Engaging African ethnic minorities as blood donors

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CHAPTER 1

General Introduction
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“Blood is life; breathing. If you don’t have blood, you can’t breathe. And if you breathe, it means you have blood.” – Anonymous woman of Ghanaian descent

Blood donation is a form of prosocial behaviour where an individual has blood drawn to be used in blood transfusions, or the production of biopharmaceutical medications (Greening, Glenister, Sparrow, & Simpson, 2010; Masser, White, Hyde, & Terry, 2008). In many high-income countries, blood collection agencies depend on voluntary, non-remunerated blood donors (Allain, 2011), meaning that blood donors donate their blood out of benevolence (Ferguson, Farrell, & Lawrence, 2008). However, various demographic and socio-economic groups are not evenly represented in national blood donor populations. This may cause challenges for the blood collection agency and the patients in need of blood transfusions, such as the unavailability of well-matched blood products (Burgdorf et al., 2017; Lattimore, Wickenden, & Brailsford, 2015). One such strongly underrepresented but highly needed group in high-income Western countries are ethnic minorities, especially of sub-Saharan African descent (Nance, 2009; Shaz & Hillyer, 2010). The main objective of the research described in the thesis was to systematically develop and test strategies to recruit more blood donors with the needed blood group antigens, i.e. of African descent.

Blood donation

The blood donation process differs depending on national policies, but in most circumstances adults register as blood donors at a local or national blood collection agency. When it is judged that this new blood donor is eligible to donate blood according to the eligibility criteria, he or she will donate 450-500 mL of blood in a procedure taking approximately ten minutes. A blood donor is allowed to donate three to six times annually, depending on sex and blood bank policies.

In the Netherlands, the blood supply is organised by one organisation responsible for the donor-to-patient blood supply chain, from the collection, screening, processing and to the supply of blood. It is the only Blood Collection Agency (BCA) in the world that additionally produces plasma pharmaceuticals, reagents, scientific research and provides diagnostic services and education (European Blood Alliance, n. d.). The Dutch blood bank organisation is called Sanquin, a reference to the word “blood” in Latin languages. Sanquin was established in 1998 through the merger of 23 separate blood banks. The Dutch blood bank organisation is self-sufficient, meaning that all patients who need blood in the Netherlands, will receive blood from Sanquin (apart from rare emergencies whereas blood has to be imported). The Dutch blood donors donate on a non-remunerated basis, voluntary and anonymously. Dutch whole blood donors receive foods and soft drinks after every donation, and are offered a small token at every tenth donation as a form of appreciation. They do
not receive money for donating blood, but travelling costs are refunded on request. In 2018, there were about 340 thousand registered donors donating 724 thousand units (413 thousand whole blood donations and 311 thousand plasma apheresis) (Sanquin, 2019a).

**The need for African blood donors**

The inclusion of more (specific) ethnic minority and migrant groups as blood donors is desirable for several reasons, such as being more representative of reflecting the population’s inhabitants diversity, or because the minority or migrant population is so large that their inclusion is needed for the main blood supply (Murphy et al., 2009; Van Dongen, Mews, de Kort, & Wagenmans, 2016). The most important reason for the inclusion of ethnic minority groups of African descent from a health care perspective, is to prevent or alleviate qualitative shortages (Van Dongen et al., 2016). A qualitative shortage may be caused by an underrepresentation of blood donors with- and/or an overrepresentation of patients in need of these specific blood group compositions, leading to a shortage of specific blood group compositions, besides the generally known ABO and Rhesus-D blood groups (Reid, Lomas-Francis, & Olsson, 2002; Sins et al., 2016).

