

# **Access and Utilization of Norwegian Healthcare Services among sub-Saharan African Migrants**

Patterns, Perceptions and Experiences



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(Ph.D.)**

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## **Dedication**

I dedicate this thesis to my late mother: Ma Misline Yitcheu Mbanya, as a gratitude to my amazing mum. You were my home, mother. I had no home but you!!!





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## Summary

Approximately 4.4% of the EU-28 population are people of non-member countries, and 17.7% of the total Norwegian population are people with a migrant background. Several high-income countries, including Norway, have made substantial progress in improving the health of the population by addressing inequity in access to healthcare. However, access to healthcare may not be the same across population groups, and migrants may not be benefiting from healthcare services in the same manner as the rest of the population.

In Norway, healthcare needs for sub-Saharan African (SSA) migrants, including women exposed to female genital cutting, may vary for many reasons. First, migrants from SSA are often from countries with systems of self-referral, high user fees, and low utilization of health services. In addition, they may believe in traditional African healing practices and have African cultural attitudes and beliefs that can influence healthcare-seeking behaviours. Secondly, when in Norway, they are faced with a different kind of healthcare system organisation, socio-economic challenges, and perceived racial discrimination that influence their ability to seek healthcare. Therefore, understanding the pattern and the experiences of SSA migrants' access to healthcare and use of healthcare services is essential since migrants form an increasing population in Norway.

Knowledge about the health of SSA migrants and their ability to access health is needed by health professionals and policymakers to make informed decisions. Access to healthcare by migrants is a fundamental human right for the highest attainable health. Further, knowledge of migrants' health and access to healthcare may aid as a guide in improving their health and serve as an important step for effective disease management and intervention for better health outcomes. Additionally, failure to address the health needs of migrants could have an impact on the host country.

The study aims to assess and explore the pattern and factors influencing access and utilization of healthcare services among SSA migrants living in Norway. Specifically, the study seeks to evaluate the differences in healthcare utilization and morbidity burden among migrants from four SSA countries. Additionally, the study will explore the challenges and experiences that impede SSA migrants' ability to access the healthcare system for different health needs and different healthcare settings.

This study uses a complementary research approach, including quantitative and qualitative research techniques. Quantitatively, using registry merged data from the National Population

Register and the Norwegian Health Economics Administration, we studied the visits and medical diagnoses from each consultation registered by the primary health physician in Norway in 2008; totalling for 36,366 patients. Descriptive analyses were conducted for socioeconomic variables, use of primary healthcare and Major Expanded Diagnostic Clusters (MEDC) for migrants from four selected SSA countries (Somalia, Ethiopia, Eritrea and the Republic of The Gambia). Chi-square and logistic regression analyses were used to assess the differences between migrant groups in the use of primary healthcare (PHC) [general practitioner (GP) and emergency room (ER)], and the differences in the distribution of morbidity burdens. Qualitatively, a purposive and snowball sampling technique was used to recruit participants from cultural groups and religious organizations. In total, 60 in-depth interviews (IDIs) and two focus group discussions (FGDs) with nine participants per group were conducted to explore the challenges and experiences that impede access and utilization of healthcare services. A thematic approach and an interpretative phenomenological analysis (IPA) were used in the qualitative analyses.

The findings from the quantitative study (paper I) revealed that the use of GP increases with age for all migrants, but patterns of ER use were different with respect to age group. However, there was a significant difference among different migrant groups in the use of GP and the ER, with Somali migrants using the PHC more. The morbidity burdens registered among all migrants were quite similar, although Somalis registered a higher proportion of ear-nose-throat, general signs and symptoms, and respiratory concerns, while Gambians registered more musculoskeletal problems.

The qualitative studies (paper II & III) highlight that SSA migrants face challenges to access healthcare in and out of the healthcare settings. The perceived challenges were: access to information, comprehension/expression and language barrier, dissatisfaction with care providers, poor attitudes of the care providers perceived as racial discrimination, financial restriction, long waiting times, and family and job responsibilities. Apart from the GP and the ER, migrants lacked information about the available healthcare services for psychological and psychosexual health-related issues and counselling. Participants also required information about the kind of treatments offered in different healthcare services as well as information about measures of disease prevention, like vitamin D and iron deficiency, which were said to be shared among the SSA population. Having such information could serve as a guide for making appropriate healthcare decisions and disease management plans. Many participants expressed dissatisfaction with the long waiting times for doctors' appointments, specialist care, and

emergency room services. Furthermore, co-payment for a physician appointment, dental and eye care, and physiotherapy services were perceived to be unaffordable for most of the participants. Again, hospital appointments were missed due to family and household obligations and ensure job security.

Further, SSA migrants preferred consulting doctors with a migrant background because of the respect, attention, and treatment SSA migrants perceived from them. A lack of comprehension from both the care providers and the patients caused the patients to take more time to communicate their health needs or be understood by care providers. In addition, SSA migrants perceived racial discrimination in healthcare settings, including care professional's use of double gloves during healthcare and asking for HIV/AIDs tests. Participants also reported that they were being ignored and neglected during healthcare, and healthcare providers were asking disturbing and interrogating questions to circumcised women during healthcare. The perceived discrimination in healthcare settings caused feelings of frustration, anger, trauma, "suspect," and vulnerability. Inappropriate diagnoses or treatment regimens and lack of female genital cutting (FGC) knowledge were perceived as unskilfulness of the care providers.

In addition to the above-mentioned factors, husbands' dominance, lack of family support, and avoiding disclosure of health problems were unique challenges for women exposed to FGC. The perceived lack of family support and husband's influence over women were reported to be barriers to healthcare-seeking for FGC health-related problems. Women were shy and ashamed to present psychosexual health problems to healthcare professionals and were avoiding to seek help for FGC related health issues due to fear of rejection, separation, and divorce from members of their families. Women also reported that they did not get enough support from healthcare providers, especially during maternal healthcare because care providers were perceived to have insufficient knowledge and experience treating patients with FGC. The perceived lack of confidentiality at the healthcare settings highly impedes women's ability to access maternal health services, because some women were concerned that they were "showcased" to medical students. This also caused tension between care providers and women. Women also complained of an unannounced home visit (after a hospital consultation) by child protective services and police. These were perceived to be uncomfortable, fearful, traumatizing, and adding to women's worries caused by FGC and also causing distrust toward the care providers.

This study illustrates that the Norwegian healthcare system is not equally accessible by all residents. Although there is a similarity in the morbidity burden across four SSA migrant groups including Somali, Ethiopian, Eritrean, and Gambian patients differences exist between them in the use of the PHC. Consequently, SSA migrants' health needs are inadequately addressed by the Norwegian healthcare system. SSA migrants experienced and face challenges at the system level, healthcare provider level, and patient and family level that constrain them from accessing healthcare services in Norway. Although different factors affect migrants' access to healthcare in general, SSA migrants are constrained by perceived discrimination and racism, which may be specific for people from SSA or people of the same racialized group. This not only affects their ability to access and use healthcare services but it is also perceived as affecting participants' mental health and emotional state. It is important to emphasize actions or interventions for improving access to healthcare while considering ethnic origin and cultural sensitivities. If we are to see a positive impact on SSA migrants' health, it is necessary for Norway to ensure the implementation of these interventions, in order to reach an explicit goal for equity in healthcare so to attain Universal Health Coverage. Including these interventions will be essential.

## Definition of concepts

Migration	The movement of people from place to place, intending of settling in a new location, either temporarily or permanently (1).
Migrants	Persons born abroad of two foreign-born parents (first-generation migrant) or Norwegian-born to one or two migrant parents born abroad (second-generation migrant). The country of origin is based on their country of birth given status as the first-generation migrant, or mother's country of birth if the parent was born in Norway (second-generation migrant) (2).
Race	Historically, is based on a group of persons with common physical features, like the complexion, hair and ancestral origin. The modern concept is based on social origin, rather than the biological concept in the past (3).
Ethnicity	A social group or an individual alleged he/she belongs to or recognizes with, respect to certain characteristics as geography and ancestral root, certain cultural identities, and language (3).
Health	A state of complete physical, mental and social well-being and not merely the absence of disease or infirmity (1).
Access to healthcare	A concept which measures the capacity of the health system to reach the population without excluding part of it from receiving healthcare services. Ensuring a high degree of access to healthcare improves people's overall health status, prolongs life expectancy, and decreases health inequalities (4, 5).
Racial discrimination	Discriminatory or abusive behaviour towards members of another race. Racial discrimination is any distinction, exclusion, restriction or preference based on race, colour, descent, or national or ethnic origin which has the purpose or effect of nullifying or impairing the recognition, enjoyment or exercise, on an equal footing, of human rights and fundamental freedoms in the political, economic, social, cultural or any other field of public life (1).
Female genital cutting	Refers to all procedures involving partial or total removal of the external female genitalia or other injuries to the female genital organs for non-medical reasons (6).

## List of abbreviations

CI	Confidence interval
CVD	Cardiovascular disease
EEA	European economic area
ER	Emergency room
EU	European union
FGC	Female genital cutting
GDP	Gross development product
GP	General practitioner
NPR	Norwegian population register
HELFO	Norwegian health economics administration database
HIV	Human immunodeficiency virus
IPA	Interpretative phenomenological analysis
MEDC	Major expanded diagnostic clusters
NCD	Non-communicable disease
NSD	Norwegian Social Science Data Services
OR	Odds ratio
PHC	Primary healthcare
REC	Regional ethical committee
SSA	Sub-Saharan Africa
TB	Tuberculosis
UN	United Nations
WHO	World Health Organization



## List of publications

- Paper I Diaz E, Mbanya VN, Gele AA, Kumar B. Differences in primary healthcare use among sub-Saharan African immigrants in Norway: a register-based study; BMC Health Serv. Res. 2017 Jul 28; 17(1):509. doi: 10.1186/s12913-017-2404-z. PMID: 28754117
- Paper II Vivian N. Mbanya, Laura Terragni Abdi A. Gele, Esperanza Diaz, Bernadette Kumar. Access to the Norwegian Healthcare System: Challenges for Sub-Saharan African Immigrants: Int. J Equity Health. 2019 Aug 14; 18(1):125. doi: 10.1186/s12939-019-1027-x. PMID: 31412853
- Paper III Vivian N. Mbanya, Laura Terragni, Abdi A. Gele, Esperanza Diaz, Bernadette Kumar. Barriers to access to the Norwegian Healthcare System among sub-Saharan African Immigrant Women Exposed to Female Genital Cutting: PLoS One. 2020 Mar 18;15(3):e0229770. doi: 10.1371/journal.pone.0229770. eCollection 2020. PMID: 32187198



## INTRODUCTION

In today's increasingly interrelated world, global migration is a reality that touches nearly all corners of the globe. The increasing diversity population in Europe countries and other high-income countries creates new challenges for health systems that must adapt to remain responsive. These challenges are increasingly recognized with regards to migrants, who comprise a growing part of European populations. For example, in 2017, the proportion of the migrant population in European areas was 22.3 million people (7). In March 2019, the migrant population of both European and non-European origin in Norway consisted of approximately 944 402 people, including 765,108 foreign-born and 179,294 born in Norway to two migrant parents. African migrants are among the six largest migrant groups in Norway, and 2.5% of people from Africa form part of the total Norwegian population (2).

The World Health Organization (WHO) considers the right to healthcare as a fundamental human right (8). Universal health coverage is one of the leading health-related objectives of most countries and a priority objective of WHO, with the aim of equitable access (9). Migrants and refugees may bring health risks to their country of destination and they may be exposed to new risk factors in transit or at their destination (10). The migratory experiences can alter the pattern of morbidity and mortality for specific diseases (10). Migrant's access and utilization of healthcare services have received global attention, although the management of migrant healthcare is a significant challenge. Migrants are exposed to numerous health risks and have different disease profiles than the host population (8). For example, 500,000 women living in the EU have been exposed to Female genital cutting (FGC), and 180,000 girls and women are at risk of undergoing FGC yearly (11). The number of TB cases among migrants in many European countries has increased (12). Moreover, migrants and their children in Norway are at risk of TB, iron and Vitamin D deficiency, mental health problems, and cardiovascular diseases and risk factors (13-18). There is, therefore, the need to improve access and utilization of healthcare services and health outcomes among migrants in Norway, most especially among African migrants as their needs and access to healthcare may be affected by their adverse living and working conditions, culture and beliefs, discrimination, and decreased socio-economic opportunities (19-22).

This thesis assesses the differences in the use of primary healthcare services and morbidity burden among four sub-Saharan African (SSA) groups. It specifically tries to explore a potential reason for the significant differences among SSA migrants' in the access and utilization of the Norwegian healthcare system. However, these reasons may not be limited only to the four major

SSA migrants groups, but to migrants from other SSA countries and beyond. The study documents the challenges and experiences of SSA migrants' access and the utilization of healthcare services in different health settings for various health needs in Oslo and its environs. In a bid to identify potential areas for improving access among women exposed to FGC, the thesis equally identifies and elucidates the factors influencing the use of healthcare services for FGC health-related problems, among women exposed to FGC in Oslo. For a related study previously reported that few women among those studied sought care for their health-related problems (23).

These are the main issues that this thesis contributes to the public health literature. It bridges the knowledge gap of SSA migrant's access and use of the Norwegian healthcare system. To our knowledge, this is the first study that has explored the disparity of use of the PHC services, differences in the morbidity diagnoses among SSA migrants, and the factors influencing access and utilization of the Norwegian healthcare services among migrants from different SSA countries. The research findings provide substantial new evidence and perspectives for healthcare services research in Norway, and it also strengthens existing ideas on healthcare service research. The thesis provides a better understanding of how SSA migrants access and use healthcare services in Norway. The thesis contributes to providing additional knowledge to healthcare professionals and policymakers about migrants' ability to access and use the Norwegian healthcare system to make informed decisions. It may also contribute to generating solutions for a positive encounter with the healthcare services for better health outcomes and the wellbeing of SSA migrants.

This thesis is divided into six different sections. First, a brief introduction and overview of the proportion of migrants in Europe and specifically in Norway is defined. Then, section one is the background information of the following topics: Norway, SSA, Migration, Norwegian healthcare delivery system, determinants of health, access to healthcare, and equity in healthcare. The rationale of the study, the research questions, and the objectives are presented in section two. Section three describes in detail the research methods and ethical considerations. The main research findings are presented in section four. Then section five takes up the discussion on research findings and methodological issues. The sixth section concludes with recommendations for future research based on the main findings.

