Haemoglobinopathy screening: an end to institutional racism?

The NHS Sickle Cell and Thalassaemia Screening Programme was launched in 2004. The objective of the programme is to offer a sickle cell and thalassaemia screening programme to all pregnant women in high prevalence areas in a timely manner, and to facilitate informed decision-making. Thomas et al. report an action research project, conducted in 1999–2000, investigating the early offer of antenatal screening for haemoglobinopathies in primary care. Among those screened, the results suggest that when screening is offered in primary care, it is conducted earlier in pregnancy (on average at 9.7 weeks gestation) than when conducted during a hospital visit (13.7 weeks gestation) or by a community midwife (12.5 weeks gestation). However, the proportion of pregnant women screened in primary care was only 35% — far fewer than would be expected to have had the test had it been offered to all. Thomas et al. highlight a number of problems concerning the feasibility of screening in primary care. Since the study was conducted, there has been a demonstration project in which many of the difficulties outlined by Thomas et al. of engaging primary care in conducting antenatal screening for sickle cell and thalassaemia, were overcome. Despite this apparent success, Wright et al. noted that they failed to record an increase in knowledge about screening in those having the test. The findings of these studies highlight a number of issues that all of those involved in prenatal screening are being met.

Evaluation of screening therefore requires that the proportion of pregnant women offered screening in a timely fashion is known — and not the number of women undergoing testing. It is, of course, more difficult to report on offers of tests, and more difficult to have a complete data on numerators and denominators. It is, however, vital that these are reported reliably so that it is clear whether the stated aims of screening are being met.

There is a general consensus that an informed choice or decision has two core characteristics: first, it is based on relevant, good quality information; and second, the resulting choice reflects the values of the decision-maker. Using a standardised measure, it is now possible to assess the extent to which screening programmes are facilitating informed choices.

To make informed choices about screening, all individuals need good quality information, presented in ways that can be understood by those with high, as well as low, levels of literacy. The NHS has been slow to respond to the informational needs of its diverse populations. This is despite the 2001 amendment to the Race Relations Act that introduced a statutory duty for public authorities to promote race equality.

Change, however, is on the way, being led by the NHS National Sickle Cell and Thalassaemia Screening Programme. By 2006 we will, for the first time in the UK, have a screening programme in which information about the test is available in 30 languages,
and in written and audio form. The use of audiocassettes is vital not only for those whose language is predominantly a spoken one (Sylheti, for example) but also for the estimated 23% of the adult British population who are functionally illiterate. This initiative is to be applauded: we can only hope that other services follow suit and rapidly.

In addition to being offered information about the test in ways that meet their literacy needs, those providing the information need to check that it has been understood. Such checking is not routine: in an analysis of five videotaped consultations from each of 2094 trainee GPs, 45% did not check understanding in any of their five consultations, and fewer than 1% did so in all five. Such checking can be very effective in increasing understanding, particularly for those with low levels of education.

Finally, tests need to be presented in ways that help individuals to make choices that reflect their own values and not those of the person presenting the test options. Decision-aids can achieve this, further consultation, and fewer than 1% did so in all five. Such checking can be very effective in increasing understanding, particularly for those with low levels of education.

In the context of sickle cell and thalassaemia screening, the recent launch of the NHS programme has begun to address many of the organisational challenges of facilitating timely and informed choices for women from diverse ethnic backgrounds as well as for women with wide literacy needs.

Further research and continued audit will be needed to ensure that we have moved far away from the charge of institutional racism—which, in the previous decade, could rightly be levelled at the provision of this and other services in the UK.

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REFERENCES

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The changing face of assessment: swings and roundabouts

‘The novelties of one generation are only the resuscitated fashions of the generation before.’
George Bernard Shaw. From the preface to Three Plays for Puritans.

This quotation aptly reflects the tensions in the pursuit of a ‘Holy Grail’ ideal assessment. In the early 20th century the goal was integration. Flexner, the late 19th century American educationalist, held the firm belief that assessment must focus on a student’s ability to assess in full ‘a concrete case to collect all the relevant data and to suggest the positive procedures applicable to the conditions disclosed.’ Long cases and oral presentations were in favour. Subsequently, the logistics of ensuring fair and equitable challenge across cases and during unstructured vivas led to an increasing focus on more objective testing methodologies (some believe at the cost of being too reductionist), such as multiple choice questions (MCQs) and objective assessment.