its assumption should be questioned—namely, that it is usually in patients' best interests to know in full, at an early stage, about the likely time and mode of their death.[1] Patients' and doctors' supposedly harmful "collusion" in avoiding the issue is often therapeutic in the long as well as the short term.

When one of my close relatives was diagnosed as having late stage terminal cancer, the remaining year of her life was made much easier for her and us by the apparent hope offered by chemotherapy and the focus on the comparatively trivial day to day changes in her wellbeing. Death was not openly discussed with my family until six weeks before the end, and I for one did not feel shortchanged by having such a short time to say goodbye. I would prefer to spend six weeks dying rather than a year.

To give an extreme hypothetical example: if ever we were to gain the ability to predict well in advance our own time and mode of death exactly, who in their right mind would want to live out their life knowing that information?

And as anyone who has gone through "hypochondriacal medical student syndrome" may testify, it is not always best to be in the know.

Tom Ball *fifth year medical student*
Imperial College Medical School, London W2

1 The AM, Hak T, Koeter G, van der Wal G. Collusion in doctor-patient communication about imminent death: an ethnographic study. *BMJ* 2000;321:1376-81. (2 December.)

Doctors should adopt patient's perspective

EDITOR—As a so called survivor of cancer I welcome the paper by The et al examining doctor-patient communication on imminent death.[1] Like others, I am quite angry about the lack of honesty I see in oncology; does the pronouncement of "you have cancer" give the oncologist the right to present information to a patient in a way that controls treatment decisions by patients? I certainly believe that that is what happened in my case, and I have watched countless others misled into false hope, often given chemotherapy until they die. These people become tied into this treatment plan and spend their last months and days in medical facilities instead of living their lives.

The et al did not, however, mention the enormous pressure that healthcare providers, families, and society in general put on patients with cancer to have treatment, even in the face of certain death; we are made to feel guilty on many levels if we do not comply with the oncologist's suggestions. Many patients are really not making informed decisions if doctors provide only enough information to insure patients have life altering treatments that are often not fully explained. That sliver of hope becomes a giant expectation of survival on the part of the patient and family.

If my cancer returns, which is probable as I have advanced breast cancer with nodal involvement, I will stay as far away from oncologists as possible and live my life to the fullest. I am saddened when I see people tied into treatment even if it does give them a few more months because most of them do believe, as The et al pointed out, that by undergoing treatment there is still hope, even when there is none. Those working in oncology need to take a look at their specialty and ask for whose benefit the treatment is—the patient's or the doctor's. So many times it is about the doctor and his or her ego and what he or she thinks is right instead of what the patient really wants. What arrogance.

Kitty McCague *journalist*
202-B Oak Street, Washington, MO 63090, USA
krazykat@usmo.com

1 The AM, Hak T, Koeter G, van der Wal G. Collusion in doctor-patient communication about imminent death: an ethnographic study. *BMJ* 2000;321:1376-81. (2 December.)

Bicycle helmets

Risk taking is influenced by people's perception of safety and danger

EDITOR—Rivara et al in their editorial on bicycle helmets offer the study by Cook and Sheikh in the same issue as representative of evidence that has persuaded them of the benefits of wearing helmets.[1 2] The first calculation presented by Cook and Sheikh does not inspire confidence in the rigour of their study—35 056 cycling injuries are 0.28%, not 2.8%, of 12.6m hospital emergency admissions. They say that the 24.2% decrease in numbers of head injuries that they report from 1991 to 1995 is attributable to the increase in helmet wearing but present no evidence either of the magnitude of this increase or of any change in mileage cycled.

The official record shows that the number of cyclists killed and seriously injured per 100m km cycled increased by 8.6% whereas the figure for all drivers and riders decreased by 16.7% (for fatalities the figures are 0 and –20% respectively). These statistics indicate that any decrease in cyclists' head injuries over this period has been more than offset by increases in other serious and fatal injuries among cyclists.

In their Cochrane review, Thompson et al used the dubious tactic of attributing to one of us (MH) the argument that helmeted cyclists feel "invincible"—a word not used—"and therefore ride in a more reckless manner," and they then say that they believe these arguments to be specious.[3] In their editorial they again attribute to MH an argument he does not make—that the risk to cyclists is unchanged by helmet wearing. The wording of the relevant part of his report states: "Cyclists are less likely to ride cautiously when wearing a helmet owing to their feeling of increased security. In this way, they consume some, if not all, of the benefit that would otherwise accrue from wearing a helmet."[4]

Thompson et al dismiss the overwhelming evidence that risk taking is influenced by a person's perception of safety and danger.[5] The onus of proof lies on those who argue that cyclists are the unique exception to this well established behavioural phenomenon.