# 1. BACKGROUND

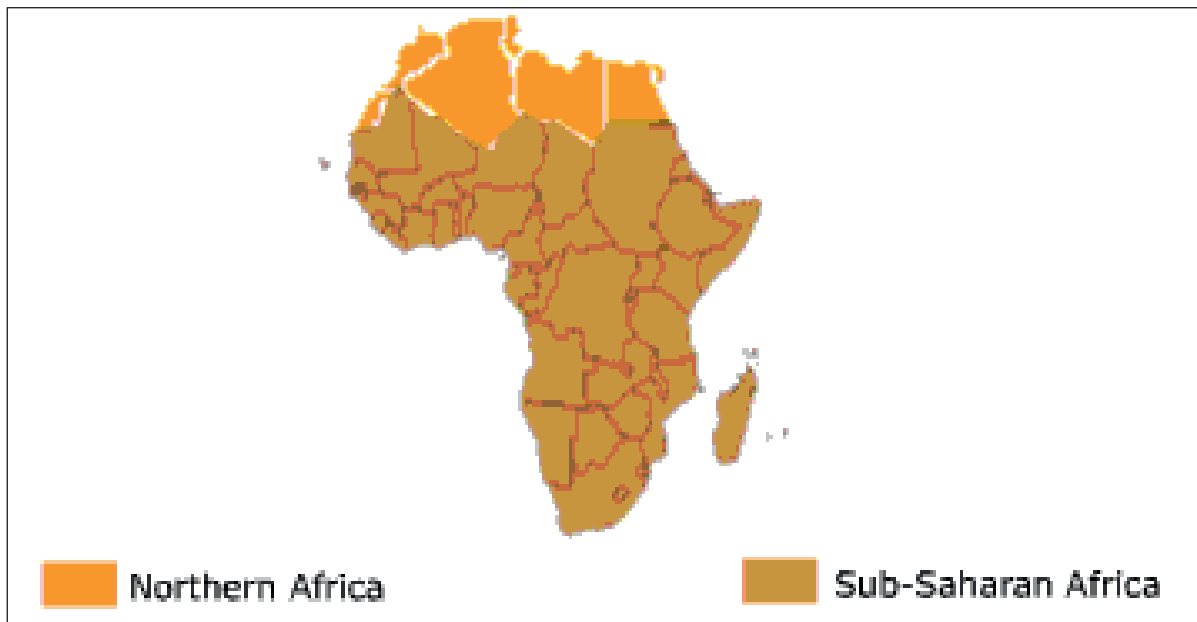
## 1.1 Norway

Norway is in Northern Europe the western portion of the Scandinavian Peninsula with coastlines at the North Sea and the North Atlantic Ocean. Norway is bordered by Sweden, Finland, and Russia, and it shares maritime borders with the United Kingdom, Iceland, and Denmark. Norway has Central European Time Zone with local time being UTC +1h. The population is approximately 5.3 million, with a life expectancy of 80.91 years for men and 84.28 years for women. It has an area of 323, 808 km<sup>2</sup> (125,022 sq. mi.), including the fresh waters but not the territories of Svalbard (61,022 km<sup>2</sup>) and Jan Mayen (377 km<sup>2</sup>). It has high plateaus, steep fjords, mountains, and valleys (24). The temperature is mild at the coastline and colder inland. Norway's largest cities are Bergen, Trondheim, Stavanger, and Drammen, with Oslo as the capital city. Norway has administrative and political subdivisions in the levels of counties and municipalities. Norway citizens are called Norwegian (s), and apart from Norwegians, there are other ethnic groups, such as migrants.

Above 79% of healthcare professionals are employed in health and social services. Two million patients were in the general hospital in 2017, and 32% of the inhabitants 80 years and above used the home base services in 2016. In 2017, there were 14.4 million consultations at the GP, with approximately 2.7 visits in all ages and more consultations among females. Eighteen percent of persons with five or more GP consultations were of migrants' background, while 12 % were Norwegian born to migrant parents (25).

## 1.2 Sub-Saharan Africa

Sub-Saharan Africa consists of the African countries found in the south of the Sahara Desert. According to the UN, the African Transition Zone is a "semi-arid region of grasslands created by the collision of the Sahara Desert and central African rain forests." The African Transition Zone stretches over a million square miles and is over 3500 miles in length. This semi region separates the Sahara Desert environment and peoples of North Africa, from the tropical rain forests of Central Africa (26, 27). The African Transition Zone cuts across the southern border of the Sahara Desert, at the largest portion of the continent. Many of the countries in the African Transition Zone are part of SSA, and these countries are divided into regional components: Central Africa, East Africa, West Africa, and Southern Africa. The Horn of Africa is often included in the region of East Africa. The regions have both similarities and differences. The cultural layout varies widely between countries and tribal groups, but there are common cultural patterns across all sub-Saharan African regions (26, 27).



*Figure 1: Map of Africa showing countries in sub-Saharan Africa*  
*Source: UN (26)*

Sub-Saharan African countries are rich in natural resources, and these account for a significant share of output and a major share of export earnings, which boost the economic growth and exports in many SSA countries (28). It is also known for its beautiful topography, climates, and tourist sites, which have historically attracted many tourists and foreign investors (29-31). Sub-Saharan African countries are also recognized for their agricultural potentials, and they are among the highest producers of gold, diamond, timber, coffee, and cocoa among other regions of the world (32).

However, the SSA mineral wealth hardly dents the poverty level in this region. Growth in GDP per capita in low-income countries in SSA has continued to fall behind most other regions, with SSA being home for some of the poorest countries in the world (33). Poverty is evident in the rural areas and the urban slums of the largest cities. Civil wars are part of every region's history, while violence and conflicts continue in some areas (34, 35). Sub-Saharan Africa is recognized not only for infectious diseases and maternal-child health but also for non-communicable diseases (NCDs), including cardiovascular disease (CVD), cancer, diabetes, and obesity (36-38). Some poor SSA countries are renowned for social and structural determinants such as inadequate access to healthcare, water scarcity, and lack of sewage treatment. A weak national health system can be regarded as a significant contributor to poverty and inequity in the regions of Africa. Individuals who are having better health move up and less often move down the social ladder than non-healthy individuals (39). The health of many people in SSA remains in

jeopardy, and most regions struggle to meet the basic standard of care and make the improvement needed to combat health problems. Millions of the SSA population suffer from diseases that are relatively simple to prevent or treat, with systemic barriers being the primary cause preventing progress for effective healthcare delivery (40).

### **1.3 Migration**

Migration is the movement of people from place to place intending to settle in a new location (1). Migration can be either internal within a country or international to another country. There are different motives for why people move to other areas or regions. Poverty, natural disasters, political oppression, war, conflict, and globalization are drivers of the movement of a population (41). Consistently, high-income regions have increased population due to immigration, while low-middle income regions have lost population because of emigration. The net flow of individuals from low-middle income to high-income regions has increased, reaching averagely 3.2 million per year between 2000 and 2010 (42). According to UN Population Division estimates, the number of international migrants worldwide stood at almost 258 million (or 3.4 percent of the world's population) in 2017 (42).

In the preindustrial era and currently, environmental factors as droughts, natural disasters, and climate all influenced human decisions about where to migrate (43-45). Generally, a push factor such as political unrest or lack of job opportunities and pull factors such as better job opportunities or having relatives in a destination an individual intends to move to could influence people's decisions to migrate (46). Internal migration is also common, where people move from the rural area to the cities or vice versa, either for work, marriage, or study (47, 48).

#### **1.3.1 Norway and Migration**

Norwegians were prone to emigration during the 18<sup>th</sup> and 19<sup>th</sup> centuries. A big wave of Norwegian emigrants left for overseas countries (49, 50) as labour migrants to seek a better life, and seemingly, the elderly Norwegian emigrate to avoid the colder temperature in the winter seasons (51). Norway has been recognized for its reputation of providing humanitarian assistance since the time of the Norwegian scientist and diplomat Fridtjof Nansen who became the first League of Nation's High Commissioner for Refugees in 1921 with a task of helping hundreds of thousands of refugees as well as helping them to acquire legal status and attain economic independence (52). Norway has been home to diverse ethnic groups for a long time. Apart from the Sámi, who have been in Northern Norway for two thousand years, in the 1960s, there was a flow of migrants from the neighbouring Nordic countries. A common labour market was established in the 1950s between Norway, Sweden, Denmark, and Finland (Iceland joined

in 1982), allowing citizens and foreigners to travel freely between the Nordic countries. During this era, there was a net migration of 853 persons between 1966 and 1970 in Norway (53).

In the late 1960s, as the Norwegian economy improved, there was a need for more labour and many people arrived from other countries to find work. The first labour migrants came from Morocco, Yugoslavia, Turkey, and Pakistan. Around the 1970s, many people also came from Asia, Africa, and Latin America. Today, many of them still work and live in Norway, and other migrants, including refugees and those for family reunification, have eventually followed them. At present, Norway's migration policy is similar to that of the European Union (EU). As a wealthy nation, Norway is still a destination country for migrants and refugees. Because of its robustness in labour market and its continuous commitment to humanitarian protection, the net migration in Norway was 21 349 persons in 2017. According to Norway Statistics Central Bureau, there are 979,254 of migrant heritage (migrants and Norwegian-born to migrant parents) which constitute 18.2% of the Norwegian population. Migrants from the African continent constitute 14% of the total migrant population in Norway, and 12.3% are from countries in the SSA region. Additionally, in the years 2010 to 2019, there were 138, 479 (41, 935 are of African origin) migrants who became Norwegian citizens (2).



### **Definition of immigrants according to the Norwegian Directorate of Immigration (UDI).**

- Immigrants are persons born abroad of two foreign-born parents and four foreign-born grandparents.
- Norwegian-born to immigrant parents are born in Norway of two parents born abroad and in addition have four grandparents born abroad.

### **Definition of different legal immigrant categories**

- **Family immigrant:** Also, referred to as family unification or forming a family. A spouse, fiancée or children of someone who lives legally in Norway, refugee or a Norwegian citizen can apply for family unification.
- **Labor immigrant:** Also, referred to as work immigrants. These are those who want to live and work in Norway. EU/EEA nationals are entitled to work and live in Norway. However, if staying in Norway for more than three months, they must register with the police. They acquire the right of permanent residence after five years of legal residence. Citizens from the Nordic countries are exempted from the general rules on residence permit and registration because of the common Nordic labor market agreement in 1957. Foreign nationals outside the EU/EEA wanting to work in Norway must have an employment offer. With an employment offer, they can then apply for a residence permit.
- **Refugee:** A refugee is a person who meets the requirements for being granted protection (asylum) in Norway.
- **Education:** International student with an admission letter from a Norwegian education institution can live and study in Norway.

*Figure 2: Definition of migrants according to the Norwegian Directorate of Immigration  
Source: Statistic Norway*

### **1.3.2 Africa and Migration**

The history of SSA is seen as one of refugees and mass migration. In 2017, there were approximately 4.15 million sub-Saharan African migrants in Europe (54). In the underlying forces of emigration in SSA, Adepaju in 1994 pinpoints four conditions, referred to as “regimes”- economic, demographic, political and, cultural exert a pull on migrants (55). Essential to this analysis is the deteriorating economic conditions, which compel skilled and unskilled labour to migrate, political instability which ends up in conflict and war and causes change in demographic patterns that leads to unemployment. Other factors that exert a pull on migrants include the prevalence of certain cultural practices such as FGC and forced marriage (56-58). Migrants tend to move in expectation of higher wages and better employment, and some move because of the effect of drought and famine (59, 60). Miller, in “the homeless in Africa,” identifies civil and ethnic conflicts, colonial and racist domination, oppressive governments, foreign invasion, and natural disasters as central to Africa’s refugee dilemma (61, 62). In the past decades, many SSA regions were trapped in war, which resulted in induced refugees or led to emigration (63).

### ***1.3.2.1 African migrants' history and profile in Norway***

Although the first waves of African migrants came to Norway in the 70s, the numbers of migrants with African backgrounds continue to rise. In the 90s, 1,326 people migrated as refugees, labour, family unification, and education. Presently, Migrants from Africa and Norwegian-born to African migrant parents constitute 2.5% of the total population of Norway (2). As of 2017, 1.1% of the African population in Norway is of SSA origin, and today, there are 112,786 migrants from 55 countries in SSA (2). Many African migrants in Norway migrated for reasons of family reunification and refuge (64).

### ***1.3.2.2 African migrants and the role of the communities***

All human beings are said to be social, however, African scholars seem to agree that “Africans displayed a sort of sociality that was both distinct and more than the normally expected level of sociality” (65). African migrants highlight the idea that communalism held a significant place in traditional Africa, and it symbolizes the values of traditional African life (66). Living or being together and the sense of solidarity and brotherliness are the basis of the extended family system in Africa. Communalism guarantees individual obligations within the communal relationship and provides access to extended social support and community networks (66). Community ties reinforce ethnic identity and provide assistance and support to ensure stable transitions of migrants in host countries (67).

The existence of a strong community among migrants and its importance in fostering integration has long been recognized (68). Migrant's community is the foothold from which they move with strength, and it opens the way for further developments. This functions by supporting newly immigrated members in acclimating to the receiving country and easing the strains associated with immigration. Some ethnic migrant groups integrate culturally but maintain distinct social identities, indicating the centrality of the migrant community (68). The presence of traditional social networks provides psychological security, control, and contentment necessary to socialize with the larger society (68). The sense of belonging and community affinity proves essential for healthy integration. Furthermore, ethnic communities measure their success to the extent that they participate in their receiving country economy and the subsequent increase in the standard of living in their country of origin rather than their receiving country living standard (66). Consequently, they maintain justification for the long and challenging journeys they have endured.

