Chapter 5

SCREENING FOR ANAEMIA AND HAEMOGLOBINOPATHY BEFORE AND DURING PREGNANCY: A QUESTION OF ETHNICITY?

Suze M. P. J. Jans¹,*, Martina C. Cornel² and Antoinette L. M. Lagro-Janssen³

¹Midwifery Science, EMGO+ institute for Health and Care research, VU University Medical Center & Academy of Midwifery, Amsterdam, The Netherlands
²Community Genetics, EMGO+ Institute of Health and Care research, VU University Medical Center, Amsterdam, The Netherlands
³Department of Primary Care and Community Care, Women’s Studies Medicine, Radboud University Medical Center, Nijmegen, The Netherlands

ABSTRACT

Ethnic diversity poses certain questions within the healthcare setting and challenges health care professionals to deliver equitable health services. The prevalence of anaemia (a low haemoglobin) and haemoglobinopathy (carrier) status (serious autosomal recessive disorders) differs between ethnic groups. Haemoglobinopathy carrier screening for reproductive choice is currently not a standardised offer in the Netherlands.

Professionals caring for pregnant women with different ethnic backgrounds such as midwives, obstetricians and general practitioners, should be aware of the possibility of anaemia as this occurs more frequently in pregnancy. If anaemia is present, carrier status should be investigated in those women with a higher risk ethnic background before any treatment is started, since iron treatment may be harmful in carriers. Asymptomatic bacteriuria and the subsequent risk of pyelonephritis may also occur more frequently in pregnant haemoglobinopathy carriers. Therefore these women should be investigated more frequently for these conditions.

* Corresponding author: Dr Suze Jans, Midwifery Science, EMGO, VU University Medical Center, Amsterdam, The Netherlands, s.jans@vumc.nl.
Health professionals use ethnicity to deliver appropriate health care for all groups within society but evidence shows that they struggle with the operationalisation of this concept, making them uncertain whom to offer screening for haemoglobinopathy. Although a screening instrument based on ancestry has been shown to be effective, increasing ethnic admixture and the view of the patient organization for haemoglobinopathy that the accent should not be placed on certain ethnic groups supports a universal screening offer.

Evidence underlines the necessity to solve ethical and practical barriers before a haemoglobinopathy screening programme is introduced. This can only be done with adequate governmental leadership after which professional organizations can be called upon to meet the implementation requirements of such a programme.

**INTRODUCTION**

Ethnic diversity raises certain questions within the healthcare setting. Clinical health professionals struggle with these questions on a daily basis, especially those who work in areas where this diversity is greatest such as in the urban areas of the countries of Europe. Major ethnic health disparities exist in terms of health outcomes [1, 2]. The prevalence of certain disorders differs between ethnic groups and studies have shown that pregnancy outcomes are not the same for all ethnic groups in the Netherlands and that access to health care is still a major issue [3]. Health care professionals and policymakers should take these differences into account in the way health care is delivered to avoid health inequalities. This does not always happen and most professional guidelines lack attention to ethnic differences [4].

Ethnic differentiation in policy recommendations should be evidence based and lead to appropriate care for all ethnic groups. The topic of this chapter is the screening of anaemia and haemoglobinopathies (HbP) before and during pregnancy against the background of ethnicity. HbP is the umbrella term for the autosomal recessive disorders such as sickle cell disease and thalassaemias.

This chapter will consist of two parts: In the first part we discuss anaemia in pregnancy amongst different ethnic groups in an Amsterdam population and the effect of a positive HbP carrier status on the outcome of pregnancy. In the second part we will discuss the attitudes and barriers concerning the introduction of an ethnicity based HbP carrier screening programme.

**Anaemia and Haemoglobinopathy**

Anaemia means a low haemoglobin (Hb) level and is determined by a simple measurement of Hb by taking a blood sample. Screening for anaemia in pregnancy is standard midwifery practice, both in the Netherlands and elsewhere [5-9].

As a result of structural abnormality or a reduced production of normal globin proteins, a link exists between anaemia and HbP. HbP is the umbrella term for disorders such as sickle cell disease (SCD) and thalassaemia. These are autosomal recessive disorders that cause variable but life-long morbidity and a shortened lifespan due to multi-organ ischaemic damage [10-12]. They are considered to be the most prevalent monogenetic disorders
worldwide: each year approximately 300,000 babies are born with a severe form of HbP. The prevalence of a positive HbP carrier status has been estimated at 0.03-40% depending on ethnic origin [12, 13].

