

# How Well Does Midwifery Education Enable Professionals to Work With Families and Individuals Affected by Sickle Cell and Thalassaemia?

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## Abstract

*More often than not, the midwife is the first health professional to bring up the topic of antenatal screening testing. This paper sets out to ask the questions: What is the best way to train and educate midwives, or any other allied health care professional, practising in low prevalence disease areas within the United Kingdom? How can we ensure that they will retain sufficient enough vital knowledge on infrequently occurring conditions and then be able to adequately draw upon this learning at a later stage, when they do present? This examination revolves around the findings from a small exploratory study titled Are Their Genes Compatible? The study took place in February 2005 and focused on the knowledge and attitudes of pre-registration midwifery students, practicing midwives and midwifery lecturers towards antenatal screening for sickle cell and thalassaemia disorders in a large nursing and midwifery school in Wales, which has four-linked NHS trust hospitals attached. Findings demonstrated to the author that the research subjects were unaware of the basic but important aspects of Haemoglobinopathies, despite the introduction of some training (average 1-2 hours) across all Welsh universities. Responses relating to the comfort in information giving and responsibilities for informed decision making highlighted even more concerns. The study was part of a one year Health Professions Wales research fellowship award.*

## Keywords

Sickle cell, haemoglobinopathies, midwifery education, antenatal screening, and low prevalence disorders

## Introduction

Weatherall and Clegg (1981) identified that serious inherited blood disorders were gaining recognition as one of the most important public health issues facing society. In the UK, there are now an estimated 12,500 people with sickle cell disorder (SCD) and 800 with beta thalassaemia major with distribution across the UK significantly uneven (Darbyshire 1997). Prevalence of SCD in England has increased massively by 45-60 per cent in the past 10 years (Streetly 2005), with the main concentrations of people living around

the areas of London, Birmingham, and Manchester.

Although Wales has only 45 registered patients at its one sickle cell centre in Cardiff (Liburd 2006), historically though, Wales has a long history of minority ethnic settlement. These are pocketed mainly around the South Wales coal ports and who tend to be at greater risk of Haemoglobinopathies (Saltus and Esprit-Griffiths 2005). 1.8 per cent of the general population are estimated to be at risk of carrying a sickle cell gene however, this rises massively to 86 per cent in those residing in South Wales alone (Health Education Authority

Report 1998). Migration of people into the area whether for employment purposes, education or to join already established family members, alongside the policy to disperse refugees has also meant that areas like Wales, that have previously had fewer people affected with haemoglobin disorders, are now starting to grow. Without dwelling too much on exact numbers of pregnancies affected and those at risk too much, when we balance each case of sickle cell and thalassaemia against human suffering and the effects on the families, all of these are significant regardless of where they are.

Kennedy (2006) emphasises how the good society has a duty to provide solid information to families and individuals facing difficult screening situations. However, despite Britain's growing multi-ethnicity, for a long time, there seemed to have been a reluctance to allocate regional & national funds for conditions that did not primarily affect the majority white population (Anionwu et al, 1993, 2001).

At present though, England now offers universal screening through the NHS Screening Programme (Department of Health 2004). However, outside England differences remain in the screening that is offered. Midwives then, are often the health professional who introduces the screening process as well as being the link profession who may be called upon to give specialist advice to other disciplines, for example to a social worker dealing with an affected individual who has also been approached by other family members concerned about their higher risk of being affected by a haemoglobin disorder based on their ethnic or genetic profiling. Therefore, it is extremely important that midwives have a sound knowledge of these conditions and are confident to provide advice to others.

The author's other concern is that, although midwives and other providers of health care are responsible for maintaining their own professional development, those in low prevalence areas may not actually see the need to do this owing to lack of exposure, awareness or understanding of the genetic or cultural component of conditions like sickle cell or thalassaemia.

The Inclusions Exclusions conference (REU/SSRG 2005) highlighted that racial and ethnic disparities health need and education remain an important consideration for policy makers. Therefore, comments raised earlier by Weatherall and Clegg (1981) still remain a significant public health issue of importance today for many sufferers, families, support groups, health and social care professionals and providers across the UK. Resource distribution and funding allocation will also be pertinent. This also strengthens the author's sentiments that improved professional education needs to be at the forefront of these attempts to improve services.