### ***1.3.3.3 African migrants and the role of faith-based organizations***

African migrants migrating abroad bring their religious identities with them, and generally, their religion is everything to them away from home (69). Religious organizations are essential for migrants' adaption in the community and can provide an opportunity for migrants to spend time with their ethnic and language groups. Religious organizations serve an essential role in providing information about jobs, housing, and survival to newly arrived migrants. These organizations can also be effective at addressing sensitive public health topics among other migrants (70, 71). In the absence of the extended family, faith-based organizations functionally fill that void by serving as a source of spiritual and social support, as well as for material and financial assistance for those in need (72). Traditions of community service in combination with cultural and spiritual comforts, together with material assistance, enhance membership and participation in faith-based organizations for newly arrived and other migrants (72). Migrant's fellowship in ethnic churches to reinforce a primary relationship with other congregants. Traditional foods, customs, and religious expectations provide a comfortable code of conduct that strengthens cultural identity in the African diaspora.

## **1.4 The Healthcare Delivery System in Norway**

### **1.4.1 Administration of healthcare**

The Norwegian Health Economics Administration Database (HELFO) is a secondary institution linked to the Norwegian Directorate of Health. HELFO is the national contact point for healthcare, and it is their responsibility to protect the right of healthcare providers, the rights of the residents of Norway, and to provide information and guidance on health services. Through the webpage, [helsenorge.no](http://helsenorge.no), residents can choose or change their GP or apply for reimbursement of medical expenses. The healthcare system in Norway is structured on the principle of universal access, and it allows the residents to choose the GP of their choice. Norway has a three-level government structure: the state, county councils, and the municipalities. The government manages and finances the hospital sector. The municipalities manage primary healthcare, while the state is responsible for secondary healthcare. Every member of the Norwegian national insurance scheme is free to access healthcare services. The regional health authorities under the Ministry of Health and Care Services manages the public hospitals in Norway. Private hospitals exist, and the government funds most of the private hospitals (73, 74).

### **1.4.2 General practitioner**

All inhabitants who have registered with the National Population Register (NPR) as living in Norway, in addition to asylum seekers (with temporal identification number) and their families, have the right to a GP/family doctor, known as “fastlege” in Norwegian. One can choose his/her GP, and register with them free of charge, providing the doctor one chooses has vacancies. The GP is responsible for ensuring continuity in healthcare for the patients registered and act as gatekeepers to secondary healthcare. The GP is also responsible for referral to specialist care when needed, and patients have no direct access to a specialist. Healthcare in Norway is subsidized, but residents must co-pay for all treatment and consultations at primary and secondary care. However, once a person reaches an annual limit of medical expenses of NOK 2,369, they receive an exemption card for free treatment for chronic diseases and for all health consultations for that year. Children below sixteen years and pregnant women receive free healthcare (73).

### **1.4.3 Emergency department and medical services**

Doctors and nurses at the accident and emergency departments can be contacted every day even 24 hours a day in the big cities. These departments are offered for patients in need of emergency care when treatment for illness and injury cannot wait until the next day to be provided by a regular GP. Persons with an immediate healthcare need can show up at the general emergency outpatient clinic without any referral or scheduled appointment. The government (financed through the four service delivery regions, each with its regional health authority) operates emergency medical services in Norway. Because of the topographical nature of Norway, with communities situated in different geographical zones, vehicle ambulances are supplemented with the marine ambulance, helicopters, and fixed-wing aircraft for delivering emergency care and services (74).

## **1.5 Determinants of Health**

### **1.5.1 Factors influencing health and well-being**

The health status of individuals or a community is determined by their circumstances and the environment (75). Policymaking, a person’s characteristics and behaviour, social and economic factors, the physical environment, and access to and use of the healthcare services have a considerable impact on health. Policies at the local, state and federal levels affect individual and population health. Increasing taxes on tobacco and alcohol sales, for example, can improve population health by reducing the number of people using tobacco products and consuming alcohol (75). The physical environment including safe water, air quality, homes, communities, and roads all contribute to good health. Employment and working conditions have an impact

on health as well. For example, residents who are employed are healthier particularly those who have more control over their working conditions. Individual characteristics such as biology and genetics play a part in determining lifespan, and the likelihood of developing certain illnesses and conditions (75). Other factors influence health also, including age, gender, and individual lifestyle behaviour such as smoking, lack of physical activity and overeating (76). There are also social determinants of health, such as education, economic stability, community safety, availability of adequate housing, and healthy foods (77). Social support networks in the form of support from families, friends, and communities are linked to better health. Customs, traditions, and the beliefs of the family and community all affect health (78). Healthcare service needs should be a significant determinant of healthcare utilization, although other factors, such as the ability to access care (whether it is available, timely, convenient, and affordable), clearly influence health (79).

### **1.5.2 Healthy Migrant effect**

Growing international evidence supports the epidemiological paradox that migrants have better overall health than non-migrants do upon arrival in their new countries (80, 81). This condition is known as the “healthy immigrant effect.” An assumption is that migrant’s health advantage is explained by the fact that the positive self-selection of individuals who might systematically differ from those who do not migrate in terms of health and social characteristics. The migrants who leave their countries of origin are not necessarily a random sample of the population they left behind. The concept of positive self-selection in migrants assumes that only the healthiest and most enthused individuals decide to move and are ready to embark and undergo the distressing experience of migration to a new country. At the national level, receiving countries can enforce a positive selection of healthy migrants through their migrant admittance policies (82, 83).

It is postulated that the newcomers’ health advantages diminish dramatically, and may eventually converge toward the health status of the native-born population, or may even become worse. One argument is that the deterioration of migrants’ health, results from specific characteristics, including taking on the host country’s cultural norms, poverty, living in substandard housing, not having access to medical care, adoption of foreign diet, smoking, and substance abuse (84-87). Other complementary postulates are that migrants face barriers in using the healthcare services because of language, cultural differences, lack of information and different experiences with their new healthcare system (88-90). These challenges may lead to

deteriorating health over time due to inappropriate use of preventative health services, improper diagnosis, and insufficient treatment of health problems.

**1.5.3 Migration and health**

The relationship between migration and health is multifaceted, and its impact varies considerably across migrant groups and between individuals within such groups. Circumstances surrounding the migration course may exacerbate health vulnerabilities and risk behaviours, especially those who involuntarily migrate while fleeing disaster. Migration has multiple determinants on health that cut across economic, policies, human rights and equity issues, and social norms. Because of factors related to lack of legal entitlements, stigma, discrimination, language, societal barriers, and low economic status, irregular migrants may be excluded from accessing healthcare services, immunization campaigns, and health-promotion interventions (91, 92).

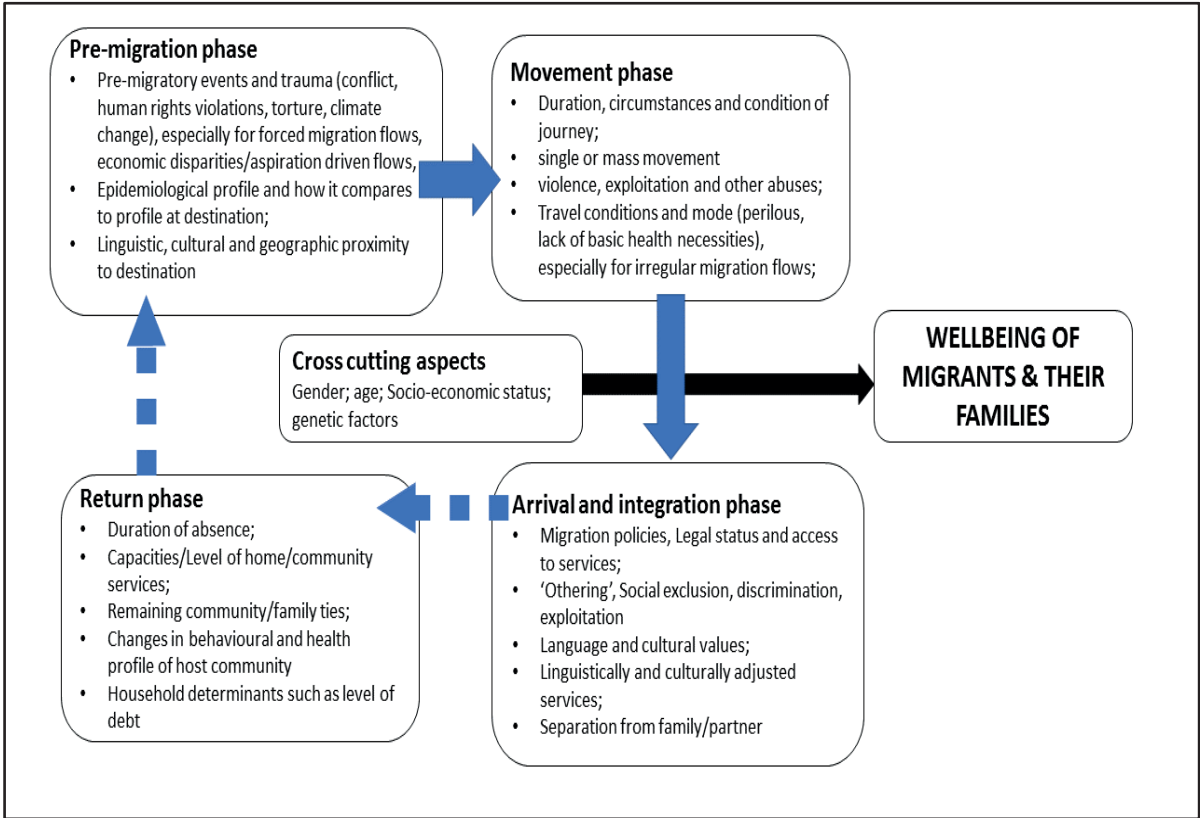


Figure 3: Factors influencing the health and well-being of migrants and their families in the phases of migration  
 Source: Migration Data Portal (92)

#### **1.5.4 Migrants' health in Norway**

The rise in immigration to Norway has had an impact on the healthcare system and healthcare professionals in several ways, as well as lawmakers. Migrants in Norway are dissimilar with respect to ethnicity, educational levels, social conditions, lifestyles, and health needs (93, 94). Previous research reported that despite migrants' heterogeneity, their use of the primary and specialist healthcare is different among migrant groups (95-97). Although the Norwegian health systems are built on the same principles of universalism and equity and are funded primarily through taxation, inequality still exists throughout (73).

Migrant groups in Norway differ significantly between and within themselves, in terms of risk factors and disease. Migrants from low-income countries are reported to have a higher incidence of reproductive health and related complications, such as perinatal complications and pregnancy outcome, infectious diseases (such as TB), HIV/AIDS, imported malaria parasite, and mental health problems (such as psychological distress and acute mental health disorders) (98-103). Migrants display modifiable lifestyle risks, including obesity, and vitamin D deficiency. Additionally, they can exhibit high levels of cardiovascular risk factors such as diabetes, alcohol consumption, smoking, and changes in dietary habits (104-108). Several Norwegian studies found an association between migration and poor health. This included higher multi-morbidity with the reason for migration and length of stay, diabetes risk with the length of stay, increased death risks with the length of stay, increasing prevalence of multiple sclerosis, and ethnic differences in the incidence of cancer (96, 109-112). Other related conditions among migrants include antimicrobial resistance, poor oral health-related quality of life, high migration stress on mental health during pregnancy, and acculturation stress being associated with parenting stress (84, 113-116).

### **1.6 Access to Healthcare**

#### **1.6.1 Theoretical frameworks/concepts for understanding access and use of healthcare services**

Access to healthcare remains an important concept in health policy and healthcare service research, and utilization of healthcare is central to the performance of the healthcare system. Healthcare utilization is the description of the use of services by persons for different purposes for the maintenance of health and well-being, or obtaining information about one's health status and prognosis (117). Apart from the need related factors, it is well acknowledged that healthcare utilization is also strongly dependent on the structures of the healthcare system and patients' social characteristics. Several conceptual frameworks/models have been proposed for assessing access and use of healthcare services. One of the first acknowledged models was the

behavioural model of health services use developed by Ronald M. Andersen (118). This idea has been used extensively in studies investigating the use of health services (Figure 4). This behavioural model is a multilevel model that demonstrates the factors that lead to the use of health services. According to the model, the usage of healthcare services is determined by three major components of individually or contextually predisposing factors, enabling factors, and need (118). Predisposing characteristics are individual factors such as age, gender, education, occupation, ethnicity, family status, and health beliefs. The health belief could be attitudes and knowledge related to health and health services. Enabling factors could be family support, access to health insurance, one's community, and individual income to pay for health services. Enabling factors could also include organizational factors, which are those considered to serve as circumstances enabling service utilization, including transportation and waiting times for healthcare. Need characterizes both perceived and actual need for healthcare services. At the individual level, need depends on how a person perceives the general health or the presence of illness condition. It also depends on professional assessments (119-121).



