is confirmed in primary care.[13] Offering antenatal screening in primary care would, however, require a considerable change in practice for GPs and midwives. It may be that such a change could be best achieved by midwives and GPs working more closely together; an alternative is to consider rapid referral systems to midwives for women who are pregnant.

The considerable delay between pregnancy confirmation in primary care and antenatal sickle cell

COMMENTARY

Important role for primary care in ensuring informed choice and timely screening and care

Sickle cell disease is now as common as cystic fibrosis in England and is one of the commonest reasons for admission to hospital in London.[1,2] The paper by Dormandy and colleagues reports that a cohort of women in a deprived inner-city setting confirmed their pregnancy early on (median gestation 7.6 weeks).[3] Despite this early confirmation, antenatal sickle cell and thalassaemia testing did not occur for many weeks (median gestation 15.3 weeks). These results raise two problems. First, services in their present form are falling a long way short of the NICE guidelines that to achieve truly informed choice women should be offered antenatal sickle cell and thalassaemia screening by 10 weeks gestation; and second, the failure to test early in pregnancy results mostly from an NHS failure to deliver early testing rather than from women failing to report their pregnancy early.

So what are the possible ways forward to ensure that all pregnant women have access to good quality antenatal sickle cell and thalassaemia screening in a timely manner? One solution would be to offer antenatal sickle cell and thalassaemia screening in primary care when women first report their pregnancy. Given the findings reported here, this method would be likely to achieve earlier testing for many women. Such a change, as well as requiring changes in general practice and midwifery care, would be difficult because antenatal sickle cell and thalassaemia screening could be perceived as somehow different from other aspects of maternity care.

An alternative way forward would be to acknowledge that sickle cell and thalassaemia screening could be considered as a test for life rather than an antenatal test. It could be conducted in primary care at any stage, not just when the woman is pregnant. To ensure joined-up care the carrier test result could be included on the maternity referral form, much as relevant history is now included.

In the wider view this would fit well with the development of a coherent preconception screening and care policy offered to women and couples as part of young adult checks, contraceptive care, and pre-pregnancy planning.[4] The findings of Locock and Kai show that parents would welcome an sickle cell and thalassaemia screening programme before pregnancy.[5] At present such a policy and service is lacking from the NHS despite the obvious benefits it would provide. In the case of sickle cell and thalassaemia screening countries such as Cyprus and Iran who offer preconception programmes, and in the case of Iran have even passed a fatwa to allow prenatal diagnosis and termination early in pregnancy, have achieved most success.[6] A national preconception screening and care programme would help to clarify that the current 'turf war' between midwifery and primary care is unhelpful and would demonstrate the important role for primary care as key to the long-term care of women and their families, which starts before pregnancy and continues through childhood and often into the next generation.

The data reported here highlight an urgent need for action, and the debate about how to achieve change should not lose sight of the need to achieve change. An important area for general practice to address is the lack of knowledge in primary care about the need for early antenatal testing, which patients will increasingly expect to be routinely provided in this setting.[6] The experience of the PEGASUS (Professional Education for Genetic Assessment and Screening) programme commissioned by the NHS Sickle Cell and Thalassaemia Screening Programme is that, to date, primary care has been a difficult audience to engage.

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