John Adams *professor*
Department of Geography, University College London, London WC1H 0AP

Mayer Hillman *senior fellow emeritus*
Policy Studies Institute, London NW1 3SR

1 Cook A, Sheikh A. Trends in serious head injuries among cyclists in England: analysis of routinely collected data. *BMJ* 2000;321:1055. (28 October.)
2 Rivara FP, Thompson DC, Thompson RS. Bicycle helmets: it's time to use them. *BMJ* 2000;321:1035-36. (28 October.)
3 Thompson DC, Rivara FP, Thompson R. Helmets for preventing head and facial injuries in bicyclists. In: Cochrane Collaboration. *Cochrane Library.* Issue 3. Oxford: Update Software, 2000.
4 Hillman M. *Cycle helmets: the case for and against.* London: Policy Studies Institute, 1993.
5 Adams J. *Risk.* London: University College London Press, 1995.

Debate is counterproductive

EDITOR—Whereas one could claim that Cook and Sheikh in their paper are presenting facts, the editorial by Rivara et al is biased, if not narrow minded.[1 2] I have three main objections against the editorial's conclusions.

Firstly, the objections of many cyclists' organisations do not so much concern the question of whether a helmet is effective in reducing the risk of head injury. They concern much more a side effect of helmet legislation and helmet promotion: its impact on the level of bicycle use. There is clear evidence that compulsory helmet wearing has a negative impact on cycle use. Whether this is also true for campaigns to promote helmet wearing is not clear, but such campaigns contribute to a (false) perception of cycling as being disproportionately dangerous. As cycling (as a means of exercise) has a positive impact on health, the key question concerns the balance between the gain of reduced head injury on the one side and the loss of health effects of cycling by a decline of cycle use on the other hand. This is not addressed at all in the editorial. Several people have argued that the positive (life extending) health effects of cycling outnumber the negative health effects of road accidents involving cyclists by a factor 20. The implication is that one should be very cautious with any policy that could have an adverse effect on the use of bicycles.

Secondly, I cannot understand why the helmet debate is so exclusively a debate about cycling. Head injuries occur to all road users. It would only be logical if the debate of helmet wearing should be extended to car drivers and pedestrians as well. There is no evidence that cyclists have a disproportionate risk of head injury in comparison with other road users.

Thirdly, the helmet debate is diverting the attention from the policies that could be much more effective in increasing cyclists' safety. It is illustrative that the helmets debate is most fierce in those countries where cyclists have few rights and facilities. Traffic calming and good bicycle infrastructure are much more effective when it comes to preventing casualties and injuries (including head injuries).

Tom Godefrooij *senior policy officer*
Fietsersbond (Dutch Cyclists' Union), PO Box 2828, 3500 GV Utrecht, Netherlands
godefrooij@fietsersbond.nl

1 Cook A, Sheikh A. Trends in serious head injuries among cyclists in England: analysis of routinely collected data. *BMJ* 2000;321:1055. (28 October.)
2 Rivara FP, Thompson DC, Thompson RS. Bicycle helmets: it's time to use them. *BMJ* 2000;321:1035-36. (28 October.)

Using helmets alone will not prevent serious bicycle injuries

EDITOR—Cook and Sheikh report a 24% reduction in serious head injuries to cyclists in England across a four year interval, roughly from 1991 to 1994, during which the number of injured cyclists admitted to hospitals remained essentially constant.[1] This reduction is noteworthy and cries out for rigorous analysis. Cook and Sheikh speculate that increased use of cycle helmets could have been a major causal agent but offer no data on this point. In so far as the decline in cyclist head injuries was not tied to an increase in helmet usage, the suggestion in the editorial by Rivara et al, that cycle helmets should be mandatory, was astonishing.[2] Rivara et al overlooked compelling evidence that reforming transport policies is key to reducing casualties among not only cyclists but other road users as well.