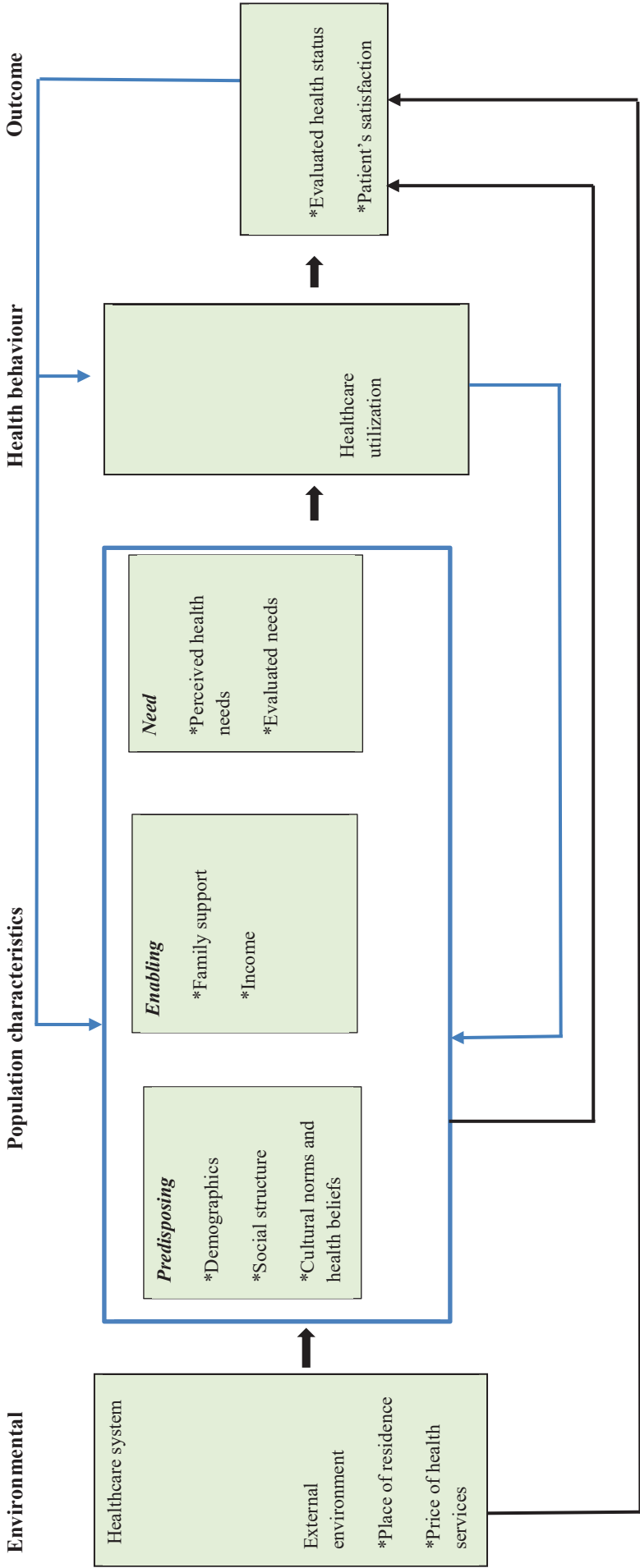


Figure 4: An adaptation of Andersen model

More extensive conceptual frameworks for access to healthcare services have also been proposed by different authors. These frameworks highlight that access is a complex concept, which should be measured in different dimensions. One of the frameworks is by Levesque and colleagues (Figure 5) (5). Levesque and colleagues identified five major dimensions of accessibility of services: approachability, acceptability, availability and accommodation, affordability, and appropriateness. They also highlight five corresponding capabilities that persons have to interact with the dimensions, including the ability to perceive, seek, reach, pay, and engage, in order to produce access (122-125). According to this framework, access is the opportunity to recognize healthcare needs, to seek healthcare services, to reach and use the services, and have the need for services satisfied. Although this framework introduces a conceptualization of access to healthcare through the five dimensions, it also proposed some indicators that have to be measured. These include measuring whether people receive services in terms of perceived needs and whether people know about available services and how to utilise them (5). However, they emphasized that an accurate assessment of access needs a combination of different measures to accurately judge whether the characteristics of services, providers, and systems are aligned with people, households, and the community's abilities.

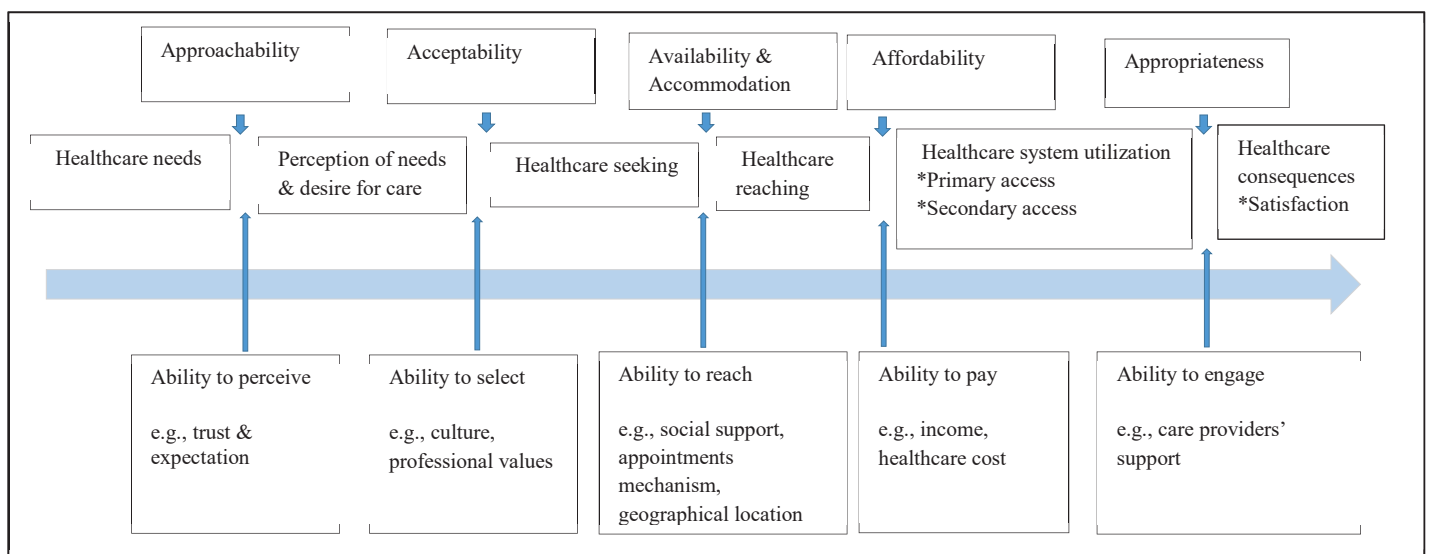


Figure 5: An adaptation of Levesque et al conceptual framework for access to healthcare

According to the framework, to approach healthcare services, patients should be able to identify that the health services exist and that the services can be reached and should be able to have an impact on the health of the patients. Information regarding the services and the kind of treatment

offered could contribute to making the services approachable. To approach a service, an individual must have the ability to perceive a need for care. This perceived need could be determined by personal knowledge about health, health literacy, and belief related to health and sickness. Acceptability of services are those factors, cultural or social, that would make an individual accept the aspect of the services, and the person is able to judge for himself that it is relevant to seek care. For example, a female patient not wanting to be attended to by a male healthcare provider. The ability to seek care may relate to individual personal autonomy and the ability to choose to seek care. Healthcare services are said to be available and accommodating when the physical space and the care providers can be reached both physically and in a timely manner. The ability to reach healthcare relates to personal mobility (e.g., elderly) and knowledge about health services. Affordability relates to the direct cost of healthcare services and related expenses. Patients' ability to pay for needed care or receive care from the health system may be affected by the price of care (even with a co-payment), and patients' income. Healthcare appropriateness denotes the "fit between the patients' needs and the services." It includes the amount of time spent assessing the health problems and determining the right treatment as well as the quality of the services provided. The ability to engage in healthcare relates to a patients' participation, involvement, and full engagement in care that is offered and provided.

Levesque and colleague's framework was useful in the design of the study. I used this conceptual framework of access to healthcare to study, understand, and stimulate the subject's access and utilization of the Norwegian healthcare system for Paper II and Paper III (Figure 5). Relating to the Norwegian setting, I used the components of the framework to frame questions that could capture individual, social, and system factors influencing the access and use of healthcare. These frameworks helped us to comprehend and classify SSA migrants' challenges or experiences.

Access to healthcare remains an important concept, although its definition is complex and is represented by varying interpretations of concepts across authors (123, 126-128). Aday and Andersen suggested access to healthcare to be meaningful, in terms of whether those who need care get into the healthcare system or not (129). They further went to suggest that access might describe the actual individual or population group into the healthcare system. "Having access" signifies a possibility to utilize a service if required, and "gaining access" denotes the commencement into the process of utilizing the service. Aday and Andersen again stated that service availability is a limited measure of access to healthcare, because people in need may

have access to healthcare, but might encounter difficulties in utilizing the services and ultimately potential access may not be realized (130). Pechansky and Thomas claim access is a concept denoting the degree of “fit” between the client and the system. Access here is viewed as a general concept that summarizes some specific areas, including the dimension of access of fit between the patients and the healthcare system (123). Anderson and Newman’s framework presents scopes of accessibility, including the health environment (system factors, clinical factors and provider’s factors), and patient’s perspective (predisposing factors, enabling factors, barriers, and perceived need) (131). According to Gulliford et al., and Pechansky and Thomas, accessing healthcare is only possible if the services are available and supplied adequately, and the extent to which population obtained access depends on organizational, social, financial, and cultural barriers (123, 132). According to Mooney, the availability of healthcare service is measured with reference to the cost of individual obtaining care, and the cost might include transportation and other inconveniences incurred in obtaining care (133). Mooney stressed that access is solely a question of supply, while utilization is a function of both supply and demand, and that equality of access is about equal opportunity.

### **1.6.2 The concept of Intersectionality**

Intersectionality theory, originating from the black feminist critique of western second-wave feminism, has been accused of disregarding how an individual could be oppressed through multiple factors such as race, class, and sexuality. The term intersectionality, created by Kimberlé Crenshaw, highlights the ‘multidimensionality’ of marginalized subjects’ lived experiences. Kimberlé Crenshaw explains the concept of intersectionality to denote the various ways in which race and gender interact to shape the multiple dimensions of “Black” women’s subjective experiences. Intersectionality theory supports the enhanced awareness of inequities in the social determinants of women’s health and emphasized the importance of drawing attention to the ways in which inequalities are interdependent (134, 135). The use of this concept in this thesis is to understand how the impact of the interaction between various factors form a unique form of inequality among SSA women exposed to FGC in the access and utilization of the Norwegian healthcare services. This concept helped me emulate how different factors co-exist, and they can independently or collectively overlap to influence health-seeking of an individual.

## **1.7 Equity in healthcare**

The most worrisome political matter regarding immigration is the ability to serve and provide equity of access to healthcare services among the population. Equity is a basic human right that builds the foundation of all areas of primary healthcare. Equality is easily explained to be 'sameness', and equity is referred to as 'fairness' (136, 137). A concern to ensure that healthcare resources are organized to meet the needs of different groups in the population is central to the concept of access (132). Measuring health inequities can be attained by measuring health needs, access to healthcare, and the quality of care. The difficulty in accessing the equity in access to healthcare stemmed from the fact that different groups are diverse, healthcare needs for similar health problems vary, and different people have different priorities (132). There are two dimensions of equity the horizontal and the vertical.

Horizontal equity refers to equity between people having the same healthcare needs, whilst vertical equity refers to those with unequal needs who should receive different or unequal healthcare (138). The horizontal form of health equity is assessed with respect to health services availability, health service utilization or health service outcome. The vertical dimension of equity is when people with different needs require access to services that are differentiated in terms of volume and quality (133). This vertical dimension to equity is acknowledged to be more challenging to measure because there is little consensus on how vertical equity could be judged to exist.

### **1.7.1 Healthcare accessibility and Challenges**

Disparities in health and healthcare are posing a persistent challenge around the world (139). In general, despite the government's best intentions to create equitability in health and healthcare, studies around the globe presented that the minority population has more difficulty in obtaining medical care (140). The rise in immigration around the world, including Norway, has impacted healthcare systems and healthcare professionals in several ways, as well as lawmakers. Differences in accessing healthcare among population groups within a country have been attributed to cultural and sociological factors and the availability of healthcare delivery services (141). Factors such as perceived discrimination, racism, lifestyle choices, and environmental factors are reported to be associated with the decline in migrants' health status (142-145). Lack of access to healthcare services by migrants represents a concern for the host countries, and the delay in accessing healthcare services is said to lead to late diagnosis, delayed treatment, and possible morbidity (146, 147).

All migrants legally residing in Norway have the same assured entitlements to healthcare as the non-migrant population. However, studies have shown inequalities in access to healthcare exist in practice (23, 148). The differences in accessing healthcare in Norway can be enhanced by the growing challenges associated with the diversity and disparity in migration status. The increasing cultural diversity in Norway creates opportunities and challenges for healthcare providers, healthcare systems and legislators to provide and deliver culturally competent healthcare services (149).

## **2. RATIONALE FOR THE STUDY, RESEARCH QUESTIONS, AND OBJECTIVES**

### **2.1 The rationale for the study**

Research suggests that access to healthcare is the critical factor for improved population health outcomes and healthcare system sustainability. Migrant's disparities in health and access to health services have attracted increased attention in high-income countries in recent years, and there are deliberations on whether migrants benefit from services as much as the non-migrant population (150-152). Health is a fundamental human right that builds the basis of all areas of primary healthcare. The general principle of equality and non-discrimination is a fundamental element of international human rights law. According to WHO and Whitehead M, "health inequities are systematic differences in the health status of different population groups and social determinants of health are mostly responsible for health inequities (75, 137)." Access to comprehensive, quality healthcare services is essential for the achievement of better health and the opportunity to enjoy life and pursue one's life plans. In a fair healthcare system, equal needs are assumed to lead to equal utilization of services. However, access and utilization do not seem to be equal for all individuals and society, thus becoming a challenge for the healthcare system (136, 153, 154). Some groups or individuals are underprivileged and unable to achieve this fairness because of their social position or other socially determined factors, which then negatively affect their health and their quality of life in general (75, 137).

Norway's national health policy is aimed at offering equal access to healthcare for all Norwegian residents, regardless of social class or ethnicity (73). Subsequently, according to the Norwegian migrant policy, migrants have the right to use health services in the same manner as other residents. However, several reports from previous findings revealed that access to healthcare and quality of care differs among residents in Norway (155). Somehow, despite the virtual universality of Norway's health system, the marginalized migrant population continues to experience challenges in access and use of the healthcare system (155). According to the Norwegian knowledge centre for health services, substantial differences in health indicators between population groups in Norway exist, with higher mortality among people with low income and educational levels (155). Previous studies in Norway have also suggested that some groups of migrants in Norway are at risk of long-standing illness, poor mental health, and poor overall wellbeing (14, 156-159). It has been reported that there are various factors hindering access and utilization of healthcare services, and delay in receiving healthcare leads to

unfavourable health outcomes, hospitalization, morbidity, mortality, and increased healthcare costs (160, 161).

