

of the control population to adopt the advice on diet and life-style given to the test group, as happened in Finland (Pyörala K. Lipoproteins and coronary heart disease in diabetic and non-diabetic subjects in eastern and western Finland. Presented at Symposium on Lipoproteins and Coronary Heart Disease, Espoo, Finland, January 1985).

Familial hypercholesterolaemia is different. The lipoprotein changes in plasma — elevation of low-density lipoproteins plus some reduction of high-density lipoproteins components — are expressed from the first few days of life with little change until diagnosis and treatment,^{1,2} and thus the integrated, that is, time-based exposure to component abnormality, can be approximately determined.³ Clinical expression is also severe, although variation and particularly inter-familial variation is wide. It is not clear that growing interest in and recognition of this disorder in recent years has led to clinical benefits, but experienced units do not write off patients with familial hypercholesterolaemia for the following reasons:

1. Most patients are still identified because of a clinical event, including death. The benefits of earlier recognition and treatment remain to be assessed, for which greater awareness and extensive family screening are required.

2. Rigorous treatment of some patients plainly induces regression of tissue deposits, with freedom from clinical cardiovascular disease to an age beyond that at which such expression has arisen in other untreated members of the same family. This has also been shown for homozygote sibling pairs, in studies from the Hammersmith Hospital and St George's Hospital.^{4,5}

3. In assessment of response to treatment, denial of treatment to a control group is unethical. Comparisons between good and bad responders are also unhelpful as the basic defects involved may differ. Experienced units also see patients and families where major treatment and apparently good compliance produces trivial change in lipoprotein profiles or clinical course. Parental studies in homozygotes, and more recent gene probe studies in heterozygotes show that familial hypercholesterolaemia is significantly heterogeneous,⁶ and responses to treatment may also vary. Subgroup analysis is proceeding rapidly, and may allow improved definition of prognosis, and of amenability to treatment by different approaches: some patterns may indeed be untreatable.

4. Calculations based on integrated exposure to plasma abnormalities, as determined from age and lipoprotein profiles at first presentation,³ show that progression of features like corneal arcus and clinical ischaemic heart disease, are more closely related to age than to extent of abnormality in plasma, indicating that progression is becoming time-dependent rather than dose-dependent. These observations also suggest that inadequate advice and treatment, with only moderate control of lipoprotein abnormalities, are unlikely to offer benefits; many patients receive such advice before referral to informed units.

5. New drugs now on trial which inhibit the rate-limiting enzymatic step of endogenous cholesterol synthesis, appear in combination to offer the prospect of complete normalization of lipoprotein profiles in many patients, although any other effects remain to be revealed.

6. Patients identified should also be allowed the benefits of control of other major risk factors such as hypertension and smoking.

Present approaches to familial hypercholesterolaemia are not widely effective, but the assessment of reasoned changes to those approaches, through which any benefits can be assessed, cannot be ethically dismissed. For a start we need to know what can be done if patients are identified early, treated rigorously, and offered the diagnostic and therapeutic advances now in hand. The original point of this correspondence remains that general practitioners are important in early recognition; from this all else follows.

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Deaths — why inform just the hospital?

Sir,

I agree with Dr Balfour that it is indeed an unhappy experience to be faced by a relative whose loved one has died, when we have had no knowledge of the fact (*August Journal*, p.401). This does not only happen when the hospital forgets to notify the surgery, but also when the family or close relative forgets to inform us. As a practice administrator in a four-partner group practice with 11 700 patients, I have always had a special interest in medical records and their upkeep. We still use the Lloyd George envelopes, and, though these are often regarded as too small for the amount of detail to be recorded, I still believe it is possible to use them efficiently.

Many of the patients who require the district nurse may also need the services of other agents, for example, social services or after care services, or may require a wheelchair. Our practice has devised a system to ensure that these other agencies are informed about a patient's death. If a request is made to any service the procedure is as follows:

1. An entry in red is made in the patient's records. For example, 'D/Nurse — general care, Tel: 12345. Wheelchair ordered from Leeds (ALAC), local office 25656.'

2. The front left-hand corner of the record envelope is coded. (This is usually in the space for the last change of address. For example, 'D/N 12345. SS 23456. ALAC 25656.')

Recording the telephone number makes it quicker for the next person using the notes to contact the same service, considering that there are several social service teams covering our practice area, and in some cases two teams covering the longer roads.

When the practice is notified of the death of a patient, the record envelope and the age-sex cards are removed from

the files. I personally deal with the deaths, and check through each envelope to make certain that all the contents relate to the patient. I then notify each service that has been involved with the patient and tick the relevant code mark. If the patient did not die in hospital but has hospital records, we send a standard letter (photocopied in batches) to the hospital records department, giving all the necessary details about the patient, especially if there has been a referral where an appointment might still be outstanding.