Couples in which both partners are carriers of HbP have a one-in-four chance (25%) in each pregnancy of giving birth to an affected child. However, recessive disorders are not always apparent in families, which means that most couples are unaware of their carrier status and the birth of a child with a severe HbP disorder is therefore usually unexpected [14]. Carriers can be identified by a simple and cheap blood test (High Performance Liquid Chromatography, HPLC).

As a result of the heterozygote advantage in malaria, HbP occur more frequently in those areas where malaria is or was endemic such as Africa, the Mediterranean region, the Middle East and South-East Asia. Because of migration, HbP now also occurs in non-endemic countries. In the Netherlands, each year approximately 60 children are born with a serious HbP disorder [15]. Carrier prevalence has been estimated at 4-26% for Dutch citizens of immigrant descent [16, 17].

Ethnicity Related to Anaemia and Haemoglobinopathy Carrier Status

Existing literature shows that it is evident that the question of ethnicity cannot be ignored when dealing with anaemia in pregnancy and when health professionals want to provide adequate care for all pregnant women and women with a pregnancy wish in an ethnically diverse society [7, 18, 19].

The first edition of the KNOV (Royal Dutch Organisation of Midwives) anaemia guideline did take differences between ethnic groups into account by introducing separate reference values for pregnant Black women, but when the guideline was evaluated primary care midwives in the Netherlands still commented that the guideline did not meet the needs of all ethnic groups and that anaemia was detected too late [20]. Separate reference values for Black women were based on evidence that Hb levels among Black people are on average lower than among other ethnic groups. However, it is unclear whether these lower levels are physiological or due to underlying pathological conditions which warrant further investigation and treatment instead of separate reference values. Others commented that HbP carrier status should be investigated [20, 21].

The assumption voiced by Dutch midwives that pregnant women of non-Northern European descent are at a higher risk of anaemia was confirmed by a cohort study carried out in Amsterdam [19]. However, the findings of this study are not easy to interpret. Ethnicity was defined according to the National Perinatal Register of the Netherlands as identified by the midwife: practice based but perhaps with suboptimal validity. The study uses terms such as ‘Northern European’ and ‘non-Northern European’ which are obviously very broad and apply to a large variety of ethnic groups. However, so are the terms used for the sub-groups such as Mediterranean, may mean anything from Italian, Croatian and Turkish to Moroccan whereas “Black” could be anyone with a background from the wide diversity of the African continent, the former Dutch colonies of Suriname and the Antilles and so on. Besides the obvious geographical and genetic (HbP) differences, combining women in these groups ignores more complex but very relevant issues such as migration, differences between generations, socio-economic factors and culture, which may all influence lifestyle and
nutritional factors and therefore also anaemia. Although the study confirms a difference in risk for anaemia amongst different ethnic groups, it is unable to elucidate on the factors that lie behind this finding.

A systematic review that was published in 2010 which aimed to investigate the effect of HbP carrier status on the outcome of pregnancy, also encountered problems with the definition of ethnicity [22]. The definition was sometimes absent or not always clearly defined which could have influenced the results. On the basis of the available evidence the study concluded that pregnant women who are HbP carriers are at low risk of adverse pregnancy outcomes. Women can be reassured that they can continue to receive care in a low risk setting.

Although the HbP topic yields sufficient results in search engines such as Pubmed, only a few studies evaluated the effect of HbP carrier status on the outcome of pregnancy. These studies are relatively old and have many methodological problems [22]. It is curious that despite the fact that HbP are some of the world’s most prevalent autosomal recessive disorders, there is an apparent lack of research interest in this specific topic. This fact is also recognized by the WHO which expressed concern over the insufficiency of relevant epidemiological data which may present a challenge to effective and equitable management of sickle cell disease and trait [24].

The studies mentioned here show that it is important that clinicians such as midwives, obstetricians and GPs provide tailored care for pregnant women with different ethnic backgrounds. The European project partners of the Amsterdam declaration towards migrant-friendly hospitals agreed on basic principles in their statement, one of which was identifying the needs of people with diverse backgrounds and monitoring and developing services with regard to these needs [25]. Although the statement is aimed at hospital care, it could easily be transferred to primary care. Paying more attention to those groups at higher risk for anaemia such as women from non-Northern European descent, and the complexities behind this such as the possibility of a positive HbP carrier status supports meeting those needs. Besides, this would answer the call of the WHO in 2006 to pay more attention to those a risk for HbP [24].