In Norway, research about the extent of the variation in healthcare service utilization and the incidence of disease events between various migrant groups have been explored, with some studies using registries (109, 162-164). Although studies among migrants exist, the cause of the differences in access and use of healthcare services has not been fully explored. We aim to explore SSA access and use of the Norwegian healthcare system. The existing literature that recognizes variations among subgroups of migrant populations' access and use of the Norwegian healthcare system excludes country of origin data. Also, SSA migrant data is often embedded within the broader population of "African" migrants and/or in combination with other migrant groups from different regions of the world (109, 163-165). Exclusion of the country of origin and grouping migrant population as a unit may have significant implications for understanding healthcare needs, practices, and outcomes as the African population ascribes to varying languages, cultural views, education achievement, racial discrimination, and patterns of migration. In addition, prior to migration, SSA migrants have been exposed to different health system organisations, including systems of self-referral, high user fees and low utilization of health services (166-168). SSA migrants are from regions with possible low socio-economic status, low educational level, diverse cultures, and high disease burden. Once in Norway, SSA migrants are faced with a different lifestyle and different kind of health system organisation. For that reason, language proficiency, cultural differences, dissatisfaction with provider interaction, and other socially determined factors might be challenges among SSA migrants (169-171). In that respect, understanding SSA migrant's patterns, perceptions, and experiences in accessing the Norwegian healthcare system should be prioritized. These are the areas in which this thesis seeks to contribute.

## **2.2 Research questions**

- What are the patterns of use of primary healthcare services among migrants from sub-Saharan Africa? (Paper I)
- What are the proportions of the major expanded diagnostic cluster among SSA migrants at primary healthcare services? (Paper I)
- What are the factors influencing SSA migrants' access and use of the Norwegian healthcare system? (Paper II)
- What are the experiences of SSA women exposed to FGC in seeking healthcare for FGC related health problems? (Paper III)



## **2.3 The aim of the individual studies**

### **2.3.1 General objective**

To describe the differences in the use of primary healthcare services, to describe differences in the morbidity burden among four SSA groups, and to provide a better understanding of individual and societal factors influencing sub-Saharan African migrants' access and utilization of the Norwegian national healthcare system.

### **2.3.2 Research Objectives**

- To evaluate the use of primary healthcare among migrants from four countries in sub-Saharan Africa living in Norway.
- To document the differences in the morbidity burden among SSA migrants from four countries in sub-Saharan Africa living in Norway.
- To describe the perceptions and the challenges in access and use of the Norwegian healthcare services among sub-Saharan Africans migrants.
- To explore the barriers and experiences in access and use of healthcare services in Norway among sub-Saharan African migrant women exposed to female genital cutting.

## 3. MATERIALS AND METHODS

### 3.1 Collaborative partners

This research was fully financed by the University of Oslo. This study is in collaboration with the Unit of Migration and Health, Norwegian Institute of Public Health, and the University of Bergen, Norway.

### 3.2 Research setting

In this study, we included only legally residing migrants i.e. those with Norwegian personal identification numbers. We based our estimations on the major groups of “born outside Norway” and “Norwegian-born to parents born outside Norway—these are people having migrant heritage in Norway. The first substudy of this research was a registry-based study covering the entire country which used a cross-sectional design to evaluate the use of PHC among SSA migrants from Somalia, Ethiopia, Eritrea, and Republic of The Gambia in 2008. The qualitative studies were conducted in Oslo, the capital city of Norway, among all SSA migrants, using qualitative design methods (IDIs and FGDs). Oslo is the largest city in Norway, and it is both a municipality and a county. Oslo is the administrative and economic hub of Norway. It is also a centre for trade, industry, and shipping. Oslo is an international city that has been rated first in terms of quality of life among other cities in Europe, but it is also one of the most expensive cities in the world.

At the end of the third quarter of 2018, Oslo had a population of 679,886, and currently, Oslo has a population of 693,494 and 33.8% of the people have a migrant background (2). People with African background constitute 6.0% of the total Oslo population, among which 4.7% are migrants from SSA (2). The city has a land area of 426 km<sup>2</sup> and a population density of 1,581 people per square kilometer. The urban settlements have a population of 1.467,000 million (2). The migrant population is growing beside the native Norwegian population. In 2017, 21,349 people migrated to Norway, among which Eritrean (2,098) was the highest among the African migrants, followed by the Somalis (557). Additionally, there are large migrant populations of SSA origins living in Norway—including Somalia (43,273), Ethiopia (12,036), Eritrea (29,102), and the Republic of The Gambia (1,855). Other fast-growing migrant population, are migrants from Sudan, Congo, South Africa, Kenya, Ghana, Nigeria, and Uganda (2).

The city of Oslo has a large migrant population with many Norwegians born to migrant parents. More than 30% of the Oslo population are of migrant background. Pakistanis are the largest

ethnic minority in Oslo, followed by migrants from Sweden, Somalia, and Poland. There are also migrants from Iraq, Iran, Vietnam, Turkey, Morocco, the Philippines, and Sri Lanka (2).

### **3.3 Research methodology and approach**

This research study design and method utilized quantitative techniques to assess the proportion of use of the Norwegian healthcare services and the burden of disease among SSA residents. The study also utilized qualitative techniques to explore the perceptions and experiences of migrants in accessing and utilizing the Norwegian healthcare system. For the quantitative study, due to the numerical consideration of individuals in each SSA country, we included four SSA countries: Somalia, Ethiopia, Eritrea, and The Gambia. Subsequently, in the qualitative study, we included other ethnic groups from varied regions of the SSA. Hence, we explored the perceptions and experiences of migrants from different SSA countries for different healthcare settings and health problems, both at the individual level and as a group. This was to enable us to see SSA migrant's experiences at different angles.

#### **3.3.1 Quantitative study**

##### **3.3.1.1 Data source and Recruitment**

For the quantitative study, Norwegian linked registry data under the management of the University of Bergen was used for secondary analyses. This data was used to assess the use of primary healthcare services (GP and the ER) and the burden of disease among migrants from four SSA countries. This part of the project forms the basis of Paper I.

Participants included in the linked registry database were from the NPR and HELFO. The NPR database had information on demographic variables, migrant background, and length of stay in Norway. Administrative claims for all patient consultations with GPs and ER services were obtained from the HELFO database, and the information from the consultations was used as “yes or no” and as numerical variables. This database contains the number of visits to GPs and ER for each individual in 2008. Each consultation claim has a minimum of one medical diagnosis based on the International Classification of Primary Care (ICPC-2) registered by the physician. These ICPC-2 diagnoses were classified based on the Major Expanded Diagnostic Clusters (MEDC) of the Johns Hopkins University Adjusted Clinical Groups (ACG®) Case-Mix System (172), which assigns ICPC-2 codes found in claims to one of 27 MEDC. The ACG System is endorsed to be used for research purposes (173). A detailed description of the linked register data and the categorization of the variables are described in Paper I (148).

### **3.3.1.2 Data management and analysis**

#### ***3.3.1.2.1 Variables***

Descriptive statistics in frequencies (percentages) and mean with standard deviations were used to summarize and describe the datasets at baseline. Chi-square tests and analyses of variance (ANOVA) were used to compare the distribution and differences among migrants from the four countries. Using regression analyses, the association between variables and differences between groups was established. Regression analysis is a statistical method used in studies involving modeling and analyzing several variables, where the relationship includes the dependent (outcome) variable and one or more independent (explanatory) variables. The dependent variable is presumed to be systematically predicted by the independent variables. Alternatively, independent variables are thought to independently affect the outcome variable.

#### ***3.3.1.2.2 Dependent variables***

The use of PHC, including the GP and the ER, was the primary dependent variable. Results were presented separately overall and for each of the countries. The relationship between different independent variables and the use of the Norwegian health services (primary outcome variable) were computed among migrants for the four countries with Somalia as the reference category.

#### ***3.3.1.2.3 Independent variables***

Using the Norwegian linked registry data, several models were conducted. The results of the first model were presented for the unadjusted analyses, and the second model was adjusted for age and gender, while a third model was adjusted for gender, age, and employment status. An additional variable length of stay was included in another logistic regression model, conducted for each of the countries separately. (See appendix for the table.)

### **3.3.1.3 Qualitative study**

The qualitative part of the research project was to explore the perceptions and experiences of migrants from sub-Saharan Africa in accessing the Norwegian healthcare services. This part of the project forms the basis of Paper II and Paper III.

#### ***3.3.1.3.1 Study participants***

Study participants were adult SSA migrant men and women, living in Oslo; Migrants and Norwegian-born to migrant parents, persons with legal residence, above 18 years of age, and willing to participate were included in the study.

### ***3.3.1.3.2 Recruitment***

As mentioned above, culturally, Africans are tied to the tradition of communalism. So, with this idea and being an African myself I used cultural groups and religious organizations as an entry point for recruitment. I first identified different established cultural networks, including faith-based organizations and other cultural groups. I met the leaders of the different groups and informed them of the intentions and reasons for the research. The leaders were provided informational letters to read and distribute to the congregation and members of the cultural groups. After two weeks, an appointment was made for initial contact and for a brief introduction of the researcher. Eligible participants were identified and were informed in detail about the research study. Within these networks, participants were recruited for the study. Key informants also introduced people for possible recruitment.

### ***3.3.1.3.3 Sampling technique***

Purposive and snowball sampling was used to recruit participants for the study. The snowball sampling is also known as chain-referral sampling. We were introduced to the initial participants by leaders of organizations, and future participants were later referred by the initial participants (174). The purposive sampling is also known as judgmental. The judgment lies in the researcher to select the respondent to participate in the study and expected to be representative of the population (175). This sampling technique was applied to select women exposed to FGC because they all have a common characteristic, and we were keen on understanding issues surrounding FGC in greater detail for one particular population rather than being concerned about the generalizability of the results. Female genital cutting is a sensitive topic, and those that have been cut are difficult to find so the women in this study were recruited through their acquaintances and friends.

### ***3.3.1.3.4 Data collection method***

The research candidate collected all the data for the qualitative studies (Paper II & Paper III). Because we needed a detailed understanding of participant's experiences, both at an individual level and as a group, in-depth interviews (IDI) and focus group discussion (FGD) were used in collecting the data. The FGDs and the IDIs were held at a location chosen by the participants. Assigning participants to the two methods was determined by the participants. Each participant decided whether he or she wants to be interviewed or partake in the group discussions. Participants gave both written and verbal consent to participate, and a place and time were agreed upon by all participants. The IDIs and FGDs were conducted in English, Norwegian, or French (where applicable). Before the interviews and FGDs, the venue for the interviews and

group discussions were prepared, and the interview and discussion scripts were prepared in the form of an interview topic guide. The topic guide scripts for both the IDIs and the FGDs were broadly the same. The interviews and group discussions began with an introduction of the interviewer and interviewee. The aim of the study was repeated, although it had been given at the point of recruitment. The interviewees were reminded to stop at any time if they wanted to ask questions or if they needed any clarification. The interviewer and interviewee went through the information sheet and the consent form. The interviews and the discussions were concentrated on the subjects and the subject matters. During the IDIs and FGDs field notes were taken. Field notes captured some information of interest, social environment, nonverbal communication, and formal interaction. All interviews and FGDs were audio-recorded to ensure the reliability of data generated. Soft drinks/tea/coffee and pizza/pita rolls were either provided during or after the interviews and the group discussions.

#### **3.3.1.3.4.1 In-depth interviews (Paper II & III)**

The dramaturgical model of interviewing was adopted for the IDIs, whereby the interviewee is allowed enough time to develop an account of the things that are important to them and to display their feelings during the interview (176). According to Berg and Lune, and other authors, the “dramaturgical model” of interviewing emphasizes on the interviewer using the constructed relationship between the interviewer and subject, to draw out information from the subject (176, 177). In this context, the researcher showed empathy, understanding, and respect to the participants. Participants were given enough time to reveal their experience, identity, and personality, in doing so, the researcher talked less in order to avoid the restriction of the data disclosed. Further, the researcher clearly explained the purpose of the interview. The interview was not one-sided, rather an “active interviewing” where the interview was viewed as a meaning-making occasion in which the meaning of the actual circumstance is constructed (178). Interview questions were asked in a systematic and structural way, and some questions were probed for a deeper meaning of an actual circumstance and for detailed information. In total, 60 SSA migrants were interviewed. Forty-seven participants participated in paper II, and 13 participants participated in paper III. The IDIs lasted between 45 to 75 minutes. Questions for all the interviews started with open-ended questions to gather the general characteristic of the participants, followed by the key issues intended to be explored in the interviews. However, the topic guide remained flexible to allow participants an opportunity to highlight other issues that were of concern to them. The motive was to allow for the exploration of unanticipated themes.

The interview guides for paper II and paper III were designed to capture information for each study's objectives.

#### **3.3.1.3.4.2 Focus Group Discussion (Paper II)**

Focus Group Discussion is generally a tool used in health research for collecting data to inform needs assessment, evaluate services, and conduct research in group norms (179). The FGDs consisted of a group of informants guided by a moderator. Participants were nine per FGD, with a mixture of migrants from different SSA countries and different social backgrounds. The duration of the focus groups varied from 90 to 105 minutes. When moving from one theme of questions to the next, participants were allowed to ask questions for clarity. To ensure that all participants were given equal opportunity to participate in the discussion, the moderator instigated the participants to speak following a particular order. Shy participants were also encouraged to speak. In-depth probing was used without leading the participants.