The composition of blood group antigens in an individual depends on his or her genetic background. Especially for the Duffy antigen system, large differences are present between ethnic groups in the prevalence of blood group antigens. About 68% of the African/Black individuals are Duffy-negative (in haematological terminology described as Fy(a-b-)) while this is less than 0.1% among individuals with a European/White genetic background (Howes et al., 2011; Reid et al., 2002). Evidence suggests that this could be due to a higher resistance to malarial diseases in Duffy-negative individuals (Cyrklaff et al., 2011). Another significant difference between ethnic groups is found in the MSN blood group antigen system, where the so-called U-phenotype occurs in <0.1% of most ethnic groups, while the prevalence is 1.5% among individuals of African descent (Reid et al., 2002). As being anti-U is clinically relevant – a mismatch can lead to serious a transfusion reactions– it is hard to find a precise match for individuals who are U-negative.

During a one-time transfusion, for instance due to an accident, it is not necessary to control for all of the extended blood groups. However, extended blood group matching is crucial for chronic transfusion patients (Yazdanbakhsh, Ware, & Noizat-Pirene, 2012). One inheritable blood disorder often requiring multiple blood transfusions, is sickle cell disease (SCD) (Lonergan, Cline, & Abbondanzo, 2001). In this chronic hemopathology, the red blood cells –which are normally disc shaped and flexible– have an abnormal, sickled shape. These abnormally shaped red blood cells have a limited ability to transport oxygen and can easily clot in small blood vessels causing excessive pain attacks, called sickle cell
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crises. Such crises can also be triggered by rapid temperature changes, changes in altitude, dehydration, and physical and psychological stressors. SCD will become apparent when an individual inherits an abnormal copy of the haemoglobin gene from each parent. Even though most SCD cases occur in sub-Saharan Africa, the prevalence of SCD is increasing in Western high-income countries due to migration and childbirth between carriers of SCD (Peters et al., 2010; Piel et al., 2010; Shaz & Hillyer, 2010). Thus, the patients who depend the most on multiple, well-matched blood transfusions often express blood groups with limited availability in the blood donor pool in Western high-income countries. This shortage increases the risk of alloimmunisation (creating antibodies against the transfused blood antigens) and eventually transfusion reactions (e.g., fever, skin rash, loss of consciousness) and even death among this patient group (Alkindi et al., 2017; Miller et al., 2013). To enable equal care and increase the quality of life of those patients with sickle cell anaemia, the blood donor pool should more accurately represent a country's patient population, meaning more blood donors of sub-Saharan African descent are needed (Shaz & Hillyer, 2010; Van Dongen et al., 2016).

BloodMatch Availability

In 2014, the BloodMatch program was initiated by Sanquin to achieve comprehensive and cost-efficient full blood donor typing to fulfil the increasing demand of hospitals for more extensively typed donor blood (Sanquin.org, 2017). It consists of three projects: BloodMatch Benefits, BloodMatch Supply and BloodMatch Availability. The present thesis is a result of the latter project.

To start with recruiting and retaining ethnic minority populations most relevant in terms of rare blood group matching, it is imperative to know which specific ethnic minority populations should be targeted to fulfil the demand for chronic transfusion patients. On the first of January 2018, Statistics Netherlands reported that 13.1% of the Dutch inhabitants have a non-Western background (Figure 1). A Dutch inhabitant is defined as a migrant if he or she is born abroad (first generation) or if he or she was born in the Netherlands but at least one of the parents was born abroad (second generation) (Statistics Netherlands). About 230 thousand of those non-Western migrants (10.3%) originate from a Sub-Saharan African country, being only 1.3% of the total population in the Netherlands. Sub-Saharan Africa includes African countries that are fully or partially located south of the Sahara (UN, 2010). However, about 350 thousand migrants originate from Surinam, South-America, and 160 thousand migrants originate from the (former) Netherlands Antilles and Aruba, constituting 3.0% of the total population in the Netherlands. A major part of these migrants are of African descent due to the colonial era and thus might also have the blood groups sought for.
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Figure 1. Overview of migrant population in the Netherlands in 2018