Professionals caring for pregnant women with different ethnic backgrounds such as midwives, obstetricians and GPs, should be aware of the possibility of anaemia. If anaemia is present, carrier status should be investigated in at least those women with a higher risk ethnic background before any treatment is started, since iron treatment may be harmful in carriers. Asymptomatic bacteriuria and the subsequent risk of pyelonephritis may occur more frequently in pregnant HbP carriers as shown in the systematic review discussed above. Therefore health professionals involved should investigate pregnant women who are known HbP carriers more frequently for these conditions.

**Carrier Screening and Reproductive Choice**

No medical service exists in isolation. The related effects of a positive HbP carrier status on the outcome of pregnancy and diagnostic clarity when looking at anaemia in pregnancy, testing for HbP carrier status also raises discussion about reproductive choice. As mentioned earlier, carrier couples have a 25% chance of giving birth to an affected child with each pregnancy. Some have argued that HbP carrier screening should be part of the midwives’ anaemia guideline [21]. However the answer to the question whether or not HbP carrier
screening for the purpose of reproductive choice should be offered during the preconception period or in early pregnancy, does not belong in a guideline on anaemia. Moreover, the expanded Neonatal Screening (NNS) which was implemented in the Netherlands in 2007 and included a test for SCD raised the same question: As a result of the unintended finding of HbP carriers in the programme, the old discussion whether or not a broad HbP carrier screening programme should be introduced was renewed [26].

A paper on the case history demonstrates the influence of the heritage of past events on general health care policy such as screening, and more specifically on HbP screening policy [27]. It showed that the registration of ethnicity was of influence during the decision making process. The results were generated through a unique research method which allowed for an in-depth analysis and an exploration of hidden and sensitive elements in the past discussion. Interestingly, the analysis follows on from an earlier witness seminar that was held in the Netherlands [28], which reported on the unholy alliance of political parties and the government against prenatal screening in the eighties out of fear for eugenics. The HbP witness seminar takes this one step further: Not only reproductive screening was politically unacceptable, but the registration of ethnicity was as well and for similar reasons. As opposed to a long history of neglect of African-American health in the United States (US), the heritage of the Second World War influenced the decision-making process in the Netherlands causing a barrier for the introduction of HbP carrier screening [27].

Strikingly, during the discussion in the nineties, no role existed for any patient representatives. The anthropological study that was part of the 1994 report on the possibility of introducing a HbP carrier screening programme, showed very little knowledge amongst groups at higher HbP risk, but those who were indeed familiar with HbP disorders, expressed to be willing to accept prenatal screening and were open to the possible consequences of such screening [29]. Since then a few studies have been carried out amongst the groups at higher risk in the Netherlands [30-32]. In order to resolve existing challenges, future decision-making on an extended screening programme needs to include representatives from groups most at risk of HbP to support a programme that adequately supports the needs of societal groups and to ensure adequate implementation of such a programme, as is advocated by the International Alliance of Patient Organizations (IAPO), in all aspects of health care [33].

Long before the introduction of the English sickle cell and thalassaemia screening programme (http://sct.screening.nhs.uk, last accessed 30 April 2012) researchers commented on the fact that long term neglect of adequate screening and care of HbP conditions by the British health services are pointed to by users as reflecting racist marginalization [34, 35]. Since then a comprehensive programme has been introduced in England. And although it does meet with difficulties, the programme has been successfully implemented and evaluated [36-40]. Although the Netherlands has introduced NNS for SCD, societal discussion about HbP carrier screening is practically absent outside the call of a committed few [26, 41]; the discussion does not seem to have moved forward from the one held in the nineties as described in the witness seminar.

**Definition of Ethnicity**

With such obvious differences in prevalence in both anaemia and HbP, it is important that ethnicity is adequately defined. For example a recently published guideline on
hypertension by the Dutch midwives organization points out that being of African (sub-Sahara) descent is a risk factor for hypertension in pregnancy, making ethnicity in itself a confounder for one of the outcomes in the systematic review discussed earlier [42-44]; again pointing out that an adequate ethnic definition is important.

Although a questionnaire showed that midwives have a positive attitude towards ethnic registration, the results of a focus group study showed that both midwives and GPs find defining ethnicity problematic and complex [45, 46]. Mixed backgrounds of their patients and clients made them uncertain about whom to offer screening. These results correlate with the complexity of determining ethnicity which is often misleading as demonstrated by others [47-50]. These arguments would therefore support a universal screening offer.

