Using CD4 lymphocyte count to predict survival with HIV infection

EDITOR,—Andrew N Phillips and colleagues used the CD4 lymphocyte count to predict long term survival after HIV infection in men with haemophilia,¹ but the biological variables that influence the CD4 count limit the applicability of their results to other risk groups—for example, homosexual men.

I studied 25 HIV positive patients who had been followed up for more than six years in my clinic. Eleven were homosexual men, of whom three died of AIDS and three others developed AIDS during the follow up; one patient had a low CD4 lymphocyte count ($100 \times 10^9/l$), but the four others remained asymptomatic with counts of over $300 \times 10^9/l$. Nine patients had been injecting drug users: two of these died in the sixth and seventh years after diagnosis while the rest remained asymptomatic with CD4 lymphocyte counts of over $300 \times 10^9/l$ during the six years of follow up. The five other patients were either haemophilic or thought to have been infected through blood transfusion. One of these died after 10 years and one had a CD4 lymphocyte count of $50 \times 10^9/l$, but the three others were asymptomatic with counts of over $500 \times 10^9/l$.

A linear decline in the CD4 lymphocyte count is not seen in all homosexual men who are HIV positive. After an initial drop in the count at the time of seroconversion there is either a gradual downward slope or, after a variable period, a much steeper slope with flattening of the curve when it drops below $50 \times 10^9/l$. The repeated antigenic stimulation of CD4 cells infected with HIV and of coinfections—for example, with herpes simplex virus, hepatitis B virus, or cytomegalovirus—may account for the wide variation in survival in homosexual men. The use of antiretroviral agents and prophylactic treatment of opportunistic infection will further alter the natural course of events.

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Knowledge about tests for HIV antibodies among pregnant women

EDITOR,—Angus Nicoll and colleagues highlight the increasing prevalence of HIV infection in pregnant women in London.¹ We recently investigated patients' understanding of antenatal testing for antibodies to HIV at an inner London obstetric unit. Anonymous self completion questionnaires were issued to 238 women attending the antenatal clinic over three months; 16 women refused to complete them, giving a response rate of 93.3%. All the women had previously seen a doctor and a midwife during the pregnancy. Anonymous, unlinked tests for HIV antibodies were being carried out in the clinic at the time. This was referred to in information sent to the patients before they attended the clinic but was not specifically discussed at the booking visit.

Named HIV testing was discussed with 18 of the women. Fourteen were tested, and all were negative for HIV antibodies. Of the remaining 204 women, 84 believed that they had had a named test at their first antenatal visit; 64 said that they had not been tested, and 56 were unsure. Of the 84 who

believed that they had had a named test, 76 believed that the result had been negative and eight did not know their result, of whom four added the comment that it was anonymous.

One hundred and eighty six patients thought that HIV infection should have been discussed. When asked whom they would like to speak to about the test for HIV antibodies 34 chose their general practitioner, 24 a midwife, 13 a specialist HIV counsellor, and nine a hospital doctor; 106 had no particular preference. One hundred and fifty five women thought that HIV testing should be compulsory.

Our study highlights the widely held misconception regarding antenatal testing for HIV antibodies. Although in our unit named testing for HIV antibodies was not discussed with 92% of the patients antenatally, only one third were certain that they had not been told the result of the test. Furthermore, 90% of those who believed they had had a named test thought that their result had been negative. The anguish caused by such a misunderstanding has been commented on previously.² Ninety three per cent of the patients did not think it necessary to discuss the issues with a specific HIV counsellor. We support this view that antenatal carers would be the appropriate people to discuss testing for HIV antibodies and believe that the introduction of specific counsellors would further "mystify" such testing.

We believe that the universal offer of testing for HIV antibodies, with informed consent, to all pregnant women would avoid misunderstanding. Additionally, the counselling before the test would provide a unique opportunity to promote sexual health and education about HIV infection to sexually active women.