Within the BloodMatch Availability project, the blood group antigen frequencies in large Dutch ethnic minority populations living in Amsterdam were analysed (Schonewille et al., in progress). From the so-called HELIUS study – the HEalthy Life In an Urban Setting, a multi-ethnic cohort study with nearly 25,000 participants living in the Netherlands – additional blood samples were collected among study participants of African Surinamese, South-Asian Surinamese, Turkish, Moroccan, and Ghanaian descent (Snijder et al., 2017). The blood group serology results were compared with the Dutch blood donor population and the results from the Blood Group Antigen Factsbook (Reid et al., 2002). Figure 2 shows results of extended antigen-negative blood groups important for transfusing patients with SCD according to the Dutch blood transfusion policies (Evers et al., 2016; Van Sambeeck et al., 2018). The graph shows that Ghanaians and African Surinamese have a relatively high prevalence of C-, K- and Fy(a)-. The C, K and Fy(a) antigens are immunogenic, implying that a mismatch may induce serious transfusion reactions (Evers et al., 2015). The other ethnic groups, in particular the Turkish group, have a blood group distribution more similar to those in the donor pool. These results substantiate that sub-Saharan African groups, such as the Ghanaians, but also Afro-Caribbean groups, such as the African Surinamese, are crucial to be recruited as blood donors in terms of blood matching.
Figure 2. Prevalence of negative blood group antigens for different ethnic groups and the Dutch blood donor population

Challenges of engaging ethnic minorities

Although the solution of diversifying the donor pool seems simple, recruitment of the ethnic minority groups needed as blood donors has been a challenge to many blood collection agencies (Lattimore et al., 2015; Shaz & Hillyer, 2010). Although ethnicity and blood donors’ country of birth is not registered in the Netherlands, a cohort study from 2007 till 2009 among Dutch blood donors showed that only 2.5% of the donors had a migrant background, while at that time 19.8% of the Dutch inhabitants had a migrant background (Atsma, Veldhuizen, de Vegt, Doggen, & de Kort, 2011).

The underrepresentation of ethnic minority groups is not only a problem in the blood donation context, but also in other health promotion contexts, such as substance abuse treatment or cardiovascular disease risk reduction (Burlew et al., 2011; Khare, Cursio, Locklin, Bates, & Loo, 2014). Unfortunately, little is known about effective strategies to increase their health-related or prosocial behaviour (Beach et al., 2006). This gap in knowledge could be due to a underrepresentation of ethnic minority groups in research and health interventions, which could potentially be caused by a lack of culturally and linguistically adapting recruitment materials (George, Duran, & Norris, 2014; Liu et al., 2013), which can go hand in hand with mistrust towards researchers or (medical) institutions. Such mistrust can have its roots in a history of unethical events such as the infamous Tuskegee Syphilis Study and racial disparities in treatment of diseases (Gamble, 1997). In the Tuskegee Syphilis Study conducted between 1932 and 1972, African Americans with syphilis were deliberately left untreated and the researchers knowingly
failed to inform the participants about their illness (Brandt, 1978). In the Dutch context, the colonial era can bring in a mixture of negative feelings towards the Netherlands and possibly their willingness to participate voluntarily for its society (Van Niekerk, 2018). Additionally and more recently, experiences of racism and the growth of extreme right-wing parties causing social segregation and may consequently limit the willingness and possibilities to engage in prosocial behaviour (Chadderton, 2016; Thomson & Crul, 2007). This may impact the attitude of ethnic minorities of African descent towards donating blood, and thus may (partly) explain the underrepresentation in the donor pool. However, predicting and explaining human intention and behaviour is complex and time and context specific, and many other factors may play a role (Ajzen, 2011). Thus, the present thesis seeks the main reasons for the underrepresentation of African blood donors and what measures may motivate this needed target-group to donate blood.