Just inside the reception area we have a noticeboard giving details of all admissions, discharges and deaths, and so this is seen each day by our district nurses on their morning visit. The social services and after care services are informed by telephone to discontinue any services and are given details of any equipment which may have been issued along with a telephone number of a relative who may be contacted after a few days, should the patient have lived alone. The local office of ALAC is notified by phone if a wheelchair has to be collected and again a telephone number is given where possible. Finally, the cause of death is recorded on the age-sex card. This is then given to the health visitor to remember to make a bereavement visit to relatives in about two to three weeks time. Occasionally a patient may die within a short time of hospital discharge or being seen at the hospital. In these cases a telephone call is made to the consultant's secretary with the standard letter still going to the records department.

This has been my routine for the past 10 years or so, and it is satisfying when contacting any of the services to hear such comments as 'I wish other surgeries notified us as you do. Perhaps we would not lose so much equipment if they did'. Even our family practitioner committee was interested enough to ring and enquire as to what the coding meant.

On paper this may look to be a lot of work, but I can assure everyone that once the system is running it only takes a short time to operate. I am certain that if all practices thought more about putting the records straight, and carried out a similar system to Dr Balfour's and my own, then there would be many hospital appointments available to other patients, and more equipment available in the community for reissue.

One other record that I keep may be of interest. On the back of the age-sex card I keep a summary of all cancer patients with details of their treatment. This saves me having to request the family practitioner committee to return the records should we be asked for a report from the Cancer Register.

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Prevalence of disability in an Oxfordshire practice

Sir,
We regret that our previous criticisms (December *Journal*, pp.586-587) of Dr Tulloch's paper on the prevalence of disability in an Oxfordshire practice (August *Journal*, pp.368-370) have not been acceptable to him. The question of defining severity of disability is, however, central to its interpretation, and unless a validated measure is used, for example the Nottingham Health Profile¹ or the McMaster Health Questionnaire (Chambers LW, Segovia J. Indexes of health. Meeting, London Ontario), then assessment of Dr Tulloch's findings is limited to the context of his practice. We agree that this in itself is valuable and interesting, reflected in the enjoyable presentation of his findings. If however other general practitioners are to compare Dr Tulloch's work with their own experience, a repeatable measure of disability would have been preferable.

One doctor's interpretation of loss of independence might be lack of functional capability while another's might be lack of motivation or support.

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Place of birth and perinatal mortality

Sir,
May I be granted the opportunity to clear up the misunderstandings which Dr Madeley, Professor Symonds and Dr Watney express in their letters (November *Journal*, pp.536-537) and which are apparently causing some doctors to block discussion of policy on home delivery at health authority meetings.

We all know that certain maternal characteristics and events in pregnancy and early labour are associated with increased risk of perinatal mortality. Obstetricians assume that their system of intranatal interventions will make this risk less than it would be with the low-intervention care practised by midwives and non-specialist doctors. The booking and transfer policies are based on this hypothesis.

To test whether the hypothesis is supported by results, simple logic requires that the results compared should be those of the actual and not the intended treat-

ment by the two systems, after as complete allowance as possible has been made for differences in the pre-delivery risk status of the births concerned. The best instrument so far devised for assessing pre-delivery risk is the obstetricians' own labour prediction score which incorporates most of the factors which influence the doctor's booking and transfer decisions, reflecting their relative risk. The perinatal mortality of births with the same degree of predicted risk but having different systems of intranatal care, can properly be compared and it was found in the 1970 survey of British births to be far higher under obstetric management. Since this impartial finding is so unpleasant to received opinion, fault must be found in the method of analysis.

A score based on antenatal factors is criticized as being a poor predictor of outcome — of course it is. In the labour prediction score more weight is given to adverse factors occurring near delivery than to those known earlier, though the former are more likely to affect mothers with high risk characteristics. However, most of the risk occurs during birth itself and though this too is highest where the labour prediction score is highest, much of it is independent of the predicting factors. The crucial need is to establish whether the intranatal risks are higher under one system of care than under another and the analysed results, when antenatal risks are equal, show unequivocally that intranatal risks are higher under obstetric management.

The second criticism is that the labour prediction score does not make sufficient allowance for pre-delivery risk because it does not include all the possible predicting factors which have, or have not yet, been identified. All the excluded factors which have been identified and measured, such as height and smoking, are known to be interdependent with the included factors. The point of controlling for single factors in the article was precisely to show that allowing for the combined factors explained little more of the hospitals' excess mortality than did allowing for single factors, because they are largely interdependent. Thus allowing for additional interdependent factors would explain very little more. To account for the large unexplained excess the excluded factors would have to be totally independent of the included factors. No such factors have yet been identified and their effect measured. If there are potent but unidentified factors, no amount of 'clinical acumen' could produce an excess of hospital births at high risk on account of them.

This criticism, like that relating to intra-uterine deaths, was clearly dealt with (August *Journal*, p.392). Likewise, the hospitals' excess of low weight births was acknowledged (p.391) and the limited contribution this made to explaining the