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Protection afforded by cycle helmets

EDITOR,—The foreword to British Standard 6863, amended 1991, for cyclists' helmets reads in part: "The requirements of this Standard are intended for helmets that give protection in the kind of accident in which the rider falls onto the ground without other vehicles being involved." This implies that helmets are of little value when the cyclist collides with a motor vehicle. This view has been echoed by others. C Maimaris and colleagues found that, although the risk of a moderate, severe, or fatal head injury was increased threefold when cyclists were involved in accidents with a motor vehicle, helmets significantly reduced the risk of such injuries, as they did in other kinds of accidents.²

Our study of 1710 cyclists who had been injured showed that wearing a helmet that met the Australian standard reduced the risk of head injury by more than 39%.³ Of 495 cyclists who had been struck by a moving motor vehicle, only 250 had sustained a blow to the head or helmet. Wearing a helmet reduced the frequency of head injury in those who sustained a blow to the head or helmet from 71.4% (137/192) to 50.0% (29/58) ($P=0.003$) (previously unpublished data). The relative risk

was reduced to 0.70 (95% confidence interval 0.53 to 0.92), and head severity scores on the abbreviated injury scale were lower ($P=0.06$).

The number of cyclists who sustained injuries in motor vehicle accidents during the first two years after helmet wearing became compulsory in Victoria on 1 July 1990 has been compared with the number before that date.⁴ Admissions to hospital, and deaths, of cyclists with head injuries were 48% fewer in the first year and 70% fewer in the second year after the legislation came into force. Casualties with injuries other than to the head fell by 21% and 28% respectively.

These observations show that wearing a helmet substantially reduces the risk of head injury, including serious head injury, in cyclists in accidents involving motor vehicles.

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Screening for cystic fibrosis

Should begin with cascade screening

EDITOR,—We wish to respond to Theresa Marteau's commentary on our screening programme for carriers of the cystic fibrosis gene.¹ The programme, aimed at families and their partners, wishes to increase reproductive options, with most of the women not being pregnant at the time of screening. The increased options are mentioned several times in our paper.

The Cystic Fibrosis Research Trust's guidelines for bids for funding for carrier screening projects in 1989 began by saying that the main object of screening was to increase reproductive options. They continued, however, by saying that, given the nature of cystic fibrosis, screening programmes would also have as an aim a reduction in the birth of those affected by the disorder. Any genetic screening programme for what is perceived as a serious condition should be regarded as an aid to decisions about termination of pregnancy. This does not imply that there is not free choice over whether to partake in the screening or that every carrier couple detected will opt for prenatal tests and termination of pregnancy. Nevertheless, it is legitimate to monitor what couples do with the information, and behaviour in pregnancy is the easiest variable to measure; we and others therefore report the results of our screening in this way. Decisions are made after full counselling; we have no vested interest in couples who are found to be carriers opting to end affected pregnancies.

The success that we claim is based not only on detected carrier couples, as Marteau suggests, but also on the high uptake of screening by relatives, most of whom are reassured to learn their negative results.

In suggesting that the screening should be

applied widely we assumed that regional clinical genetics departments and those who care for people with cystic fibrosis, including general practitioners, would cooperate. We are confident that our counselling and that which individuals and couples would receive in other clinical genetics departments in Britain would be the same, and we are therefore happy to recommend widespread application of screening.

We accept that cascade screening will detect only about a quarter of carrier couples, as D J H Brock points out.² These "islands" of carriers and carrier couples are, however, easily accessible as a person with cystic fibrosis or a carrier is at the islands' centre and knowledge of the disorder is high among the people concerned. Whatever screening programmes health authorities introduce, cascade screening should be the starting point until the public starts to request population screening programmes, as Sandy Raeburn suggests as the ideal.³ The uptake of prenatal diagnosis per detected carrier couple will naturally be higher in Brock's screening programme than ours if Brock starts by offering the test in pregnancy. Most of the women in the carrier couples were not pregnant when our screening detected them; when pregnancy occurred only one declined tests. We do not think that the "sick family" syndrome is likely with the commonest autosomal recessive disorder, as Nadeem Quereshi claims.⁴ It is easy to reassure carriers who are detected that everyone carries a few recessive genes.

No one (except perhaps Marteau) believes that relatives should not be offered carrier screening. The only question that then remains is whether promotion of an active testing programme in relatives infringes their basic right not to know whether they are a carrier; we submit that it does not. Ideally we would like tests to be available for those who ask for them, whether relatives or not, with active promotion no longer necessary.⁵ This will be possible only when public awareness, even among relatives, is far greater than it is now. We hope that more people will now enter this debate.

