

# 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.<sup>1</sup> Thomas *et al* report an action research project, conducted in 1999–2000, investigating the early offer of antenatal screening for haemoglobinopathies in primary care.<sup>2</sup> 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.<sup>3</sup> 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 charged with providing antenatal screening for sickle cell and thalassaemia need to consider.

As reviewed in the background section of the paper by Thomas *et al*, the iniquitous manner in which screening has been offered to those at risk for sickle cell and thalassaemia in the UK has been recognised for over 10 years. This is not a problem restricted to sickle cell and thalassaemia screening. There is strong evidence to show that people of minority ethnic groups use a range of healthcare services less frequently than people of majority ethnic groups. For

example, uptake of antenatal screening for Down's syndrome is lower in South Asian women than in white women;<sup>4</sup> non-white patients with angina are less likely than white patients to be prescribed nitrates, and are less likely to receive advice on smoking cessation, weight control, exercise and alcohol consumption;<sup>5</sup> black men are less likely to undergo knee arthroplasty than white men in the US;<sup>6</sup> South Asian patients are less likely than white patients both to participate in clinical trials<sup>7</sup> and to undergo revascularisation.<sup>8</sup>

Interest in using prenatal screening services is as high in those from minority ethnic groups as other groups.<sup>4</sup> Thus, contrary to popular conception, South Asian women in the UK have similar attitudes to other women about undergoing antenatal screening for Down's syndrome, but among those with positive attitudes towards undergoing the test, they are less likely than white women to have the test.<sup>4</sup> This difference may reflect both a lower likelihood of South Asian women being offered antenatal screening tests,<sup>9–11</sup> and among those who are offered them, more barriers to access (such as poor information, lack of suitable transport or restrictions on time).

The term 'institutional racism', which is increasingly used to explain the failings of public institutions to respond to the needs of ethnic minority populations, may be used in this context to make sense of inaccessible service provision.<sup>12</sup> Institutional racism is in effect the uncritical application of policies and procedures that ignore the needs of an ethnically diverse society. Such practices, by default, favour the white population. Commitment in the UK to overcome this was enshrined in the 2001 amendment to the 1976 Race Relations Act, which made statutory agencies responsible for promoting equal opportunities and identifying and tackling institutional racism in their organisation. Before considering how this can be achieved in the context of antenatal screening for sickle cell and thalassaemia, we first need to consider the aims of screening.

The performance of screening programmes is measured in terms of uptake or coverage, as reflected in the papers by both Thomas<sup>2</sup> and Wright.<sup>3</sup> There has, however, been a policy change in the UK (and elsewhere) away from a view that screening is a public health intervention applied to populations. The shift is towards a view that participation should reflect the choice of an individual informed about the possible harms and the possible benefits of screening.<sup>13,14</sup> This is clearly reflected in the objective of the NHS Sickle Cell and Thalassaemia Screening Programme.<sup>1</sup> 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.<sup>15,16</sup>

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.<sup>12</sup>

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 audiotapes 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.<sup>17</sup> 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.<sup>18</sup> Such checking can be very effective in increasing understanding, particularly for those with low levels of education.<sup>19</sup>

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. While decision-aids can achieve this,<sup>20</sup> further research is needed to establish how this might be achieved in routine consultations in which screening for sickle cell and thalassaemia is being offered to women with a wide range of literacy and values that reflect the multiple cultures that make up the population of most developed countries.

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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## 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'.<sup>1</sup> 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