#### *What are haemoglobinopathies?*

Haemoglobinopathy is a collective term for the group of severe inherited blood disorders or a generic term for an abnormality in the synthesis, or the structure of the normal protein haemoglobin. Individuals who are fully affected by a haemoglobinopathy often have severely impaired health, whilst carriers may be faced with difficult reproductive decisions, although generally they are well (Gould et al 2000). There are over 300 different types of haemoglobin; the most common type being haemoglobin A (Hb A) which people inherit from each parent HbAA (De 2005a), see Box 1.

**Box 1: Brief inheritance glossary**

HbAF-foetal haemoglobin
HbAA-adult haemoglobin
HbAS-sickle cell trait
HbSS-sickle cell anaemia
HbSC- disease
HbS $\beta$ Thal- sickle Beta thalassaemia

*Why are they important?*

In particular, in relation to this article, it should be noted here that, women with sickle cell anaemia have high risk pregnancies and have maternal mortality levels three times that of those with HbAA (National Screening Committee Antenatal Education Group 2004). Additionally, if a neonate (newborn) with a SCD is not screened and goes undiagnosed, they are much more likely to die of an infection in infancy (Augustine 2004). However, early haemoglobinopathy detection can allow for an obstetrician being on standby during the high risk delivery or early commencement of prophylactic penicillin which can then prevent early death and morbidity from pneumococcal infections associated with impaired splenic function (Serjeant 2001).

*Prevalence*

Recent demographic figures show that over 4.7 per cent of the world's population carry a gene for a major haemoglobin disorder (Wales Antenatal Screening Programme WASP 2003), whilst the birth rate for these conditions is at least 20 per 10,000 and more than a quarter of a million affected babies are born each year (WASP 2003). Many health professionals and academics however, still feel that haemoglobinopathies would have had an even earlier or higher priority if they

weren't perceived as solely black conditions (Atkin et al 1998). The reality is, however, that although prevalence is higher in West Africans (one in four), Afro-Caribbeans (one in ten), and Asians (one in 50), the risk although lower is also significant for some Mediterranean groups such as northern Greeks and Italians (one in 100) (UK Sickle Cell Society, 2004). Prevalence is useful because it is a measure of the commonality of disease (Wikipedia 2006). High prevalence then is defined by the National Screening Committee (2006) as the estimated fetal prevalence of sickle cell disorder as greater than 1.5 per 10,000.

*UK Screening*

Screening for foetal abnormality has now become a significant part of antenatal care for almost all women in the UK today (HGC 2006). The National Screening Committee (2000) define screening as a public health service in which members of a defined population, who do not necessarily perceive they are at risk of, or are already affected by, a disease or its complications, are asked a question or offered a test to identify those individuals who are more likely to be helped than harmed by further tests or treatment to reduce the risk of disease or its complications. There is no universal cure for sickle cell and thalassaemia disorders (apart from bone marrow transplantation in a few) and medical interventions tend to focus on symptom control. Often those with a trait (healthy carriers), aren't always aware they have it. There is a growing emphasis on prenatal screening and the Human Genetics Committee (HGC 2006) asserted that the growth of prenatal (antenatal) screening in the absence of treatment is disease prevention through selection rather than by the development of cures. Therefore, those affected by this lifelong chronic condition or newly

identified during pregnancy will need huge amounts of sensitivity, advice, support, and preparation in order to allow them to make well informed reproductive choices based on information given to them (Asgharian, Anie and Berger 2003).

The HGC (2006) also has an ongoing concern with issues of equality and accountability in the provision of screening services. A briefing by the British Medical Association (2005) highlighted that there was a significant level of variation in access to screening programmes across the UK according to geography, ethnicity, and socio-economic status. At present, the NHS sickle cell and thalassaemia screening programme for England advocates that all strategic health authorities are required to offer antenatal screening to all women for thalassaemia. The policy for sickle cell screening is however, dependent on whether the acute Trust the women attends, is identified as being in a high or low prevalence area. In Trusts with a low prevalence, decisions to screen are based on the *Ethnic Question and Antenatal Screening Study* (EQUANS) (Sutton et al (2003)). In areas like Wales where the prevalence of the haemoglobin disorders is lower, the HGC (2006) suggests that targeted programmes may well be more appropriate when there is a thin scatter of such families across a wide area although they do acknowledge that this is more difficult to operate both equitably and effectively so service provision remains difficult. Thus, in Wales screening remains selective despite some earlier evidence showing that a selective antenatal screening policy sometimes fails to identify women who should be offered screening. It has also been identified that this generates particular problems for service providers, as the population will still contain some people at risk of

sickle cell or thalassaemia with the entitlement to receive the same quality of care as any other UK citizen (Department of Health 1999, Gould et al 2000). Where ethnic monitoring is not routine, it also cannot be relied upon to ensure that appropriate screening is being offered either (Welsh Assembly Government/NHS Velindre 2003). The Welsh Assembly Government has tried to improve identification of those to be at risk by additionally requiring that all Trusts to implement antenatal screening for sickle cell and thalassaemia based on a different screening question asked by midwives and developed specifically for the Welsh population by Antenatal Screening Wales (De 2005b).