An increase in helmet use is unlikely to explain the reduction in hospital admissions with head injuries. Although Rivara et al cite five studies that found that helmets reduced the risk of head injury by 63-88%, these studies used emergency room presentations, which are primarily lower severity injuries than the hospital admissions used by Cook and Sheikh. The literature indicates benefit from helmet wearing decreases as injury severity increases. A report by the authors of the editorial illustrate this limitation; their data show that helmet wearing reduces the risk of hospital admission by 12% and severe injury by just 10%. Their summary, that prevention of serious bicycle injuries cannot be accomplished by using helmets alone, frames the issue nicely.[3]

Moreover, the same study provides a plausible hypothesis for the 24% reduction in cyclists' hospital admissions for head injuries. Of the various predictors of serious injury, collisions with a motor vehicle (odds ratio 4.6) dominated the other factors—bicyclist speed faster than 15 mph (odds ratio 1.2) and helmet use (odds ratio 0.9).[3] Limiting the capacity of motor vehicles to cause harm offers the greatest potential for reducing serious injuries to cyclists.

From January 1991 to December 1994, a period closely corresponding to that analysed by Cook and Sheikh, pedestrian fatalities in England declined by 25% whereas the number of cyclists killed declined by 29%.[4] Since we can be sure that pedestrians were not donning protective headgear, the search for explanations should look to changes in the overall road environment. The first half of the 1990s was a time of great change in governmental policy towards transportation. As the *BMJ* reported at the time, bicycle lanes, pedestrian priority areas, and traffic restrictions were part of the manifestos of both the Conservative and the Labour parties.[5] These changes in policy have paid off in continued large reductions in the number of people killed while walking and cycling—nearly halving the number of non-occupants killed in 10 years[4]—without compelling either pedestrians or cyclists to wear helmets.

Peter Jacobsen *public health consultant*
4730 Monterey Way, Sacramento, CA 95822, USA
jacobsenp@medscape.com

PJ owns shares in Bell Sports Corporation, manufacturers of helmets.

1 Cook A, Sheikh A. Trends in serious head injuries among cyclists in England: analysis of routinely collected data. *BMJ* 2000;321:1055. (28 October.)
2 Rivara FP, Thompson DC, Thompson RS. Bicycle helmets: it's time to use them. *BMJ* 2000;321:1035-36. (28 October.)
3 Rivara FP, Thompson DC, Thompson RS. Epidemiology of bicycle injuries and risk factors for serious injury. *Inj Prev* 1997;3:110-4.
4 Department of Environment, Transport, and Roads. *Transport statistics Great Britain: 1999 edition.* London: Stationery Office, 1999.
5 Godlee F. European cities move on banning cars. *BMJ* 1992;304:797-8.

Subsequences and consequences need to be distinguished

EDITOR—With reference to the articles by Cook and Sheikh and Rivara et al, cyclists were the only group of road users in the United Kingdom in whom the rate of fatalities increased during the 1990s, yet cycling was in decline all through that decade.[1 2] Cyclists were the only group to start wearing helmets during that time.

Cook and Sheikh selected 1991-5 for their study, when the country was in the

deepest recession since the second world war. Casualties and severity of injury fell for all road users. In 1994-8, fatalities among cyclists jumped by 25%, and cycle helmets became much more widely used. Maybe some helmeted cyclists believed that they had more protection than was actually the case? This increase in fatalities cannot be accounted for by any trend for other road users.

Scuffham et al studied the effects of voluntary helmet wearing in New Zealand during 1989-92, when the use of helmets rose from almost nothing to 65%.[3] They did not find a reduction in admissions for head injuries. Later, examining the effect of a law of 1994, which increased measured wearing rates to 95%, they concluded a reduction of 19% in admissions for head injury (including superficial injuries in their definition).[4] They admit that their results are inconsistent, maybe because they did not explain a disturbance in the injury trends during the years immediately preceding the law. Experience in the United Kingdom shows that, if there is a decline in cycling, the rate of injuries does not fall by as much. Proponents of helmets never take into account that any deterrence of cycling will increase the risk of death for those who continue to cycle.

Robinson's analysis of Australian legislation of 1989-92 showed that no prevention of head injury resulted from sharply increased helmet wearing.[5] The reduction in cycling (–35%) was much greater than the reduction in admissions for head injury (–15% to –20%), indicating an increase in risk, probably because of the reduction in cycling.

In the United States the safety record of car users is bad. If the United Kingdom had the same mortality per head as the United States, we would see around 10 000 fatalities per year instead of 3500. So why do Rivara et al build their professional reputations on cycle helmets when driving standards in the United States are a far more serious public health issue?