**Figure 6: Key issues explored during in-depth interviews and FGDs**

**(Detailed interview/FGD guide is at the appendices)**

**Healthcare for related health problems**

- The perception on the general health, the common health problems and how it is reported for healthcare
- Experiences and challenges in visiting the general practitioner, emergency room, other healthcare services
- Reflection on the barriers to accessing the healthcare system and experiences navigating the healthcare system.
- The issues that make it difficult to access healthcare (e.g. language)
- The factors that make it easier in seeking healthcare
- The factors that make it difficult in seeking healthcare
- Beliefs in the care (e.g. advice, prescription) offered by the healthcare workers at the health facilities
- Awareness of healthcare services
- Access to health information and the general perception of the Norwegian healthcare system

**Healthcare for FGC**

- Perception of general health and decision to seek help for FGC
- Barriers to access to healthcare for FGC
- Family involvement in healthcare
- Knowledge of FGC health consequences
- Awareness of healthcare services
- Access to health information and the general perception of the Norwegian healthcare system
- The factor that makes women want to seek healthcare for FGC

**3.3.1.3.5 Data analysis (Paper II)**

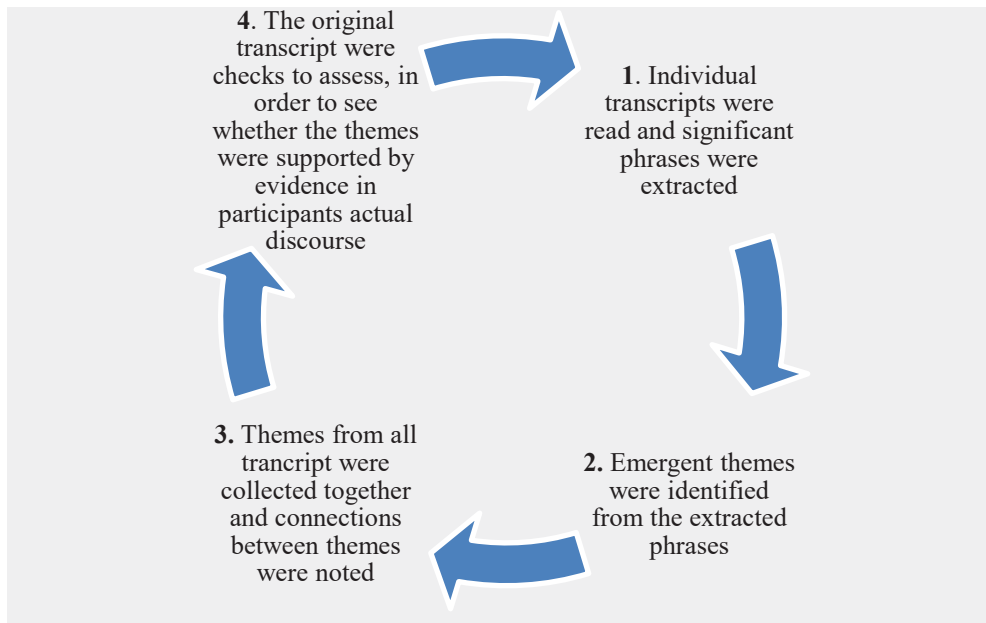
The IDIs and FGDs were audio-recorded and transcribed verbatim and translated into English (when applicable). The transcripts were then imported into NVivo 11 Pro. A framework method was used to manage the analysis of the data (180). This is an analytic approach within the family of analytical methods, including thematic or qualitative content analysis, used in the management and analysis of qualitative data in health research. This approach allows for all the stages in the management and analysis of qualitative data to be systematically conducted.



Interview data were analyzed for themes and patterns, and the themes and sub-themes emerged from the data analysis (181, 182). The themes for the interview were identified during the review of the transcript. An initial coding scheme was generated from a consecutive review of the transcripts. Then, with the initial coding scheme, we coded the second set of transcripts and revised the theme until no new theme was identified. Less relevant codes were dropped, and the important and interrelated codes were brought together based on how relevant and connected they were to each other. The codes were later grouped into each theme, and the relationships among the themes were interpreted. Transcripts were checked for errors in transcription in order to maintain consistency. Field notes were maintained to document the additional information and interpretations during each interview.

#### ***3.3.1.3.6 Data analysis (Paper III)***

Concerning the experiences of women exposed to FGC, we analyzed the data following the practical guide of interpretative phenomenological analysis (IPA) by Smith et al. (183, 184). IPA is an approach to psychological qualitative research with an idiographic focus, meaning it aims to offer understandings into how a person, in a given context, makes sense of a given phenomenon (185). IPA is a useful methodology for examining topics that are complex, ambiguous, and emotionally laden. This approach involves a comprehensive examination of participants' lived experiences and is suitable to understand individual personal experiences. Superordinate themes were developed based on emergent themes across transcripts. The themes were grouped based on the theoretical similarities to highlight important aspects of the participant's account. A schematic figure of how IPA analysis was done is presented in Figure 7.



*Figure 7: Interpretative phenomenological schematic analysis of data*

### **3.3.1.4 Research ethical consideration**

Ethical assessment in medicine and healthcare is exerted in many fields. Due to the sensitive nature of health data, many ethical associations have developed protocols that guide ethical principles in medical and healthcare research. The project “Access and Utilization of Norwegian Healthcare services among sub-Saharan African Migrants” was carried out in Norway. The implementation of the research study was guided by ethical principles of autonomy and respect for human persons (186).

Prior to the commencement of the overall research project, a protocol of the research project, an information letter detailing the research procedures, and an informed consent form were submitted to the appropriate Research Ethical Committees. Ethical approvals were obtained from the Norwegian Regional Committee for Medical and Health Research Ethics (Regionale Komiteer for Medisinsk og Helsefaglig Forskningsetikk (REK) (2016/799/REK vest)) and the Norwegian Center for Research Data (Norsk Senter for forskningsdata (NSD) (53374/3/AMS)) for the research project. REK and NSD were informed about the set of variables to be used from the register study (paper I), and other relevant information pertaining to the registry data were provided to both institutions. We had the appropriate approvals in hand before publishing paper I and before commencing fieldwork for paper II and III.

For the register study (paper I), consents were not needed from the participants, but the REK application for the register study is reference: 2009/1747 “Immigrant Health in Norway.” This

study was based at the University of Bergen. The first author who managed the data conducted the analyses and shared the result outputs with the team. However, the plan of the analyses was made by the whole team, based on the knowledge on which variables were available.

For paper II and III, the research subjects gave both oral and written informed consent, although the participant's preference varies depending on individuals and the research context. The process of informed consent was taken in a culturally appropriate manner because the research subjects migrated from regions of the world where culture is profoundly respected. For instance, a "round of consent" was obtained from the head of the household, namely a husband, a father, the head of a religious organization, or a leader of a cultural group. Culturally because the heads of households are the most respected, and they play an important role in the house and the community, their consent occasionally is required before inviting individuals to participate. Community/household consent was for permission to invite individuals to participate, but this did not surpass the consent of individuals who were to participate in the study.

The Helsinki Declaration and the Oviedo Convention require that a substantial amount of information be given to potential participants and further require that the information provided to them must be understood by the participant. In that respect, an information letter was provided to the research subjects in this study. In the information letter, a brief background of the research topic, objectives, and the importance of the study were stated. It was mentioned in the information letter that participants' personal data would be treated confidentially and the data would be anonymous. Furthermore, the participants were informed both verbally and in the information letter that participation was voluntary and they could withdraw their consent to participate in the study at any time, without stating any particular reason, and without any consequences. Participants were assured that the information gathered would be deleted after completion of the Ph.D.

#### **3.3.1.4.1 Research methods and ethical consideration**

For the quantitative research method, the study was based on the reuse of registry data. So, the participants did not need to give their consent. However, as explained above, the REK application for the registry study is available (2009/1747). For the qualitative project, recruitment of the participants was done within the communities, cultural groups/associations, and religious organizations. The researcher presented herself to individual participants, religious leaders and the family head where applicable. Verbal approval was obtained before the researcher approached the participant to participate in the study. The participants were again

informed of the goal and procedure of the study in the language they understood best and they were requested to ask questions for clarity. This was to ensure the participants understood all the information about the study. We clarified to the participants that we were independent researchers and not an NGO and were not going to expose any material or personal data to any organization, but the data would be used for the purpose for which it was intended.

The participants were informed that the research methods would be both in-depth interviews and focus group discussions. They were told to choose freely in which research method they would like to be a participant. Each interview and focus group was preceded by an extensive informed consent process, and participants were again briefed on information about the study. This was for recollection since some time had passed from the time, they received the information letter. All participants gave their consent for the interviews and the focus group to be audio-recorded. In the context where the interviews and the focus group discussions were undertaken, all attempts were taken to formulate questions in words familiar to the participants. Each research subject was adequately informed of the anonymity of the report in any scientific forum, including reports in international journals or at conferences. The informed consent in both Norwegian and English is available in the thesis (See appendix).

#### **3.3.1.4.2 Data storage and handling**

Data for the register study was stored and handled at the University of Bergen following procedures as requested by REK. All paper documentation, including informed consent forms and voice recordings of the in-depth interviews and focus group discussions, were kept safe and in a secured location. Data stored in an external hard disk and in a private computer had restricted access by use of a password and was anonymized by giving coded keys to all the participants. Participants were not referred by names. A list of names corresponding to coded keys and contact information was made in order to contact participants during fieldwork. This form could only be accessible by the research teams. After the fieldwork was completed, all consent forms, lists of the names and corresponding coded keys and all the voice recordings were deleted.

#### **3.3.1.5 Reflexivity**

According to Malterud, what you choose to investigate, the angle of investigation, the choice of research methods to be used, the findings, and the dissemination of the results are affected by the researcher's background and position (187). In this study, I noticed that there is a difference between what is called "standardized methods" of interviewing that we read in textbooks and the experiences during data collection. Interviewing has often been seen as a one-

way process, where the researcher asks questions and receives information from the participants. Based on my experience in the field, in order to reach your objectives, you have to put in more time, and you are also asked questions pertaining to yourself. During the interview with women exposed to FGC, I came to understand that to gain an in-depth flow of information, I had to find a way to balance the power disparity. After introducing myself, the women saw me as a student and as someone that is academically more than them, knowledge-wise. I had to tell them I am one of them, and they should feel free to tell me their experiences and what is bothering them concerning their health problems caused by FGC. I told them they could feel comfortable sharing how they go about seeking access to and the use of healthcare services. My background as a researcher, an African migrant, and a woman created a relaxed atmosphere. I was considered as one of them, so I had a healthy relationship, which was built on mutual trust and respect. This was important because it encouraged open and honest responses.

During my research, I noticed that the way a researcher speaks and interacts with the informants is important. Although I was expecting to hear only from them, I end up revealing my personal identity as these women asked me many questions. They asked questions of advice, personal questions about my family life, questions about the research and questions that were based on request. They asked me questions about my sexual life and my experiences during childbirth as a non-circumcised woman. "I could feel their feelings." All these questions were problematic but ultimately unhelpful to avoid. After research, I have a social relationship with the women I interviewed.

## 4. MAIN FINDINGS

Summaries of the major findings of the studies incorporated into the thesis are given below. The comprehensive findings from each study are elaborated in the original publications.

### **4.1 Paper I: Differences in primary healthcare use among sub-Saharan African immigrants in Norway: a register-based study**

*Published in BMC Health Services Research*

This descriptive quantitative study aims at documenting whether migrants from sub-Saharan Africa specifically from Somalia, Ethiopia, Eritrea, and the Republic of The Gambia use primary healthcare (general practitioner (GP) and the emergency room (ER)) differently. We also assessed the distribution of morbidity burden among them.

Participants were all legal migrants (people with Norwegian personal identification numbers) from the above-mentioned countries, staying in Norway for at least six months in 2008. Data were obtained from a merged data from NPR and HELFO, comprising a total of 36,366 persons. We used the number of visits and medical diagnoses from each consultation registered by primary health care physicians in Norway in 2008. Chi-square and logistic regression analyses were used to compute the differences between migrant groups in the use of GP and ER and compare the distribution of morbidity burden.

Approximately 66 % of the participants visited PHC in a period of one year. The average number of visits was 2.42 for the GP and 0.24 for the ER. The use of GP increased with age for all migrants, irrespective of country of origin. By age groups, the use of GP was similar for the four countries, except for the young Somalis adults (15–44 years) who used the GP more than those from other SSA migrant groups. For all countries, children and the elderly used the ER more, although Somalis were over-represented in all age groups. Somalis used both GP and ER more often than all other groups studied, except for unadjusted analyses of GP use for the Gambia. Nevertheless, Somalis, as well as Gambians, reduced their use of PHC after six years of stay in Norway. The medical diagnoses registered were somewhat similar for all the migrants, although Somalis registered a higher proportion of ear-nose-throat, general signs and symptoms, and respiratory, while The Gambians registered more musculoskeletal problems than all other migrant groups.

This study demonstrates that the use of primary healthcare in Norway differs among different SSA migrant groups, although with similar medical diagnoses. Nevertheless, the use of PHC among some SSA groups reduces with a longer duration of stay in Norway.

## **4.2 Paper II: Access to Norwegian Healthcare System – Challenges for Sub-Saharan African Immigrants**

*Published in BMC International Journal for Equity in Health*

This is a qualitative study that aims at documenting the challenges faced by migrants from sub-Saharan Africa in accessing and utilization of the Norwegian healthcare services. The challenges are those factors that constrain or hinder the efforts of SSA migrants in seeking healthcare.

The sub-Saharan African migrants residing legally faced accessibility barriers to Norwegian healthcare services. The main themes that emerged following the analyses of the data were: “the challenges before accessing the healthcare system” and “the challenges when in the healthcare system.”

We found that SSA migrants faced challenges prior to accessing the healthcare system. Prior to contacting the healthcare services, lack of information about the availability of the existing healthcare services and the kind of treatments offered was a hindrance to access healthcare. In addition, migrants would prefer consulting doctors with a migrant background than doctors with a non-migrant background. Their preference stemmed from the respect, attention, and treatment they perceived to get from them. Consulting with a private doctor was also preferred to consulting with care professionals in the public sectors for the same perceived reasons. Without their choices, they did not seek healthcare. Financially, although healthcare is subsidized, some SSA migrants could not afford healthcare because of insufficient funds. Dental and eye care, and physiotherapy were out of reach for most of the SSA migrants. These services were perceived to be expensive. Furthermore, the frustration from the long waiting times at all healthcare system levels caused frustration and boycotting of healthcare. Family responsibility and job security were prioritized over seeking healthcare, and most SSA migrants would prefer to take care of their family and postpone a hospital appointment. Missing one’s job was said to reduce family income and participants believed this could cause financial constraints for both their household and their family back in Africa.

Communication or expression difficulties represent one of the significant barriers to receiving appropriate healthcare when in the healthcare system. Participants dread the fact that they could not convey their health concerns in Norwegian, and the physicians were unable to comprehend their health concerns. In such a case, they complained of taking too much time trying to get their symptoms through to the health professional. Additionally, some participants were unable



to adequately describe their symptoms to the doctors, because the doctors were rushing to attend to the next patient. The perception of discrimination and the negative stereotypes of the care providers emerged as a barrier to access during healthcare. Some participants professed that the care providers did not appear interested in them during healthcare, and this was perceived as a racial issue. Racial discrimination perceived in the healthcare setting was a barrier in receiving appropriate care. The use of double gloves by the care providers during medical procedures and the inclusion of HIV/AIDS tests among listed tests were perceived as suspecting SSA migrants of communicable diseases. They perceived it as inadequate conduct on the part of the healthcare providers. These were seen to be disrespectful, unfriendly, and a preconceived idea about Africans. The perceived feeling of being ignored and neglected during healthcare caused frustration and led them to avoid healthcare services. This was perceived as being treated as second-class citizens. Incorrect diagnoses and inappropriate treatments led to dissatisfaction and were perceived as unskillfulness of the care providers.