### *Education*

Dyson et al (1993) implemented a study in England in the mid 90's that comprised of a convenience sample of midwives and senior midwives over 26 sites across England. Data was collected over four months and 850 questionnaires were completed under supervision (401 on sickle cell anaemia and 449 on beta Thalassaemia) 527 by qualified midwives and 320 by students. Although Dyson et al (1996) reported worrying findings, which demonstrated that research subjects were unaware of the important aspects of the haemoglobinopathies, more positively however, they highlighted that knowledge levels could be improved by education.

Therefore the provision of an in-depth taught learning package that is available to aid health professionals involved in the English screening programmes through PEGASUS (Professional Education for Genetic Assessment and Screening) should be seen as a positive attempt to improve midwifery knowledge. Unfortunately, though, this commitment relates to England only. When funding discontinues after 2008, it

is not known whether English let alone Welsh or Scottish Midwives will also then be eligible for this useful face-to-face training, although they may later be able to access these available through online resources ([www.pegasus.nhs.uk/](http://www.pegasus.nhs.uk/)).

In the meantime, all midwives in Wales involved with antenatal screening can be provided with a copy of a comprehensive Education Pack that was developed by the Wales Antenatal Screening Project with the assistance of MIDIRS Midwifery Digest and funded by the Welsh Assembly Government. The pack is an example of best practice and includes comprehensive information on all antenatal screening tests, a written communication skills course, and a CD ROM of presentations and other learning resources. However, unlike PEGASUS, it is based on self-directed study. The concern is again that although midwives are responsible for maintaining their own professional development through PREP requirements (Nursing and Midwifery Council, 2004) through reading around unfamiliar subjects, acquiring new skills and keeping up to date, Welsh midwives in other low prevalence areas may not actually see the need to do this (in this instance) owing to infrequent presentations, awareness or misunderstanding of the wider implications of SCD's.

### **Study aims and purpose**

Sutton et al (2003) recommended that further research should be commissioned to examine the role of the midwife in haemoglobinopathy screening and such research should place the views of those living with haemoglobinopathies and their carers at its core. The author set out to replicate a smaller scale version of Dyson and colleagues' (1993) English study in Wales at the University of Glamorgan.

The research question/hypothesis was formed from the presumption that one to two hours teaching on sickle cell and thalassaemia disorders was insufficient training for Welsh student midwives, qualified midwives or midwifery lecturers to adequately provide informed antenatal screening advice to others.

The main aims of the study were to:

- assess midwives', student midwives' and midwifery lecturers' knowledge of and attitudes to sickle cell disorders.
- establish whether the groups studied felt adequately prepared to offer basic haemoglobinopathy screening advice to others, including expectant mothers/parents, students, colleagues, other health care professionals and academics.
- identify whether previous or current training and education on the subject was adequate enough to prepare professionals to implement informed antenatal screening or training.

Ethical approval was successfully obtained early on during the fellowship period from the School's ethics committee. As all the participants were either working or studying at the University Clinical Trust, ethical approval was not deemed necessary.

### **Methods**

The research approach was a descriptive study based on the use of self-completion questionnaires. In regards to study design a thirteen point multiple choice questionnaire was developed to assess knowledge and attitudes of sickle cell anaemia and thalassaemia was constructed. This was based on a shortened combination version of the two Dyson and colleagues' (1993)

questionnaires and permission was obtained from Dyson to base the questionnaires on some of the questions previously validated for his earlier study. In order to contextualise my findings additional questions were asked regarding professional status, previous training details and if participants felt adequately prepared to offer screening advice to others which brought the total number of questions to sixteen.

Following a small pilot study using a proposed questionnaire, that used a convenience sample of six, the author distributed the self completion multiple choice questionnaire with the three professional groups of subjects; pre-registration student midwives (n=10), post registration student midwives (n=14) and midwifery lecturers (n=5).