**Behavioural change and interventions to promote blood donation**

One behavioural theory that has been applied multiple times to predict and explain blood donation intention and behaviour, is the Theory of Planned Behaviour (TPB) (Ajzen, 1991; France et al., 2014; Lemmens et al., 2005; Veldhuizen, Ferguson, De Kort, Donders, & Atsma, 2011). Figure 3 represents the visual model of the TPB. The TPB is an extension from the Theory of Reasoned Action (TRA) (Ajzen & Fishbein, 1980). In both the TPB and the TRA, a person's attitude and subjective norm towards a certain behaviour relates to the intention to engage in this particular behaviour, which in turn relates to the actual engagement of the person in that particular behaviour. In the TPB, perceived behavioural control is added as an additional predictor of intention and behaviour. With regards to blood donor behaviour, attitude refers to a person’s evaluation of the (un)righteousness and (un)pleasantness of donating blood (France et al., 2014). The subjective norm refers to judgements of family members, friends and other influential peers on blood donation and whether these peers donate(d) blood. The perceived behavioural control refers to the person’s judgement of how confident and in control he or she is in succeeding in donating blood. A systematic review studying predictors of blood donations discovered that intention is a strong predictor of behaviour, followed by perceived behavioural control, attitude and subjective norm (Bednall, Bove, Cheetham, & Murray, 2013).
Still, in the aforementioned systematic review ethnicity or country of birth was not taken into account as a predictor, while other demographics such as education level and marital status were incorporated in the prediction model. As blood donors of African descent are underrepresented in the donor pool of many Western countries, an explanation might (partly) lie in differences in attitude, subjective norm, perceived behavioural control or a combination of factors compared to the majority population in such country.

Unfortunately, Bednall et al. (2013) did not take ethnicity or country of birth into account, even though differences in or interactions between these TPB determinants may differ between ethnic majority and ethnic minority/migrant populations. The same goes for many other studies describing intervention development or evaluation in the blood donation context specifically (Bagot, Murray, & Masser, 2016; Godin, Vézina-Im, Bélanger-Gravel, & Amireault, 2012). One systematic review focused on blood donor interventions on ethnic minorities in Western high-income countries, identified only eight studies until March 2017 (Makin, Francis, Polonsky, & Renzaho, 2019). These interventions included four one-off information and education interventions (e.g. emailed information, videos) and four multifaceted, community-based interventions (e.g. outreach activities and repeated blood drives at churches). Six of these interventions were conducted among African-Americans in the United States, while only one was conducted in a European context (France). Lastly, all intervention studies had some form of bias: e.g. failing to report sample sizes, no statistical comparisons with controls, and no randomised trials. Although all interventions had a positive effect on the number of blood donors and/or blood donations of African
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descent, the authors concluded that there is insufficient evidence to recommend certain interventions.

In sum, only few blood donor and intervention studies successfully engaged potential ethnic minority blood donors. Therefore, more knowledge on blood donation barriers and motivators and consequently, a better understanding of which interventions could be effective to engage potential blood donors of African descent is needed in the given context. The main barriers and motivators should be extensively studied, adequately translated in an evidence-based intervention, and its effects should be attentively evaluated, which is what this thesis aimed to fulfil.

**Intervention Mapping**

Intervention Mapping (IM) is a planning framework that helps promotion planners in the decision-making process from development to evaluation (Fernandez, Ruiter, Markham, & Kok, 2019). IM consists of six steps, shown in Figure 4 (Bartholomew, Parcel, Kok, Gottlieb, & Fernandez, 2011). IM is a cumulative and iterative process: cumulative because each step is based on a preceding step and iterative because new insights may require going back to preceding steps to refine the intervention. Furthermore, IM takes an ecological approach in understanding and intervening at multiple levels (e.g. individual or organisational) and also gives priority to stakeholder involvement. Last, IM is strongly based on theories on explaining and changing behaviour (Bartholomew et al., 2011).