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Screening in primary care is preferable

EDITOR,—We agree with the stance taken by Julian D A Cooper and Antony J Franks and by Nadeem Quereshi in response to the debate about population screening for carriers of the cystic fibrosis gene.^{1,2} We found in a survey that the general public is interested in becoming involved with the issues and showed a clear preference for screening to be offered through primary care.³

When we offered carrier testing with other health promotion through a prepregnancy care clinic in one general practice, although attendance

was low (about 1% of patients of reproductive age), interest in screening was high among participants (16/18 (89%)) and to date 10 of the 18 participants (55%) have been tested. A feature of this model was the variable length of time between learning about carrier screening and actually requesting the test—several months in some cases. The preconception approach is complementary to screening in pregnancy and will overlap with it. Although uptake may be small, assimilation of the implications of the test will be enhanced in the antenatal period.

Quereshi notes the need for adequate professional education if screening were to take in primary care.² With general practices increasingly finding it necessary to focus on activities that generate the highest income in the short term, there is little motivation to undertake many aspects of preventive health. So long as screening for genetic disorders retains its current low profile with purchasing authorities, efforts by specialist genetic centres to provide the background training and support for primary care will be wasted. We recently surveyed the 12 general practices in north Newcastle for their reaction to a proposal to develop genetic services in the community with the offer of appropriate staff support in a collaborative pilot project. Only two practices were clearly in favour. Most of the others were not in favour on the grounds of lack of time and adequate reimbursement rather than disagreement with the principles entailed.

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Audit improves neonatal (Guthrie) screening programme

EDITOR,—We conducted an audit of the neonatal screening programme for phenylketonuria and congenital hypothyroidism in the Northern region in 1993. Like Allison Streetly and colleagues, who looked at screening in south London,¹ we found that arrangements for monitoring the existing screening programmes were inadequate, though we do not have London's problems regarding mobility of families and we have a smaller proportion of people from ethnic groups than the London areas.¹ We found that in five of the districts no satisfactory mechanisms existed for checking that each baby had been screened and that in five of the 11 districts that make checks an inappropriate delay (several weeks) in checking could occur. Only six of the 16 districts had a timely failsafe mechanism in place for ensuring that all babies were screened. In addition only one district was confident that its coverage was 100%; other districts did not routinely monitor their coverage.

After the audit, information was fed back to each district with suggestions on how the screening programme could be improved. Six months later all districts except two had a timely failsafe mechanism for identifying babies who had not been screened. We agree with Streetly and colleagues that monitoring of coverage is essential and that explicit standards need to be set.¹ In our experience, audit has been a useful mechanism for reviewing the neonatal screening programme and has resulted in changes in most districts to improve the monitoring of the programme.

The audit was carried out with a grant from Northern Regional Health Authority.

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Two tier system for outpatient treatment

EDITOR,—For the second time a fundholding practice has referred a patient to me with a request for a consultation only. I understand that this means that the practice pays about £30 for the privilege of seeing me, but I am not allowed to do any investigations or obtain any x ray films. I am allowed only to see the patient and express an opinion.

Where does responsibility for the patient lie? If the problem is, say, backache, the x ray films are either inadequate or inappropriate, and I am concerned that there is a tumour and believe that further investigations are required, what do I do? The current system seems to be that I write to the general practitioner and pass the ball back into his or her court. If the general practitioner decides to take no action where does the responsibility lie? If the general practitioner decides that further investigations are required the patient has yet another trip to hospital. If the general practitioner does not act on the consultant's advice and a problem arises the consultant, in my view, has failed in his or her duty to the patient.

There already seems to be a two tier system for inpatient treatment and there may well be one for outpatient treatment too, which would operate to the financial advantage of fundholding general practitioners but, I suspect, to the disadvantage of patients.

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Waiting times in an ophthalmic outpatient department

EDITOR,—A M Ansons and colleagues describe some of the problems that a busy academic eye department is experiencing in meeting the patient's charter.¹ At around the time of the charter's introduction we conducted a survey of ophthalmic outpatient services in a district general hospital with three consultants and serving 250 000 people. Information was collected by six management students, who obtained details of 393 (95%) of the 414 patients attending clinics during one week.

Overall, 116 patients were seen by a consultant, 58 by the registrar, 190 by one of the three senior house officers, and 50 by one of the general practitioner clinical assistants. The clinics were usually fully booked but had an additional daily workload of between one and 15 unbooked patients (referrals from the accident and emergency department and urgent referrals from general practitioners) added to them. The senior house officers ran a daily casualty clinic but sought advice from a consultant or the registrar concerning 79 patients. Sixty six patients arrived later than their booked appointment (usually because of transport problems) and had to be fitted into the clinic out of