It is unclear, however, in which manner health professionals currently determine ethnicity. As Hinton et al. point out, assessing ethnicity is usually done by health professionals using their own judgment which is prone to errors [51]. The practical problem of GPs who are unable to register ethnicity in their software system, may be easily solved. However the fact that they displayed clear ethical problems of doing so needs further attention if ethnicity based HbP carrier screening is introduced in the future [45, 46]. The fact that SCD is characterized as a “Black disease” as has been (and still is) the case in the US and the UK [34, 52-54] may further complicate ethical issues as it sets aside certain groups in society, especially in the current politically hostile climate. Although there is no available empirical evidence of racism within the Dutch health system, the uneasy feelings as displayed in the focus group study clearly feeds into concerns about this issue as has also been pointed out by others who call for greater awareness of such issues [55].

Government, Law and Lack of National Policy

The fact that midwives (and GPs to a lesser extent) seemed less confident in their capabilities of carrying out a test for HbP carrier screening, may have something to do with a lack of knowledge among health care professionals which has been demonstrated by other studies directly related to HbP and Cystic Fibrosis (CF) (carrier) screening [56, 57] or related to genetic knowledge in general [58]. However this may also be related to the (partially) incorrect belief that they are legally restricted to offer carrier screening because of the Dutch Population Act [59] or to the fact that laboratory (result) forms are sometimes complicated to interpret. Easily accessible schooling for health professionals may support them to feel more secure about informing clients and patients about HbP carrier testing. But standardised laboratory forms which include advice on correct follow up when results are positive as is used in prenatal screening, would further support health professionals. ((http://www.rivm.nl/Onderwerpen/Onderwerpen/B/Bloedonderzoek_zwangeren/Voor_professionals, last accessed 30 April 2012).

Although the results of the questionnaire show that lack of intention was mostly influenced by negative peer behaviour (social norm), a reluctance to initiate screening is probably more related to the absence of appropriate policy direction [46]. Individual health professionals or their organizations could decide that HbP testing is their standard care. However, normally screening programmes are initiated by government and public health authorities and not individual health professionals. On a European level this is also the advice of the Public and Professional Policy Committee (PPPC) [60]. This would suggest that
without guidance by national policy, health professionals may not feel responsible for implementation. However preconception carrier screening is not legally bound by the Population Screenings Act of the Netherlands (Wet op Bevolkingsonderzoek, WBO) and therefore does not need a governmental license [61]. This and current political health policy which keeps governmental interference with preventive policy and reproductive choice to a minimum, complicates matters as for this reason the government may refrain from taking action. However in the case of antenatal carrier screening the discussion may be different.

With carrier screening during pregnancy, although also aiming to give parents reproductive choice, options are more restricted and could lead to prenatal diagnosis to identify a foetus with severe HbP, and thus could in principle result in termination of the pregnancy. An HbP carrier screening programme would still be regulated under the WBO but the question whether a license is required when screening is offered in the early antenatal period remains open to discussion. Unfortunately information on this subject does not give a definitive answer and will therefore need guidance from the Department of Health [62, 63].

Clearly before a genetic screening programme is introduced, it should be evaluated against the background of certain (internationally agreed) criteria [60, 64, 65]. The potential benefits and harm should be carefully considered before such a programme is implemented. These benefits include pre-symptomatic detection of genetic disorders and prevention of further harm by determining the predisposition of a person that may produce a hereditary disease in offspring [66] and thus providing reproductive choice, which is the case with HbP carrier screening. The potential harm may include anxiety, stigmatisation and discrimination [64].

The results from the focus group study underlined the necessity to solve ethical and practical barriers and clarify financial issues before a HbP carrier screening programme is implemented. Others have also highlighted the lack of financial resources, a high workload and the absence of a preconception care setting as barriers in the implementation for preconception CF carrier screening [67]. There is no reason why it should be assumed that HbP carrier screening differs in this respect. Others have discussed the possibility of medicalisation: there may be no doubt that when preconception or antenatal carrier screening is introduced a certain degree of medicalisation will occur, but this is not necessarily a moral problem. The facilitation of adequate informed decision making together with good quality provision of care of those affected by the specific disorder, in this case HbP, will address the main concerns [68].

