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 surveillance 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 a quarter of carrier couples, as D J H Brock points out. These "islands" of carrier and couple carriers are, however, easily accessible as a person with cystic fibrosis or a carrier is generally 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. 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 recessive disorder, as Nadeem Qureshi claims. It is easy to reassure carriers who are detected that everyone carries a few recessive genes.

Noreen (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. 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 Qureshi 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 preconception 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 (95%)) and to date 10 of the 18 participants (55%) have been tested. A feature of this model was the length of time taken for 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. Although uptake may be small, assimilation of the implications of the test will be enhanced in the antenatal period.

Qureshi notes the need for adequate professional education if screening were to be taken up in primary care.4 5 With general practitioners 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 cystic fibrosis 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 inadequate 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.2 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 inapplicable delay (several weeks) in checking could occur. Only six of the 16 districts had a timely failsafe mechanism in place for ensuring the all babies were screened. 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 recommendations 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.3 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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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 clinic was 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

sequence. While 104 consultations lasted five minutes or less, 88 lasted over 20 minutes. The number of patients seen within half an hour of their booked appointment time, without correction for other factors, was 228 (55%).

The survey found hospital practices that caused delays; these have now been altered. Five of the 15 clinics started more than 10 minutes late because medical staff were completing ward rounds or attending lunchtime meetings. The computer booking system was programmed to book both old and new patients at five minute intervals.

As patients and their relatives have to wait in the outpatient department the facilities provided should be reasonable; 108 patients found the seats uncomfortable, 112 did not know where the toilets were located, and 50 did not know where to obtain refreshments. Surprisingly, only four patients complained specifically about waiting times. Altogether 277 patients were over retirement age, and their apparent lack of concern about waiting may reflect an older generation's acceptance of queuing and the fact that most were not taking time off work. Also, 201 were seen by nursing staff before their medical consultation in order to check visual acuity, dilate pupils, or test visual fields. They therefore probably considered that they received attention without much delay.

The authors will report to Anscans and colleagues that the current targets for waiting times are unrealistic for many busy eye clinics.

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Research into outcomes and effectiveness

Editor,—Trevor Sheldon's critique of the research into the outcomes and effectiveness of treatment carried out by the US Agency for Health Care Policy and Research (AHCPR) is a wake-up call for the patient outcomes research teams, which are supported by the agency, is based on a fundamental misunderstanding of our programme, mission, and methods. The US Congress created the Agency for Health Care Policy and Research in December 1989 to focus on a set of important issues that were not being addressed by existing research institutions. Specifically, the law establishing the agency and the medical treatment effectiveness research that, in the words of the AHCPR, is a “new, hard look at the effectiveness and appropriateness of current health care practice in a wide array of clinical conditions. It requires examination of a broad range of outcomes (not merely mortality and morbidity but relief of symptoms, functional status, quality of life, and cost) as achieved in non-selected patients and practices.”

Many of the agency's studies of outcomes focus on conditions and procedures that are not life threatening but that impact appreciably on the quality of life—that is, low back pain, carpal tunnel, benign prostatic hyperplasia, and hysterectomy. Because many of these conditions and procedures have not been studied before, the agency's first generation of studies invested heavily in fundamentals—documenting practice patterns, showing the need for better evidence, identifying the relevant outcomes, and developing research methods and measures of outcomes. The building blocks of clinical decision making are important in their own right, and collectively they have led directly to the development of a set of rigorous studies to test hypotheses.

For example, work by the patient outcomes research team on prostatic diseases was critical in showing the weakness of evidence supporting current treatment for benign prostatic hyperplasia and in convincing the clinical and research communities of the need for a randomised trial. The team developed measures of the symptoms and treatment outcomes specific to the condition that are important to patients and a symptom scale for benign prostatic hyperplasia that has been validated and adopted by both the American Urological Association and the World Health Organisation. In collaboration with the American Urological Association the team has designed and obtained funding for a randomised controlled trial that will test directly the effectiveness of transurethral resection with two drugs (finasteride and doxazosin). Similarly, the randomised controlled trials in prostatic cancer, back pain, and other disease areas are ongoing. The trials are conducted in the United States, as well as a case-control study by the patient outcomes research team for cataract, would never have been undertaken without the preliminary analyses by the teams.

Systematic, critical reviews of the literature on their topics is another important contribution of patient outcomes research teams. The conclusions of these reviews, while often disappointing with respect to the quantity and quality of the literature, provide a valuable process that is neither simple nor inexpensive. It is not clear why the evidence regarding the effectiveness of different treatments and have led to some fundamental changes in thinking about what is critical to study. Proponents of randomised controlled trials and traditional meta-analysis who have criticised attempts by the patient outcomes research teams to synthesise the findings of non-randomised studies should appreciate the contribution of the teams in documenting the non-existing of randomised controlled trials and in some cases, the poor quality of trials that have been done.

In clinical areas where solid evidence of the benefit of treatment exists, investigators supported by the Agency for Health Care Policy and Research for determining whether these benefits are routinely achieved. The patient outcomes research team for acute myocardial infarction has shown that a significant number of patients eligible for thrombolysis do not receive it. The agency's support for these researches is in keeping with the publication of a study showing effectiveness requires analyses of practice to determine whether effective treatments are used routinely. If they are not, strategies must be developed to change practice.

For many clinical conditions, when multiple outcomes and alternative treatment strategies are considered, research (even randomised controlled) can seldom be a ”correct” decision regarding treatment. At best the evidence to guide decisions will be in the form of a set of probabilities associated with the various risks and benefits. Large simple trials offer little help, in that the outcomes that need to be measured are seldom simple. Unlike death, relief of knee pain or changes in sexual function, visual function, or affect are difficult to measure, and information has to be obtained from patients—a process that is neither simple nor inexpensive. In the absence of clear answers about best treatment the preferences of informed patients must play a major part in clinical decisions. Patient outcomes research teams have drawn in the complex area into these preferences and have shown the capacity of the teams' approach to obtain good information about these.

While we certainly do not believe that randomised controlled trials are a panacea, neither do we propose observational studies as a substitute for experimental methods. Observational methods can help to define the critical constructs and the hypotheses that need to be tested experimentally and determine whether practice patterns are consistent with evidence of effectiveness.

Experimental studies certainly have a place in research into outcomes too. This is because research into outcomes is not, as Sheldon suggests, a method; it is a conceptual framework for studying the relations between health care services and their outcomes. It uses multiple research designs and methods drawn from the full array of epidemiological and clinical research. As a new theoretical and methodological enter-