Distribution of the main study questionnaires took place in the University's School of Care Sciences. The total number surveyed (n=29) was low as annual cohort numbers for midwifery courses are significantly lower in comparison to general nursing cohorts. Access to these groups was guided by the Head of Midwifery Studies. The author was not present at the distribution of the questionnaires; these were given out by the lecturer timetabled on the agreed days, when the author was aware students would be attending university. These were later returned to the researcher in a sealed envelope in order to maintain confidentiality and anonymity. As this exercise concerned both research and education, copies of the correct answers were then distributed once the participants had completed and returned their papers to the lecturer present. The purpose of this was so participants could then individually evaluate their own levels of knowledge.

In the main study, the sample population surveyed was twenty-nine out of thirty-five total populations (82.9 per cent). This was obtained by use of quota sampling taking a minimum of 5 students from each of the year sets. 5 midwifery lecturers out of a team of 9, agreed to take part in the study. As Rees (1997) points out, if there is an ability in the research to identify individuals or places where the study took place anonymity of the participants may be at risk, therefore numbers of midwives were capped at 5 to maintain confidentiality. Overall response rate from the total number of questionnaires distributed was high at 82.85 per cent.

### **Findings**

The results were very similar to the overall findings described by Dyson and colleagues in 1993 of poor knowledge levels of basic genetic principles and inheritance patterns concerning the potential ethnic groups more likely to be at risk as well as, confusion relating to sickle cell or thalassaemia traits. In addition, it was discovered that not one of the twenty-nine participants indicated on the questionnaire, felt that they were adequately prepared to offer antenatal screening advice to others.

The survey findings showed that more than half 55 per cent of the respondents (n=16) underestimated the number of ethnic groups affected by sickle cell anaemia and still associate this disorder with those of Afro Caribbean decent only, whilst 66 per cent (n=19) underestimated those affected by thalassaemia.

There were three questions related to inheritance and traits. The majority of participants in this study (as in Dyson and colleagues' 1993 study) gave the wrong answers to these basic questions on the inheritance of these disorders with only 17 per cent (n=5) answering

three simple genetic questions correctly. However, 10 per cent (n=3) were confused about a carrier state being a less severe form of the disorder. This has been identified previously where Anionwu (1991) noted midwives' lack of clarity for the difference between the trait and the illness. There was also some recognition of symptoms but particularly high numbers for not knowing the prevalence of thalassaemia disorders here in the UK 83 per cent (n=24) which has been approximated as 200, 000.

#### *Education and training and awareness raising*

The participants were also asked whether they had ever received any training or education on sickle cell or thalassaemia disorders. The pre registration group appeared to be the main group to have received any structured teaching on the subject of haemoglobinopathy screening 90 per cent (9/10) compared to 43 per cent (6/14) of the practicing midwives and only 40 per cent (2/5) of midwifery lecturers. This was also reflected when average correct scores were compared. Although correct score differences were small, those with some educational input averaged only slightly higher scores of 8.0/13 whilst, the average score for those whom had not received any training was less, at 6.9/13. Overall though 41 per cent (n=12) had not received any training at all, while those who had, reported that the length of training varied from forty-five minutes self reading to three hours taught training within the three groups studied. The average length of education received in the Dyson study was ten minutes to one hour, therefore positively highlighting that training in this area was increasing, although may still not be enough, when considering the next points.

A further question asked participants if they actually felt prepared to offer adequate antenatal haemoglobinopathy screening advice to others. 90 per cent (n=26) of the total participants answered 'no' to this question. Of more concern was that even those who had received some degree of training still stated that they did not feel adequately prepared to offer antenatal screening advice, whilst the remaining 10 per cent (n=3) still also felt unsure.

#### **Discussion**

It has already been said that SCD's are rare in Wales. Thus, when interpreting these study findings the author acknowledges this and is well aware that many Welsh midwives may not have had first hand experience of caring for women with these conditions. Based on this assumption then, the terms and competence related to these haemoglobinopathies may well have been unfamiliar to them. However, it could also be argued that midwives may come across many other conditions they may not be familiar with and do not often encounter in practice but often have to rapidly learn and remember new key information as and when they occur whether it occurs in an emergency, for example if caring for a woman with an amniotic fluid embolism or an unexpected breech delivery.

This has led the author as a nurse educator to debate which of the following options could be the most effective investment of resources in low prevalence areas in order to improve knowledge, awareness and initiate change in clinical and community midwifery practice.

1. Should more timetable space allocated to sickle cell and thalassaemia training within pre-registration midwifery programmes?