Some of these issues can be dealt with by the representative organizations of health professionals but ethical and financial barriers will need academic guidance and negotiation with relevant insurance bodies. Besides, the Dutch HbP patient organization OSCAR, indicated in a small unpublished study that their members encounter difficulties requesting a carrier test at their own initiative. OSCAR would prefer government involvement in terms of clarification as the organization has little confidence that screening will become more readily available when patients and clients have to rely on the goodwill of health professionals alone and there for support the introduction of a programme similar to the one in England [68-70].

Leadership by Health Authorities would be preferred in order to initiate the appropriate changes, and may be needed in terms of clarifying legal matters. It could be the responsibility of the representative professional organizations of midwives and GPs (and possibly the obstetricians), to find appropriate strategies in dealing with ethnic diversity of their client and
patient populations. This is supported by Achterberg’s study in which it was argued that effective implementation of screening for HbP will require changes at both regime (suppliers and users) and landscape level (institutions, material social, political and legal infrastructure), but that such change is difficult to achieve without a health authority taking an active orchestrating role [71].

Ethnicity Tailored Health Care

The focus group study showed that health professionals use ethnicity to deliver appropriate equitable health care for all groups within society. Despite the fact that Manna et al. dispute adequate ethnic related knowledge in guidelines, increasingly guidelines seem to incorporate ethnicity related health care [4, 8, 43, 72]. However, how to operationalise this concept is a question that is less easy to answer. As we have seen health professionals are willing to offer ethnically sensitive care but struggle with the concept in daily practice. A screening instrument based on ancestry has been shown to be effective [73, 74]. According to Karlson et al. ‘ethnic’ classifications draw on phenotypic characteristics in many surveys, in this case a screening instrument, which have genetic underpinnings or geographic and / or environmental ancestry which has been shown to influence genetic profile [75]. At first instance ancestry seems to be less of a social construct than ethnicity. But some scientists belief that ancestry also has its limits because of a lack of understanding by the users [76]. However the authors argue that even in the apparently clear case of a monogenic disorder such as sickle cell disease or thalassaemia, where genetic factors can offer insight into ethnic variations of these disorders, there is a complex interplay between genetic, environmental and socio-economic characteristics to be taken into account before the extent of genetic influences can be definitively established [75]. For instance the life-span of a person with sickle cell disease or the potential influence of a positive carrier status on the outcome of pregnancy is influenced by more than just the genetic component which means that ethnic origin may be more appropriate for tailoring (midwifery or obstetric) health care.

Both the available screening instruments as developed by Lakeman and Dyson, use the term family origin [73, 74]. Only the self-assessment screening instrument as developed by Lakeman et al. offers a combined offer of CF and HbP carrier screening on order to reduce feelings of discomfort when asking the ethnicity question, which was an emerging theme in our study and which was also found by others [47]. If the implementation of a targeted screening programme is agreed upon, this would be the instrument of choice.

Introduction of a HbP Carrier Screening Programme in the Netherlands

In England as opposed to the Netherlands which only introduced sickle cell screening as part of NNS, a successful combined screening programme was introduced in 2004 (http://sct.screening.nhs.uk last accessed 25 April 2012). England conducts ethnicity based or targeted antenatal HbP carrier screening in low prevalence areas and universal screening in high prevalence areas. NNS for SCD and thalassaemia is conducted on the basis of universal screening as in the Netherlands.
The programme in England is still hampered by some implementation problems two of which are late screening offers when first appointments do not occur until 18-19 weeks of pregnancy [38, 39] and only half of the fathers of those pregnant women who are found to be a carrier, are tested [36]. Besides, preconception screening is not really an issue (yet) in England. In general women in the Netherlands are seen between week 10 and 12 of pregnancy for a first visit with their midwife and sometimes even earlier, although it is known that some women from certain ethnic backgrounds have a tendency to come late into antenatal care [77, 78]. Preconception care has been initiated by all health professionals involved [79-81], although the necessary financial support by health authorities was halted last year delaying adequate implementation [61]. The Netherlands is in a good position to implement a similar broad programme because of early pregnancy bookings and interest of health care professionals in preconception care. Besides, previous research projects have shown that groups at higher risk of a positive HbP carrier status are interested in the offer of screening [31, 32, 82] and that screening can work [83, 84]. Experience in England shows that about 30% of identified carrier couples during antenatal screening opt for prenatal diagnosis [36].