The United Kingdom is not a fit nation. Cycling is one of the few charming and harmless pastimes left in this anaesthetic, stinking world—and it is actually good for you.

Malcolm J Wardlaw *business analyst*
Glasgow G61 2SY
a.wardlaw@btinternet.com

1 Cook A, Sheikh A. Trends in serious head injuries among cyclists in England: analysis of routinely collected data. *BMJ* 2000;321:1055. (28 October.)
2 Rivara FP, Thompson DC, Thompson RS. Bicycle helmets: it's time to use them. *BMJ* 2000;321:1035-36. (28 October.)
3 Scuffham P, Langley JD. Trends in cycle injury in New Zealand under voluntary helmet use. *Accid Anal Prev* 1997;29:1.
4 Scuffham P, Alsop J, Cryer C, Langley JD. Head injuries to bicyclists and the New Zealand helmet laws. *Accident Analysis and Prevention* 2000;32:565-73.
5 Robinson D. Head injuries and bicycle helmet laws. *Accid Anal Prev* 1996;28:463-75.

Mountain biking is particularly dangerous

Editor—The articles by Cook and Sheikh and Rivara et al highlight the benefits of bicycle helmets in reducing head injuries from cycling accidents.[1 2] We believe that the public does not understand the severity of injury that can arise from recreational cycling.

In our study of people with injuries from mountain biking who presented to the orthopaedic department at the Royal Shrewsbury Hospital we found that 84 patients (70 of them male) with a mean age of 22.5 years had serious injuries over a period of 12 months.[3] A total of 19 patients (23%) needed operations, some requiring multiple procedures with a prolonged hospital stay. The most common injury was fracture of the clavicle (18 (13%) patients), although this was closely followed by other shoulder girdle injuries (16 (12%)) and distal radial fractures (15 (11%)). Some more serious, even life threatening, injuries were identified. These included six patients with open and closed fractures of the femur or tibia, one of whom, an 11 year old, also had a serious head injury and required transfer by helicopter to the regional neurosurgical centre. One patient sustained neurological deficit with a fracture dislocation of the second and third cervical vertebrae and required urgent stabilisation. A further patient needed a lifesaving nephrectomy to control haemorrhage; another patient needed drainage of a serious haemopneumothorax. These and other serious injuries represented 20.3% (27) of injuries referred during the study period.

Neither article impresses the high impact nature of cycling injuries, especially offroad cycling. Previous reports from the United States and New Zealand have indicated a high use of helmets among cyclists (80-88% in offroad riders), possibly accounting for a low incidence of head and neck injuries.[4 5] They concluded that most offroad injuries were minor, and that the incidence of fractures was low.

It is important that doctors confronted with an injury associated with mountain biking take the mechanism of injury into account and prepare for serious trauma. Injuries are usually sustained by cycling at high velocity into immovable objects, with the patient wearing little or no protection. Further investigation is clearly indicated into the prevalence and effectiveness of the use of body armour (in addition to helmets), among both recreational and competitive mountain bikers. This may prove a valuable step in improving the safety of this sport.

Lee Jeys *orthopaedic research fellow*
Royal Orthopaedic Hospital, Northfield, Birmingham B31 2AP
lee.jeys@btclick.com

Gillian Cribb *orthopaedic senior house officer*
Andrew Toms *orthopaedic specialist registrar*
Stuart Hay *consultant orthopaedic surgeon*
Royal Shrewsbury Hospital, Shrewsbury SY3 8XQ

1 Cook A, Sheikh A. Trends in serious head injuries among cyclists in England: analysis of routinely collected data. *BMJ* 2000; 21:1055. (28 October.)
2 Rivara FP, Thompson DC, Thompson RS. Bicycle helmets: it's time to use them. *BMJ* 2000;321:1035-36. (28 October.)
3 Jeys L, Cribb G, Toms A, Hay S. Mountain bike injuries in rural England. *Br J Sports Med* (in press).
4 Rivara FP. Injuries involving off road cycling. *J Fam Pract* 1997;44:481-5.
5 Pfeiffer RP. Off-road cycling injuries. An overview. *Sports Med* 1995;19:311-25.