![Figure 4. Six steps in the IM approach (Bartholomew et al., 2011)](image-url)
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Step 1 of the IM approach focuses predominantly on studying the (health) problem at hand and describing the context for the intervention. An important task in this step is conducting a needs assessment, which is a systematic process of examining the behavioural and environmental determinants of the problem. In Step 2, the logic model of change is created by specifying the changes the intervention should bring. This model is created by combining performance objectives with the main determinants found in the needs assessment. In Step 3, the intervention takes shape by choosing theory-based methods (e.g. role-modelling, fear arousal) and operationalising these methods into practical strategies which can be applied to the target group (Kok, Schaalma, Ruiter, van Empelen, & Brug, 2004). Step 4 focuses on the production of the intervention, in which an important task is pre-testing materials. Step 5 encompasses the implementation plan. This is a crucial step to ensure the intervention will be implemented correctly and is sustainable, meaning the adopters of the intervention keep on using it in the long-term. Finally, Step 6 encompasses the evaluation plan of the intervention to accurately study whether the intervention achieved its goals (effect evaluation) and whether the intervention was correctly implemented (process evaluation). This information can then be used to further refine the intervention and run the IM cycle in an iterative and cumulative process again. The IM approach guided the project and present thesis, from analysing the problem as part of the needs assessment, to conducting an effect and process evaluation of a donor recruitment intervention. This thesis particularly emphasises the needs assessment, as contextual blood bank factors and individual donation factors are extensively studied.

**Aims and objectives of the research in this thesis**

The overall aim of the research described in this thesis was to systematically develop and test evidence-based strategies as to recruit more blood donors of African descent, in order to improve the availability of the needed blood types for chronic transfusion patients. This leads to the following main objectives following the IM approach:

I. Examine the overarching context of the Dutch blood collection agency in relation to blood donors of African descent.
II. Examine blood donation barriers and facilitators of individuals of African descent.
III. Develop and test strategies to recruit blood donors of African descent.

**Thesis outline**

Figure 5 presents the thesis outline and depicts how the parts in this thesis relate to each other. Part I focuses on the overarching context which may impact the behaviour and recruitment of blood donors of African descent and focuses particularly on the Dutch BCA. This is part of the needs assessment (step 1) of the IM approach. In Chapter 2, a better
understanding of the current blood donor pool (i.e. in terms of the prevalence of Duffy-negative donors), how they were previously recruited and how these recruitment strategies affected their blood donor careers was sought. Chapter 3 assessed the blood supply chain of migrant blood donors and organisational obstacles and solutions were explored through organisational interviews with key staff members working for the Dutch national blood bank organisation.

Part II focuses on individual factors – the barriers and motivators - that may impact the donation behaviour of blood donors of African descent, also part of the needs assessment (step 1) of the IM approach. Each following chapter builds on the results of the preceding chapter. First, Chapter 4 discusses blood donation barriers and motivators among individuals of African descent living in Western high-income countries through a systematic literature review. Second, Chapter 5 describes a qualitative study on blood donation barriers and motivators in the Dutch context, using the outcomes of the systematic literature review to develop an interview guide. Interviews were done with individuals of African-Surinamese and Ghanaian descent living in the Netherlands. Third, Chapter 6 reports a quantitative study on blood donation barriers and motivators among individuals of African descent using an extensive survey developed through the outcomes of the interviews in Chapter 5. Additionally, in Chapter 7, the importance of donation awareness in the decision-making process of the potential blood donor was studied. Differences in-and associations of donation awareness and donation attitudes in individuals of African- and Dutch descent were studied.

Part III focuses on developing and testing an intervention to recruit more blood donors of African descent, based on the results of the preceding parts. Chapter 8 describes the intervention development, illustrating how the steps 2 to 4 in the IM approach were addressed. Chapter 9 describes the implementation and evaluation (steps 5 and 6 of IM) of a social media campaign that also doubled as an experiment to study what kind of messages and strategies work best in terms of donor registrations. Finally, Chapter 10 presents a general discussion of the research project and its results.
A wide variety of data sources are used in this thesis. Table 1 provides a summary of the data sources, study populations and methods used per chapter.

**Table 1. Overview of data sources, study populations and methods in the present thesis**

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<td>Chapter</td>
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<td>Chapter 8</td>
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