**Targeted or Universal Screening?**

Whether to offer HbP carrier screening on a targeted or universal basis, is a discussion initiated by the balance between genetic distribution and the use of public funds to implement such a programme [51]. The fact that targeted screening on the basis of ethnicity is problematic, both from an ethical and practical point of view, would favour universal preconception and antenatal screening. A combined offer of HbP and CF carrier screening such as suggested by Lakeman et al. may also circumvent issues of stigmatisation [74]. OSCAR, the Dutch patient organization for HbP, has expressed the view that the accent should not be placed upon certain ethnic groups and has indicated that there is a considerable group of carriers amongst their members of so called “autochtony descent” (Dutch term for a person whose parents were both born in the Netherlands) [69]. SCD has been wrongly addressed as a “black disease” and care for these patients has been and very often still is shadowed by mistrust and health care discrimination [34, 54].

The ethnic structure of the Dutch population is not static as history has shown [85]. This influences the prevalence of HbP and HbP carrier status. Besides, the association with minority ethnic groups will dilute over time as the number of inter ethnic relations grow and ethnic admixture becomes more common. This will make ethnicity less suitable for stratification of the risk of HbP carrier status. How this will influence other health issues is unsure but this would certainly be an interesting question in the future although midwives and GPs have indicated that they already find this concept difficult to deal with [45]. HbP should therefore be repositioned in our thinking as a health issue and not as an ethnic issue [86]. Associating (carrier status of) HbP with particular ethnic groups may undermine the success of a possible screening programme.

Considering all these factors, a universal offer of preconception and / or antenatal HbP carrier screening would therefore be the most equitable option. Extensive literature on cost effectiveness of antenatal HbP carrier screening does not exist. However some argue that the potential of preconception counseling to prevent significant lifetime costs of affected
children, may ultimately result in a favourable cost-saving balance. Recent research has indicated that health-sector costs are about 180,000 euro’s per 10,000 pregnancies [87]. However this is based on the English health service model whereby most women receive hospital based antenatal care. The study was carried out in a high prevalence area and a cost-effectiveness study may yield different results in a low prevalence area. Because of the involvement of public funding, it was decided that ethnicity based neonatal screening was unacceptable in the USA [51]. Although preconception or antenatal screening does not have the same rational of preventing death or severe morbidity, the notions of equality and equity can still be applied for a preconception or antenatal offer of screening. Although funding for a HbP screening programme in the Netherlands would probably not be paid from public funds but rather through the insurance system, similar arguments may still apply. That aside, costs should not be the most important motive when deciding to implement a carrier screening programme.

In order to support women and their partners to make an informed reproductive choice, they need to be adequately informed about their risk which is different amongst ethnic groups. This and the fact that HbP comprises a broad group of haemoglobins of which new ones are still being identified [88, 89] means that the ethnicity question may still have to be asked in order to facilitate correct diagnosis, especially when specific mutations need to be confirmed. As the field of genetics is developing rapidly, complex DNA panels determining a wide range of genetic disorders including (carrier status of) HbP, may be offered to women and couples in the future eliminating the need to specify ethnicity. Indeed some have argued screening should be expanded to include autosomal recessive disorders such as HbP, CF and the Jewish panel which for example includes Tay Sachs disease [18].

In the mean time health professionals should be adequately supported with an evidence based screening instrument [73, 74] and guidance both from government and their professional organizations in order to solve ethical and practical barriers.

Therefore a universal offer of preconception and antenatal carrier screening linked to NNS is proposed. If this is not feasible due to economic reasons, targeted screening such as is implemented in the programme in England, could be introduced supported by an evidence based instrument to determine ethnic origin.

If we want to strive to provide adequate and accessible healthcare services for all, we need to find the right balance between providing equitable health care for all but without setting certain groups aside. If the discovery of ethnic health variations does more harm than good, we may need to retrace our steps [90]. It is important that health professionals such as midwives and GPs are aware of these issues and that discussions on equity, equality and access are part of (continuing) education programmes to enable them to provide women with the care they need.

REFERENCES


Manna, DR; Bruijnzeels, MA; Mokkink, HG; Berg, M. [Less ethnic knowledge in the Dutch College of General Practitioner’s practice guidelines on type 2 diabetes mellitus, hypertension and asthma in adults than in the supporting literature]. *Ned Tijdschr Geneeskd*, 2003 Aug 30; 147(35), 1691-6.