In most cases, the challenges and the experiences of the SSA migrants either in or out of the healthcare settings, caused them to be discouraged, disappointed, or frustrated, thus avoiding the healthcare services or made them seek alternative treatment. Therefore, this study demonstrates that the utilization of healthcare is influenced by many factors. The study highlights that SSA migrant's in Norway face barriers that impede their ability to access and use the Norwegian healthcare system. This study demonstrates that SSA migrants may be 'behind' in being able to access and use the Norwegian healthcare system.

### **4.3 Paper III: Barriers to access to the Norwegian Healthcare System among sub-Saharan African Immigrant Women Exposed to Female Genital Cutting**

*Published in PLOS ONE*

This qualitative study aims at documenting the factors that impede women's access and use of the Norwegian healthcare services for FGC healthcare-related needs.

This study is an exploratory qualitative research design, involving 13 migrant women exposed to FGC from sub-Saharan Africa (SSA) countries living in Norway. A purposive and snowball sampling technique was used to recruit participants, and an interpretative phenomenological analysis (IPA) approach was used for data management and analysis.

The study found that women exposed to FGC lack healthcare service information, and they might be caught within the complexity of different elements, perceived as discrimination, that co-exists. These elements individually or contextually overlap to impact women's ability to seek care for FGC related maternal and non-maternal healthcare needs.

Our findings revealed that women exposed to FGC experienced barriers before they are in contact with the healthcare system, including the lack of information about healthcare services for FGC-related health needs, and treatment offered at the healthcare services. Most women studied were not familiar with the Norwegian healthcare system besides the primary healthcare and the GP. Women lacked information on healthcare services for FGC psychosexual and psychological health needs and counselling. Women needed information on where to go when the need arose, and the lack of such information was perceived to be frustrating and a hindrance to their ability to access healthcare. Secondly, women stressed their family as the main barrier to contact healthcare services. Some women mentioned that family members, particularly their spouses, influenced their decision-making in seeking healthcare, especially de-infibulation. De-infibulation was not an option because some women professed their husbands wanted to open the "vaginal passage" naturally, and to some, their husbands preferred to have sex when the "vaginal passage" was narrow. Although, to some, they did not want de-infibulation in fear that their vulva might look unpleasant following de-infibulation. In addition, some women did not seek care in fear of disrespecting their spouses, and in fear of separation, divorce, financial deprivation, and rejection by their family. Thirdly, some women avoided disclosing or talking to the care providers because they were either ashamed or shy to present their health problems to the healthcare professionals, especially those women with gynecological care and psychosexual problems caused by FGC. Some were afraid of the stigma of presenting themselves as circumcised women, or judgement or blame by care professionals.

Women also experienced barriers in the healthcare system. Many women felt that the GPs and other clinic staff lacked knowledge and experience relating to FGC. According to some women, during childbirth, doctors and nurses did not know what to do. This caused embarrassment, more stress, and “worries” caused by FGC. Because of the perceived lack of skills and confidence in treating women exposed to FGC, women professed care professionals as not being a potential source of support. In addition, participants perceived care providers’ attitudes to be limiting to healthcare access and use. According to some women, care providers are more concerned about the criminalization of the practice rather than their healthcare needs. Asking intruding questions about their female children and their traveling plans to Africa were perceived as discrimination. The impromptu visitation of police and child protective service officials at women’s homes following a hospital visit was also perceived as discrimination. Women said these actions were aimed to ridicule them. They felt they were being treated in that way because of their race and because they were from Africa. Women professed these were instigating tension, mistrust, and poor relationships with the care professionals. Lack of confidentiality at the healthcare settings highly impedes women’s ability to access maternal health services, because some women professed they were “showcased” to medical students. These experiences presented challenges for women and impacted their ability to use health services.

This study revealed essential knowledge of the experiences of African migrant women exposed to FGC in accessing healthcare in Norway. This study also demonstrates that African migrant women exposed to FGC maybe ‘left behind’ in their ability to access and use the Norwegian healthcare system.

## 5. DISCUSSION

### 5.1 Summary of findings

This study sought to understand the pattern, perceptions, and experiences of SSA migrants' access and use of the Norwegian healthcare system. Literature has established several determinants of access and use of healthcare services, both barriers and facilitators (88, 170, 188, 189). The findings revealed both barriers and enabling factors to healthcare. We mention and discuss SSA migrants' challenges and experiences. The enabling factors are also described, though these are not published. The findings of the study are discussed with the assistance of the three papers. In this thesis, the discussion of the study is presented in sections. Section 5.1.1 discusses the main findings, namely the factors that constrain SSA migrants' access to healthcare. Section 5.1.2 discusses the enabling factors to access healthcare. The application of theoretical frameworks and the findings are discussed in section 5.2. Section 5.3 discusses the possible implications of the findings, while section 5.4 addresses the methodological issues. Lastly, section 5.5 discusses the strengths and limitations of the study.

#### 5.1.1 Main findings: Factors that constrain SSA migrants' access to healthcare

Findings have shown that migrants from SSA countries living in Norway use the PHC differently, although with a similarity of morbidity burden among them. Migrants in general, have been described to use PHC less than Norwegians (190), although Somalis have been reported to use the ER more than the Majority population (163). Even though many migrants in host countries face challenges in access to healthcare—including access to information, financial difficulty and long waiting times which reduce healthcare service engagement in host countries, SSA migrants living in Norway are constrained by certain challenges, perceived to be discriminations and racism, which may be specific for the SSA migrants or people of their racialized group. Sub-Saharan African migrants are faced with perceived racial discrimination in the healthcare setting because of their country of origin or their skin colour. The participants believed that the Norwegian healthcare system has significant prejudice towards migrants from Africa, and most SSA migrants felt the health professionals were judgmental because they were “black”. Accordingly, this has been reported among “black” African migrants in other high-income countries (142, 191). “Institutionalised racism” has been defined as “the collective failure of an organization to provide an appropriate and professional service to people because of their colour, culture or ethnic origin. It can be seen or detected in processes, attitudes, and

behaviour which amount to discrimination through unwitting prejudice, ignorance, thoughtlessness, and racist stereotyping which disadvantage minority ethnic people” (192).

Participants perceived the use of double gloves for medical procedures by care providers as racial discrimination. Equally, SSA migrants perceived being neglected and ignored during healthcare, and they said care providers demanded that they take an unnecessary HIV/AIDS test. Additionally, the impromptu visitation of public officials (police and child protective services) to homes of SSA migrant women exposed to FGC after hospital visits, in addition to intrusive and interrogating questions to women exposed to FGC at healthcare, were perceived as discrimination. In addition, women exposed to FGC also felt that healthcare professionals are more concerned with the illegality of FGC practices over their health needs. Furthermore, the “showcasing” of women exposed to FGC to medical students at healthcare were all perceived as discrimination. The perceived discrimination in healthcare settings not only impeded SSA migrants’ ability to access and use the healthcare services but also affected their mental and emotional states. This caused perceived feelings of trauma, psychological stress, doubt, worries, wanting to consult with doctors with a migrant background, anger, sadness, fear, “suspect”, and vulnerability.

Racial discrimination was perceived by SSA migrants as disrespectful, and this eventually caused distrust and tension between the patients and the healthcare providers. Racial discrimination has also been reported among ethnic minority groups in education and health sectors, and socio-economic status (193, 194). In healthcare settings, the profound effect of racial discrimination can be felt by its users. When a patient faces discrimination in the healthcare setting, it is reported to influence the user’s subsequent visits to, and engagement with, the healthcare setting (22, 195, 196).

In addition, male dominance over women and lack of family support were the main barriers perceived to limit women’s ability to seek care. Husbands/partners would prefer to open the “vaginal passage” naturally, and family members would prevent women from seeking care. Cross-cultural studies in African regions specify that the discrimination of women is attributable to male authority, sole decision-makers in the family, stiff gender roles that are linked to dominance, and economic disparity between men and women (197-199). However, looking at the European perspective, this could be labelled as a violation of the rights of women and a form of discrimination. However, differences in perceptions could be attributed to differences between European and African values and cultures.

In this study, apart from perceived discrimination and racism, other factors that impede SSA migrants ability to access care include: lack of information about the services and how to use the services, the knowledge and skills of the healthcare providers, long waiting times, language barrier, financial difficulty, family and job responsibilities, poor attitudes of the health professionals, and dissatisfaction with care providers. Avoiding disclosure of health problems was a typical barrier of circumcised women in the study. Many studies among migrants in high-income countries have shown a link between some of these factors and how they influence migrants' access and use of the healthcare services in host countries (189, 200-205). The findings of similar studies among migrants in other high-income countries are stated below under section 5.3 titled "Possible implication of the findings."

### **5.1.2 Enabling factors to seek healthcare**

Enabling resources are those resources acquired by an individual that contribute to decisions or choices in seeking healthcare (4). In this study not only do the SSA migrants face challenges in accessing healthcare, but migrants also highlighted important factors that encourage them to seek out care. The use of translators, the doctor-to-patient ratio in a hospital, and the rights and entitlements of migrants which are the same for all residents except those that are illegally residing were some of the enabling factors in the use of the Norwegian healthcare system. The doctor-to-patient ratio in the Norwegian hospital was commended by all the SSA migrants. Comparing to their countries of origin, the SSA migrants said the healthcare environment in Norway is clean and the doctors in Norway think of the health of the patients first before the financial aspect. All participants greatly appreciate having Norwegian health insurance, especially the fact that everyone residing in Norway is entitled to medical and care services. They appreciated the issue of free pregnancy control and the blue prescription (blå resept) for chronic illnesses, and free hospitalization and treatments, including surgery. Blue prescription is a document given to patients with chronic illnesses, and this is presented to the pharmacy as an indication that one is entitled to a partial re-reimbursement of medicines, foods, and medical supplies by the government.

Adaption to the Norwegian environment and life is easier for those that have lived in Norway for a longer duration, acquired advanced Norwegian language skills, and established social support networks. In addition, health providers in the private sectors, irrespective of their background, were reportedly polite and respectful. Knowledge about prevalent diseases including vitamin D and iron deficiency among the "black" migrants in the community, appears to be an important driver in seeking healthcare. Some participants stated that rumours of ill-

health and potential consequences are circulating in the community, thus creating awareness within the community. Some participants mentioned the internet is a source of health information, and they informed themselves before visiting the GP. To others, they depend on their family members for different types of support. Some are accompanied by family members to the physician office and act as a translator. First-time mothers also appreciate the support of their families by helping them with childcare and accompanying them to the health center for a routine check of an infant's health.

Specifically, for women exposed to FGC, there was an instance that one of the women who sought de-infibulation had a "bittersweet" experience. First, she was happy that the physical trauma caused by FGC vanished after reconstruction. She was able to enjoy sex without pain, and that improved her self-esteem. She went further and explained that she witnessed an improvement in her sexual desire. On the other hand, she was abandoned by her boyfriend because he complained that her vulva looked ugly and "abnormal."

## **5.2 Application of theoretical frameworks and the findings**

### ***5.2.1 Levesque frameworks***

Findings are better explained by the conceptual framework of Levesque et al. (5). According to this framework, in order to approach a healthcare service, patients must be able to identify that healthcare services exist and that the healthcare services are able to have an impact on the health of the patient. The study findings revealed that SSA migrants lack information about the existing healthcare services and even when the services are known, they did not know the kind of treatment the services provided in accordance with their health needs. Participants did not know the right kind of services that should be used when different health needs arose. For example, many migrants were unaware of the existence of preventive and mental healthcare services and counselling services. Those with psychological problems like substance abuse, trauma (missing their children collected by the child protective services), and psychosexual problems did not know where to seek help, and they were unaware that they could be referred to see a specialist for their health needs. Women exposed to FGC were unsure whether to make appointments with the GP for FGC health-related problems.

The next component of the framework is acceptability, which are either cultural or social factors that make an individual accept the aspect of the services, and the person can judge personally if it is relevant to seek care. In relation to our findings, some women exposed to FGC were uncomfortable consulting with a male health professional, especially in areas of gynecology

and obstetrics. According to the concept, the ability to seek care relates to individual personal autonomy and the ability to choose to seek care or not. For example, some SSA migrants did not seek care in order to take care of their children and for job security and some women chose not to disclose their health needs (especially psychosexual health needs) to healthcare providers. Relating to our findings, healthcare acceptability goes both ways—both for the healthcare providers and for the patients. For example, healthcare providers with limited knowledge about FGC could not assist women exposed to FGC. According to some participants, some healthcare providers acknowledged they lack the skills in handling patients exposed to FGC. Equally, some women exposed to FGC were uncomfortable consulting with a male healthcare professional, especially in areas of gynecology and obstetrics.

Another component is the availability and accommodation of healthcare services. According to the Levesque framework, it represents when the physical space and the care providers are reached physically and in a timely promptly. In our study, the aspect of wait times for specialist care to see a GP, and at the emergency departments were some factors that hindered SSA migrants' healthcare. Some SSA migrants did not seek care in the public sector, and some travelled abroad for treatment. The long waiting times for healthcare was perceived to prolong the process of obtaining treatment, and then wait for a referral to a specialist was too long. Additionally, accessing primary care in distant neighbourhoods appears to be difficult for recent and senior migrants who rely heavily on public transportation, as indicated in supplemental results in the thesis appendix.

Affordability, according to the conceptual framework, is the direct cost of healthcare and related expenses. This aligns with our findings since inadequate funds were cited as a barrier to healthcare services. Although the Norwegian government financed the healthcare system, the out-of-pocket expense is considered high for those with economic hardship, and this affects access to primary healthcare. Dental and eye care, and physiotherapy were perceived to be costly and unaffordable.

