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Direct marketing of cystic fibrosis carrier screening: commercial push or population need?

A recent editorial in this journal¹ expresses concern about the direct marketing of cystic fibrosis screening outside the NHS. The potential hazards of screening are stressed and it is postulated that these negative aspects may be ignored under commercial pressure.

In our view the greater danger is that the potential benefits of screening will be ignored because of inertia within the NHS. Prenatal screening for neural tube defects was first shown to be feasible in the late 1970s but did not become widespread in the NHS for another decade. Biochemical screening for Down's syndrome is experiencing a similar lag time between research and implementation. At this rate a reasonable CF screening provision would not be expected before the next century.

Initially, NHS purchasers were able to refer to the ongoing pilot studies as a reason for not introducing a CF screening service. Now that such studies have shown the feasibility and acceptability of screening, at least in an antenatal setting,²⁻⁶ new objections are raised. We carried out a successful pilot study for the Yorkshire Regional Health Authority among nearly 6000 pregnancies but our findings have received an unenthusiastic response from local public health professionals. The high cost of the test, the difficulty of finding time for counselling in a busy antenatal clinic, and lack of consensus about the need for screening have all been cited as reasons for inaction. Such arguments make private screening inevitable.

Prenatal screening increases choice, largely but not entirely through the option of avoiding the birth of an affected infant, but as the Nuffield Foundation report⁷ and your editorial point out, this must be a properly informed choice. We do not agree, however, that direct marketing necessarily means poorer quality information compared with the NHS. For four years we have marketed prenatal screening for Down's syndrome directly to the public using a nine page patients' guide, a 15 page doctors' guide, and a designated telephone helpline to provide the necessary information. Earlier this year we decided to extend our service to include prenatal screening of couples for CF. A 10 page booklet has been produced giving information on the disorder, the mode of inheritance, the interpretation of carrier test results, and the invasive procedures used for prenatal diagnosis. Couples are encouraged to discuss any aspect of this with us, using the telephone helpline, as well as the Cystic Fibrosis Trust and Support Around Termination for Abnormality (SATFA).

Thornton⁸ has argued that the demand for any new screening test should not be assessed when it is offered in a state funded programme since acceptance may simply be compliant behaviour. If a test has official approval and is provided free there is a disincentive for the individual person to weigh the benefits and hazards. If so, the growth of a private CF screening market could be of advantage to NHS planners. *Commercial push* may be a good way of assessing *population need*.

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