Beentjes, M; Weersma, R; Koch, W; Offringa, A; Verduijn, M; Mensink, P; Wiersma, T; Goudsward, L; van Asselt, K. NHG-Standaard Zwangerschap en kraamperiode [NHG guideline pregnancy and puerperium]. Utrecht: NHG; 2012. Report No.: M 32.


Van Wijk, MAM; Mel, M; Muller, PA; Silverentand, WGG; Pijnenborg, L; Kolnaar, BGM. [Anaemia. Guideline]. Utrecht: NHG; 2003. Report No.: M76.


Platt, OS; Brambilla, DJ; Rosse, WF; Milner, PF; Castro, O; Steinberg, MH; et al. Mortality in sickle cell disease. Life expectancy and risk factors for early death. *N Engl J Med*, 1994 Jun 9; 330(23), 1639-44.


Heijboer, H; van, dT; X, Peters, M; Knuist, M; Prins, J; Heymans, HS. [One year of neonatal screening for sickle-cell disease in Emma Children’s Hospital/Academic Medical Center in Amsterdam]. *Ned Tijdschr Geneeskd*, 2001 Sep 15; 145(37), 1795-9.


Jans, SM; Daemers, DO; de, VR; Lagro-Jansen, AL. Are pregnant women of non-Northern European descent more anaemic than women of Northern European descent? A study into the prevalence of anaemia in pregnant women in Amsterdam. *Midwifery*, 2009 Dec; 25(6), 766-73.


[26] Cornel, MC; Detmar, S; Plass, AMC; Moerman, D; Waarlo, AJ; de Kinderen, M; Giordano, P. Breder screenen op hemoglobinopatie [A broader screening for haemoglobinoptahy]. *Medisch Contact* 2009; Nr. 45(03 november 2009), 1874-7.


[30] Lakeman, P; Plass, AM; Henneman, L; Bezemer, PD; Cornel, MC; ten Kate, LP. Three-month follow-up of Western and non-Western participants in a study on preconceptional ancestry-based carrier couple screening for cystic fibrosis and hemoglobinopathies in the Netherlands. *Genet Med*, 2008 Nov; 10(11), 820-30.


[34] Anionwu, EN; Atkin, K. *The politics of sickle cell and thalassaemia*. Open University Press; 2001.


[40] Tsianakas, V; Atkin, K; Calnan, MW; Dormandy, E; Marteau, TM. Offering antenatal sickle cell and thalassaemia screening to pregnant women in primary care: a qualitative study of women’s experiences and expectations of participation. *Health Expect*, 2011 Mar 3; 10-7625.


[48] McAuley, J; De, SL; Sharma, V; Robinson, I; Main, CJ; Frank, AO. Describing race, ethnicity, and culture in medical research. Self defined ethnicity is unhelpful. *BMJ*, 1996 Aug 17; 313(7054), 425-6.

[49] Rankin, J; Bhopal, R. Current census categories are not a good match for identity. *BMJ*, 1999 Jun; 19; 318(7199), 1696.


[59] van Helmond, RE; Hendriks, AC; Breuning, MH. regulating the use of genetic tests: Is Dutch law an example for other countries with regard to DTC genetic testing? *Amsterdam law forum*, 2011.


[67] Poppelaars, FA; van der, WG; Braspenninck, JC; Cornel, MC; Henneman, L; Langendam, MW; et al. Possibilities and barriers in the implementation of a


[70] Bosma, AR; Cornel, MC; Donker, M. De ontwikkeling en evaluatie van patientgebonden voorlichtingsmateriaal over dragerschap van hemoglobinopathieen voor de 1e lijn.[Development and evaluation of patient oriented information about HbP carrier status in primary health care]. Master thesis Gezondheidswetenschappen, Vrije Universiteit; 2008.


[77] Alderliesten, ME; Vrijkotte, TG; van der Wal, MF; Bonsel, GJ. Late start of antenatal care among ethnic minorities in a large cohort of pregnant women. *BJOG*, 2007 Oct; 114(10), 1232-9.


[79] De Jong-Potjer, LC; Beentjes, M; Bogchelman, M; Jaspar, AHJ; van Asselt, K. NHG-Standaard Preconceptiezorg, M97 [Guideline preconceptioncare for GPs]. *Huisarts Wet*, 2011; 54((6)), 310-12.


[82] Weinreich, SS; de Lange-de Klerk, ES; Rijmen, F; Cornel, MC; de Kinderen, M; Plass, AM. Raising awareness of carrier testing for hereditary haemoglobinopathies in hi-