Deliberate self harm is common reason for emergency medical admission

Editor—Isacson and Rich offer practical guidelines for the management of deliberate self harm while highlighting the extremely weak evidence base in this area.[1] They suggest that a brief hospital admission should be considered to establish a good therapeutic relationship. Yet even for an issue as fundamental as whether or not to admit these people to hospital, the benefits are uncertain and the only relevant randomised trial was too small to detect clinically important effects.[2] Cost effectiveness is likely to be even more difficult to establish.

Deliberate self harm accounts for around 85 000 hospital admissions each year in England and Wales, and the proportion of patients who are admitted for it after assessment in accident and emergency departments varies widely.[3 4] One study of four teaching hospitals showed a threefold variation (29% to 82%) in admissions after deliberate self harm from accident and emergency departments.[4]

We examined the relation between hospital admission rates for deliberate self harm and repeat deliberate self harm, using a rigorously validated deliberate self harm register based on attendances at four accident and emergency departments in one health authority from 26 May 1997 to 29 February 1999, with data being collected until 1 March 2000 to identify repeat episodes (table). We used repeat deliberate self harm as a marker of an unfavourable outcome.

The proportion of patients admitted for inpatient care after deliberate self harm varied from half to two thirds across the four hospitals ($P<0.001$; χ^2 test with three

Admission rates for deliberate self harm, and repetition rates, across four NHS trusts, May 1997 to February 1999. Values are numbers (percentages) of patients

Hospital No	Attendances at A&E because of deliberate self harm	Patients admitted	Patients with repeat episode <12 months after index episode
1	515	255 (50)	93 (18)
2	365	203 (56)	71 (20)
3	305	160 (53)	77 (25)
4	600	393 (66)	136 (23)
Total	1785	1011 (57)	377 (21)

A&E=Accident and emergency.

degrees of freedom). There were much smaller differences in repeat deliberate self harm (P = 0.16 with same test). The lowest repetition rates were seen in the hospital that admitted the lowest proportion of cases.

These data are insufficient for us to reach firm conclusions about the benefit or otherwise of inpatient admission for people who harm themselves. More information is needed not only about the best form of psychological treatments for these people but also about the appropriateness of hospital aftercare for initial management. Some people will require admission on medical grounds or because of psychiatric risk. For many, however, follow up could be arranged through their general practitioner or community mental health team.

Adequately powered randomised trials of the process of care as well as psychological aftercare are clearly required, as deliberate self harm is now one of the commonest reasons for emergency medical admission.

O M Bennewith *research associate*
O.M.Bennewith@bristol.ac.uk

D Sharp *professor*
Division of Primary Health Care, University of Bristol, Bristol BS8 2PR

D Gunnell *senior lecturer, public health and epidemiology*
T J Peters *reader in medical statistics*
Department of Social Medicine, University of Bristol, Bristol BS8 2PR

N Stocks *senior lecturer*
Department of General Practice, University of Adelaide, South Australia 5005, Australia

1 Isacson G, Rich CL. Management of patients who deliberately harm themselves. *BMJ* 2001;322:213-5. (27 January.)
2 Waterhouse J, Platt S. General hospital admission in the management of parasuicide: a randomised controlled trial. *Br J Psychiatry* 1990;156:236-42.
3 Gunnell DJ, Brooks J, Peters TJ. Epidemiology and patterns of hospital use following parasuicide on the South West. *J Epidemiol Community Health* 1996;50:24-9.
4 Kapur N, House A, Creed F, Feldman E, Friedman T, Guthrie E. Management of deliberate self poisoning in adults in four teaching hospitals: descriptive study. *BMJ* 1998;316:831-2.

Mortuary facilities

Funding is needed, not scapegoats

Editor—I agree with Abbasi's editorial about the Bedford Hospital "bodies in the chapel" affair.[1] In a statement to the House of Commons Alan Milburn, the health secretary, asserted that this was not a problem of funding or capacity but a management failure. I would suggest that he was misinformed.

Bedford Hospital was to have had a major programme of rebuilding 11 years ago, including a new pathology department and mortuary. This plan was cancelled at the last minute as a result of the overspend on the Chelsea and Westminster Hospital. The mortuary, which was built in the 1950s when the hospital was less than half its present size, has undergone minor refurbishment, but repeated bids for the new pathology department that the hospital needs have been ignored. As recently as last year, the regional director visited the department and was shown the mortuary, but he seems to have taken little interest.