This would be in line with the Department of Health's (DoH 2003) drive to promote more culture and genetics subjects in both the nursing and midwifery curriculums. To achieve the above point, however, requires a close and reflective look at the content of the curriculum. This, according to Johnson and McGee (2005), is neither quick nor simple to achieve and often requires the input of an energetic, passionate, and persistent individual. Responses from this proposal from conference attendees and fellow academics were met with disagreement. It was argued that this would not be possible as nursing and midwifery timetables were already overly stretched in simply providing the basic nursing and midwifery topics for professional registration. If any more time was allocated to sickle cell and thalassaemia screening, valuable teaching time would then have to be diverted from other relevant, as important and perhaps more highly prevalent conditions that also needed to be included. There were many reminders that sickle cell and thalassaemia were indeed low prevalence in Wales and that the likelihood of Welsh midwives in some areas to see a case was extremely uncommon still and how easily it could be for other researchers to similarly suggest more time to be devoted to their specialist areas of interest. Those desiring further information could quite easily spend personal study time referring to the Wales Antenatal Screening Pack or other freely available resources.

2. Should post registration midwifery sickle cell and thalassaemia training updates be made mandatory for qualified staff?

Although both nurses and midwives acknowledged that annual training updates for resuscitation, fire safety, universal precautions, moving and handling were necessary in order to keep up-to-date with changes in practice and policy. It was also felt that there were already way too many mandatory training days which had to be undertaken yearly. Others decided that by adding more to this list would just become "yet another tick box exercise" but were confident that the family origins question would detect those persons thought to be at higher risk of SCD's. Midwives could then follow a screening pathway for further management options. The author was quite concerned with the heavy reliance practitioners were placing upon the family origins question. If a person at risk goes unrecognised through questioning, they could then be detected through venous blood testing. However, many practitioners were unaware that a low mean corpuscular haemoglobin level (which calculates the amount of oxygen-carrying haemoglobin in blood) could be another tell tale indicator of identifying someone with an anaemia haemoglobinopathy if earlier missed.

The ongoing struggles by managers within clinical practice to organise staff cover for mandatory study release, (even for half a day), in an already stretched environment, was also emphasised. Whilst others expressed that a full days training on a condition very rarely seen like sickle cell and thalassaemia training antenatal screening would be "too lengthy" however, designating a small part of an antenatal study day to this topic, would perhaps be useful to some.

Another senior midwifery educator additionally raised the concern that too much “surface knowledge” could potentially be detrimental to maternity care and put lives of the mother or baby at risk. Receiving a certificate for mandatory training in sickle cell and thalassaemia antenatal screening may give a midwife a false sense of security that they could then deal with a critical situation and perhaps delay the summoning of a specialist nurse, obstetrician or haematologist. This could also plunge a practitioner out of their depth or lead to a potential critical incident occurring.

3. Should we invest in more sickle cell and thalassaemia specialist nurses to support midwives instead?

Many midwives felt that if they came across a case of a haemoglobinopathy, they would simply contact (or put patients in touch with) their nearest sickle cell centre, for further information and support. However, presently there is only one sickle cell and thalassaemia specialist nurse and centre in the whole of Wales. The service is already overstretched and funded to only cover the Cardiff and the Vale area only. Therefore, centre staff cannot be heavily relied upon if an acute situation were to occur in another region of Wales.

Investment of more funding for more specialist haemoglobinopathy nurses as resources to aid clinical midwives or for another Welsh centre to be built in the north of the country could be difficult to attract or justify. This is due to Wales being labelled as a low prevalence area.

4. Do we need more research to identify more appropriate effective teaching and learning methods?

Drawing from the responses for the other options presented, it was agreed that more attractive ways should be found to engage learners in new ways of thinking that will require careful crafting in order to avoid creating or reinforcing/ racial stereotypes (Johnson and McGee 2005). The author also believes that for learning to be perceived as relevant, especially in low prevalence areas, midwives will need to be given appropriate information that give clear guidance emphasising risk awareness and risk assessment methods, support and learning resources they can consult for further understanding. It also should be emphasised that this could be information that they may well need to draw upon in practice in order for them to know how to act if these conditions were to present in the future (De and Johnson 2006).

### *Summary*

Referring back to the initial study aims then it was clear that although this was a small study, the findings still broadly replicate the finding by Dyson ten years ago that students of midwifery, qualified midwives and those responsible for midwifery education are still unaware of basic but important aspects of sickle cell and thalassaemia disorders such as prevalence and it was also evident that racial stereotypes still existed too in relation to the majority of participants still presuming that only African/Afro-Caribbeans were affected by sickle cell anaemia. It was also extremely worrying that nearly all of the participants linked to the one school surveyed (including educators) did not feel adequately prepared to offer antenatal screening advice about sickle cell or thalassaemia disorders to others with the other 10 per cent also unsure. This lack of knowledge could quite easily be the same for the other antenatal tests provided in Wales. This was also

despite the introduction of some training in Welsh nursing schools to raise awareness alongside distribution of the Wales Antenatal Screening Project learning resource pack in 2003 which only one of the participants in the study had referred to as part of their self learning purposes (De and Johnson 2006). Freely available written information for women has also become a key driver for pregnant women in Wales to seek more information about sickle cell and thalassaemia disorders and midwives are already noticing that service users nowadays expect them to provide some knowledge and information about the various genetic conditions that could potentially arise with each pregnancy. A basic understanding of sickle cell and thalassaemia disorders is crucial then if midwifery and antenatal care is to meet the needs of minority ethnic groups particularly and if genetic competence within the midwifery profession is to be improved (Genome Policy Unit et al 2003). Although there has been a drive by the DH to improve genetics & culture in the nursing & midwifery curriculum (Genome Policy Unit et al 2003) space to accommodate has been hard to come by. Interestingly, the uptake of post registration genetic courses and transcultural health modules in Wales has also been low.

### *Conclusion*

Overall, then, the study supplemented the hypothesis that 1-2 hours pre-registration teaching attendance did not seem to be adequate enough to prepare midwives to provide screening advice to others. It seems that all professional groups and not only those surveyed should be supplementing their ongoing learning, in their own time in order to maintain fitness and competence to practice safely and more effectively. Self directed teaching aids like the Wales Antenatal Screening pack is a

great example of a best practice resource tool, which can be used widely to supplement learning as part of this professional responsibility. This method of learning will inevitably have to continue until more research into the evaluation of more alternative teaching strategies, (such as those suggested in this article) are implemented and introduced. Interestingly only one person acknowledged using the Wales Antenatal Screening Pack for learning therefore perhaps more promotion of the pack's benefit, may be another avenue to concentrate efforts upon.

The author does acknowledge that while the study did uncover some important and interesting issues for midwifery screening, practice and education critics may highlight the fact that only one site was surveyed. Sample size was also not large-scale or extensive unlike the Dyson and colleagues' English study. This survey was carried out in only one school of nursing and midwifery and therefore caution should be taken in generalizing the findings across the rest of nursing and midwifery schools in Wales. Results from this study, although small, highlight a need for more wider national education on antenatal screening and not just for sickle cell and thalassaemia but for all other genetic disorders in Wales. This should also not just be for midwives but for other disciplines like social workers as well as counsellors. Additionally, if there were more PEGASUS funding, midwifery training areas could become much wider than they are at present.

The histories, settlement patterns, residential status and occupational profiles of Wales's minority ethnic groups, who may be at higher risk of a haemoglobinopathy, are different from the rest of the UK. There is a need therefore to consider the particularities of the Welsh context when examining

the health and social care of different ethnic groups in general, and the issues related to genetic conditions like sickle cell and thalassaemia (Saltus and Esprit-Griffiths 2005). Hall (2002) further supports this by reporting that, a city-centred service does not seem to take into account current immigration trends and refugee and asylum seekers, in temporary residences across 'low ethnicity' areas in Britain. Whilst locating specialist services only in areas of 'high ethnicity' could also further compound the perception of the client groups affected, raise the stigma attached to sickle cell disorders and hence achieve little in the struggle for the promotion of anti-racist health policies particularly in lower prevalence areas.

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### Notes on contributor

Diana De is Senior Lecturer in Adult Nursing at the University of Glamorgan. She has always had an interest in transcultural health care and sickle cell disorders and has written a number of publications in this field. She is currently involved in two linked research projects: *Living and Working with Sickle Cell and Thalassaemia* is a three year qualitative study aiming to empower patients, enhance the genetic competence of nurses and promoting awareness and a smaller study *Are Their Genes Compatible?* which is looking at pre-registration, post-registration education and midwifery lecturers' knowledge and attitudes of sickle cell antenatal screening as part of a one year Health Professionals Wales Research Fellowship. She has recently returned back from a Florence Nightingale Fellowship visit to the world renowned sickle cell unit at the University of West Indies, Kingston, Jamaica and the Instituto de Hematologia, Havana, Cuba and hopes to share some of her experiences in the development of a nursing toolkit for haemoglobinopathies. She has also visited St Jude's Hospital in Memphis, USA with funding from the Welsh Intensive Care Society.

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