Our chief executive, Ken Williams, was made a scapegoat, but he cannot be blamed for the chronic underfunding of the hospital. The report of the investigation into the incident contains scant retrospective justification for the Department of Health's intervention in demanding that he should step down.

Michael Frampton *chairman, medical staff committee*
Bedford Hospital, Bedford MK40 2AW
michael.frampton@bedhos.anglox.nhs.uk

1 Abbasi K. Death underfunded. *BMJ* 2001;322:186. (27 January.)

Histopathology laboratories often have inadequate mortuary facilities

Editor—As someone who finds that it isn't always fun working in pathology in the United Kingdom at present, I welcome Abbasi's editorial.[1] He rightly identifies the chronic underfunding of pathology services, including the system of laboratory accreditation run by Clinical Pathology Accreditation (UK) Ltd; these services are nevertheless arguably the most closely scrutinised in medicine.

It has been common knowledge almost from the inception of clinical pathology accreditation a decade ago that one of the commonest reasons for histopathology laboratories to be referred—that is, not accredited—was inadequate mortuary facilities.

J H F Smith *consultant histopathologist*
Northern General Hospital, Sheffield S5 7AU
John.Smith@northngh-tr.trent.nhs.uk

1 Abbasi K. Death underfunded. *BMJ* 2001;322:186. (27 January.)

These facilities are inadequate in Australia too

Editor—Inadequate mortuary facilities are a feature of hospitals in Australia as well as the United Kingdom.[1] One reason is that they are never visited by hospital administrators. Those in the hierarchy will occasionally leave their clear desks for a visit to wards, outpatient departments, even an operating theatre, but they would not even know where the mortuary is. A second problem is unclaimed bodies, which may occupy a berth in the fridge for weeks, and the undertaker with inadequate or no storage facilities who uses the mortuary as a storage area, collecting the body only on the day of the funeral.

Mortuaries are one matter. Facilities for proper viewing of the dead person and an area for sharing grief and for reflecting on past events are often inadequate and tasteless and do nothing to help the bereaved.

John Hayman *associate professor*
Department of Anatomy, Monash University, Clayton, Melbourne, 3168, Australia
hayman@netcore.com.au

1 Abbasi K. Death underfunded. *BMJ* 2001;322:186. (27 January.)

British public will have to pay more taxes

Editor—I take issue with the last sentence in Abbasi's editorial about the mortuary service: "Dignity in death comes at a price that the government should pay."[1] The government has no funds to pay for anything, save what the British public contributes in taxes, which are the fifth lowest, relative to gross domestic product, among the 15 countries in the European Union.[2]

Like spoilt children, the British public scream when any public service (health, education, railways) fails, and no one has dared tell them what they must do to get what they want. Who will have the courage to stop blaming just the government and say to the British public, "No; you will not get what you want until you ask properly?" That means, in effect, "Pay more taxes."

Francis Sheehy Skeffington *retired paediatrician*
3 Blenheim Road, Wakefield WF1 3JZ
francis@sheehyskeffs.demon.co.uk

1 Abbasi K. Death underfunded. *BMJ* 2001;322:186. (27 January.)
2 Organisation for Economic Cooperation and Development. *Revenue statistics*. Paris: OECD, 1999.

Public is unable to cope with realities of death

Editor—Abbasi's editorial about the mortuary service[1] mentions that the chief executive of Bedford Hospital resigned because corpses were stored in a hospital chapel.[2] Abbasi does not comment on the most bizarre aspect of this story.

Why is it that the general public and politicians are responding in this way? Is it because the bodies were not being refrigerated? Yet in a few days the bodies will either be decomposing under the ground or reduced to ash in a crematorium. Is it because of the indignity of the bodies being stored in a chapel instead of a mortuary or a refrigerated truck? Being wrapped in a shroud and placed in a chapel, a mortuary, a hole in the ground, or a crematorium makes no difference whatsoever.

The blame for this whole sorry affair lies with the general public and politicians who cannot face the reality of death. We should not be afraid to stand up and say so.

William Notcutt *consultant anaesthetist*
James Paget Hospital, Great Yarmouth NR31 6LA
willy@tucton.demon.co.uk

1 Abbasi K. Death underfunded. *BMJ* 2001;322:186. (27 January.)
2 Laurence J. Milburn blames hospital's managers for allowing corpses to be left on chapel floor. *Independent* 2001 Jan 17.