The last component of the framework is healthcare appropriateness, which entails the ability to engage fully in care. Different barriers revealed in our findings influenced SSA migrants' uptake of healthcare differently. Some have a direct impact, while others have an overlapping effect on shaping the utilization of healthcare services. For example, an individual may refuse to seek healthcare because of the poor behaviour of the care providers. Some women exposed to FGC did not seek care because they were avoiding intrusive and interrogative questions from



the healthcare providers about their children and their next trip to Africa. Others would boycott because their family members were not in support of them receiving care for FGC related-health problems. To other migrants, their disappointment and frustration with doctors with non-migrant background push them to consider consulting with doctors with a migrant background.

Considering the components of the framework, SSA migrants' challenges in accessing healthcare, could attribute to the differences between SSA migrants populations in the use of the PHC. With all the components reflected in our findings, the only area in which the framework did not apply was the issue of racial discrimination, where SSA migrants perceived discrimination in healthcare settings. Although this framework did not cover discrimination, the aspect of discrimination is covered in other frameworks that have a heavier emphasis on barriers and enabling resources, including the models of Andersen et al. and Penchansky et al. (123, 131). It is important to consider faith (religious beliefs) as a factor in the healthcare model, for the finding of this study reveals that faith influences an individual's health seeking behaviour.

### ***5.2.2 The concept of intersectionality***

The intersectionality approach has been of interest to many researchers because of its importance in global health investigations and healthcare service research (206, 207). Intersectionality is documented to explore the complexity of multiple issues and exemplified experiences, resulting from one's identifications with gender, age, ethnicity, sexuality, nationality, religion, tradition, race, and cultural and religious identity. These issues co-exist and individually or overlap to influence one's vulnerability (208, 209). The concept of intersectionality identify the differences within similar population groups such as women, men, migrants, indigenous peoples, and visible minorities (210), and provides a way at pinpointing inequalities, in developing intervention approaches (211). Applying this concept in this study, our findings revealed that SSA migrants face many challenges at the same time and this influences their ability to access and use healthcare services in Norway. Based on the understanding of the concept of intersectionality, one was able to understand how different aspects of SSA migrant's identities combined to generate a distinctive form of inequality in access to healthcare and which might significantly put them at a distinct disadvantage within Norwegian society. These aspects of SSA migrant's identities could relate to being a black African, woman, poor, circumcised, having different cultural beliefs, or their country of origin.

## **5.3 Possible implications of the findings**

### **5.3.1 For migrants**

Migrants from Somalia use PHC more than migrants from Ethiopia, Eritrea, and The Gambia. The differences in this study did not reflect a higher disease burden among migrants from Somalia, although Somali were over-represented in the common diagnoses presented by the migrants. Migrants from Somalia in Norway, however, have been reported to be over-represented of non-specific diagnoses and consultations at night at the ER when compared to native Norwegians (163). Additionally, studies in other countries have reported poorer health profile among SSA when compared with other migrant groups in the same country and with the majority population (212, 213). The differences among countries in this study could be explained by the diverse migrant background, differences in language skills, adaptability, and knowledge of the healthcare system between migrant groups. The differences in country profile could also be explained by differences in acculturation, differences in their health needs or because of barriers to healthcare. Having information about migrant's use of PHC is important because PHC is the first level of care where people complain about their health conditions and it is also a healthcare level where most health needs are met.

### **5.3.2 For the healthcare system**

Although access to information could be a challenge to migrants, it is notable that providing information on existing healthcare services, the treatments offered, and health information, in addition to information about the use of cultural brokers/interpreters might positively influence SSA migrants' decisions to seek care. However, lack of comprehension of the healthcare system and communication difficulties are perceived to affect SSA migrants' ability to interact with the healthcare system, as has similarly been demonstrated among migrants from low-income countries in Norway (203). An informative healthcare system is of great importance for a positive encounter with healthcare for all SSA migrants and lack of access to healthcare, especially among women exposed to FGC, could lead to misguidance (205). Other than the GP, information on existing healthcare services are needed, and this might positively influence decisions to seek care. Additionally, it would also be essential to include migrants and their communities in decisions regarding disease prevention, and in collaborations with health policymakers. This study confirms previous studies on the psychological and psychosexual health consequences of FGC (200, 214), so women should be informed about the health consequences of FGC and on what to expect when exposed to FGC, especially on issues relating to psychological and psychosexual health. Having this knowledge might reduce the feelings of

embarrassment, shame, and shyness among women and encourage them to come forward and seek help.

A higher health literacy index is needed among the SSA migrant population. This is strongly needed to increase SSA migrants' ability to obtain, process, and understand health information and healthcare services in Norway. Health literacy is a concept for the empowerment of health communication, and it is important for stimulating a more understanding of the process of health communication in both clinical and community settings (215). One way to achieve this is through community-based outreach, targeting the SSA communities. We can take advantage of community organizations like churches, mosques, and ethnic meeting groups, for these organizations periodically organize programs to educate and enlighten members on varying issues. Such forums could be used to disseminate information to SSA migrants, especially to those with limited education, on aspects relating to health and access to the healthcare system. This could benefit newcomers since such forums are usually the first entering point on their arrival. Other studies have documented that linguistic barriers can hinder access to healthcare, reduce the quality of care, and result in dissatisfaction (204). In accordance with the suggestions made by the participants in this study, there are studies that point to the benefits of greater availability of material resources in other healthcare systems (216). Particularly, studies mention positive results of using pictograms, visual aids, and documents translated into the patient's language (216).

Insufficient finances or income might affect socio-economically vulnerable persons' healthcare. Research among migrants and non-migrants suggests that inadequate funds significantly affect access to healthcare (217). SSA migrants in Norway might not be able to afford high-cost medical care such as eye and dental care, and physiotherapy. Some SSA do not attend a hospital appointment because the co-payment levy is perceived to be costly and unaffordable. To some, even if they could afford the payment, the money is needed by their families living in Africa. In this respect, the financial state of their family in Africa is indirectly impacting SSA migrant's health-seeking behaviour in Norway. Furthermore, the system in a migrant's home country may not be strong, so people are dependent on family and friends for support of any kind, even in healthcare (218). There is a common saying in most African cultures that "giving is receiving," meaning the more you give the more you will receive, which then makes the extended family members and friends important sources of help/support, especially when coping with different issues, and when in need of physical, financial, and emotional assistance. Once in host countries, the situation is different because the balance between the individual and the host country system

changes. This study expounded that phenomenon. Lacking a support system, some SSA migrants missed appointments in order to care for their children. However, it is also possible they are not able to afford a “before and after-school programme” (SFO). Notably, many SSA migrants are involved in physically demanding and energy-consuming jobs with long working hours, although this is not unusual among migrants from other low-income countries. Because of the employment exhaustion, hospital appointments were often missed, although according to others was in fear of losing their jobs. Stress was perceived to be acquired from their jobs and it was viewed as a key factor for most of their health conditions, thus confirming similar findings of Beune et al. (2006), Dean and Wilson (2010) and Boateng et al. (2012), (189, 202, 219). Lastly, although this applies to the Norwegian society in general, long waiting time is a barrier to seek healthcare or for continuity of care. Long waiting time has been shown to lead to patients’ dissatisfaction with healthcare and also to mortality (220, 221). This means that shorter waiting time should be encouraged in the Norwegian healthcare system because improved health outcome has been linked to shorter waiting time for healthcare (222).

### **5.3.3 For health professionals**

We know from the literature that there are existing determining factors that influence migrant’s access to healthcare and the extent of use of healthcare services. Literature also shows that access and the extent of use of healthcare services vary among migrants depending on their healthcare needs, healthcare-seeking behaviour, barriers to access in the host country, migrant status, educational level, health literacy, and other socioeconomic factors (169, 223-227). In this study, there is evidence that SSA migrants in Norway face challenges and perceived racial discrimination in healthcare. Health professional support to a SSA migrant is required for a positive encounter with healthcare. Care professionals should serve as a good support system to empower SSA migrants, particularly to women exposed to FGC since this population is vulnerable to racism and discrimination. Women, in particular, need care provider’s support to overcome some of the ordeals of FGC. The illegality of FGC must not override the care of women. Asking women interrogating question during healthcare interactions perceived as victimization and judging will lead to not only more stress, but also frustration, hatred, seclusion, and eventual boycott of healthcare services. It is important to tackle the complex issue surrounding FGC, but we have to be careful not to make SSA migrant women in Norway more vulnerable. Asking women private questions trigger recollections (228, 229). Importantly, failing to support women emotionally and physically might be perceived as a weakness of the healthcare system and even the legal system. Women’s empowerment is as important as the

criminalization of FGC perpetrators. This will not only help to abolish FGC but will strengthen women to “take back” their voices and have control over themselves and their well-being.

The use of double gloves during medical procedures and asking SSA migrants to take an HIV/AIDS test was perceived as discrimination. This practice implies that the care providers are unfairly suspecting patients of infectious disease, and on the other hand, the care providers might be mindful of contamination. This study confirms the study of Chen YY et al. (2015), among migrants in Canada (201). Ignoring or neglect of SSA migrants among other patients during healthcare was felt and was perceived as disrespectful and discriminatory. Seemingly, the impromptu visitation of public officials to homes of women and the breach of confidentiality among women exposed to FGC was also perceived as discrimination. If confidentiality is not guaranteed during the care of women exposed to FGC, either healthcare-seeking is not guaranteed, or it will cause tension and ruin doctor-patient relationship, and this could cause women to feel repulsive towards seeking healthcare. Failure to address women’s health needs, may aggravate their health problems and create more psychological damage. The participants expressed that they are treated in such a manner because they are “black.” On the one hand, the stereotype of associating “Africans with infectious diseases” could better explain the attitudes of health professionals towards SSA migrants. Better still, on the other hand, it could be the idiomatic phrase “the black elephant in the room” which is being ignored in social interactions (230).

Discrimination or ill-treatment because of skin colour, race, and ethnicity, have been suggested as drivers of racial/ethnic inequities in healthcare (231, 232). Racial discrimination experienced within the healthcare setting can affect an individual in many ways. It can affect how an individual perceives the healthcare system, how an individual engages with health services and care providers, or the usage and quality of individual healthcare access (22, 195). It can also influence patient satisfaction and levels of trust, and future patient uptake of healthcare (22, 196). Finally, it is reported to be associated with worse health outcomes (233). In addition, personal experiences of racism with an impact on physical and psychological health are well-known (232, 234). When dealing with issues surrounding racial discrimination in healthcare settings, it is important to ascertain the presence of the poor attitudes of the healthcare providers, especially bias towards the vulnerable populations, and the impact of this inappropriate behaviour on fostering disparities in healthcare. It would also be important to look at each section of the healthcare system within the context of the broader healthcare system for appropriate intervention (235). Culturally appropriate healthcare development has been

proposed to address the negative stereotypes in the healthcare settings, so this can be applied within the Norwegian healthcare setting (236). This study also confirms a previous study showing that migrants worry about health professionals lacking interest and spending less time on them during healthcare, and sensing rush to attend to other patients (237-239). It is important that the care providers, especially those in the public health sectors in Norway, endeavour to create a level of trust and respect that boosts the provider-patient relationship, and there is a need for cultural awareness in the healthcare setting. Health professionals must also endeavour to foster good practice, especially as SSA migrants are sensitive to the way society looks at them, and in the way they perceive discrimination. One way of building SSA migrants' trust in treatment regimens is that healthcare providers could discuss why a diagnosis or treatment is needed. In such a case, this could further change the misconceptions about “test prescription,” as this has similarly been raised by SSA migrants in the Netherlands (189).

Comparing cultural differences in the local healthcare practice with that of migrants' host country could explain reasons for the perceived unskillfulness of health professionals. Sub-Saharan African migrants have high expectations, especially in diagnosis and treatment regimens. Perceived inappropriate diagnoses or treatment would leave SSA migrants doubting the skills of healthcare professionals. This progressively leads to frustration and the eventual shunning of healthcare. Participants expect the routine examination of vital signs during every consultation, with the expectation that the doctors should hold a patients' hand, check the blood pressure, and signs of blood deficiency. Their expectation is for the physician to make a diagnosis based on physical examination. Care providers must endeavour to explain the medical procedure to patients during healthcare. This can change the ideology of SSA migrant's perceptions of the healthcare system. Researchers have suggested that culturally appropriate care can address cultural differences concerning diagnoses, symptoms, and the understanding of health investigation systems (236).

#### **5.3.4 For circumcised migrant women and their families**

A husband's dominance over a woman and lack of family support are among the main barriers to a woman's ability to seek care for FGC health-related problems. This could be because of patriarchal ideas in African society, as mentioned above (197-199). This study supports the findings of the previous study, which reported male dominance is a factor in depriving patients with FGC of independently making a decision about their healthcare (240). De-infibulation was not a choice for some women because their family members were not in support of them seeking care, or their husbands wanted to open the “vaginal passage” naturally. This was supposed to

be a cultural issue, and wishes of their spouses. However, it could also relate to the dogmas of feminists that FGC is intended to control women's feelings and enforce female sexual loyalty, and that FGC is a system that maintains male dominance and it gives men the power and right to control the emotional and sexual feelings of women (241, 242). This study supports the findings of Moxey et al. in 2016, although women in their study opted that their men should "open" them up naturally (228). A husband as a sole decision-maker has been shown to have a negative effect on the use of reproductive healthcare service (243). Women in our study could be struggling between the system in Africa and that in Norway. In Africa, the system is weak and people might depend on family and friends for support. But they may not know that the system here is different and they do not need their family or anyone's approval to seek healthcare. Programs aiming to empower women on matters of sexual and reproductive health and wellbeing should be mindful of the cultural and ethnic diversity in Norway.

#### **5.4 Discussion of the study methods**

This research study employed both quantitative and qualitative research analytical methods to assess and describe the pattern and the experiences of SSA migrants in Norway in the access and use of healthcare services. In the succeeding paragraphs, issues concerning the research methods used in the three studies included in this thesis will be explored.

##### **5.4.1 Methodological issues in quantitative research**

Paper-I uses quantitative analyses, making use of registry data. We decided to use the register data to undertake the analysis of the four SSA migrant countries in the use of the PHC in order to address issues related to heterogeneity. Through the register data, we had complete information about the use of the PHC. The register data provided enough numbers (36,366 migrants from four countries from SSA) to disaggregate SSA migrants into countries of origin and to address the research questions. We were able to stratify to see the prevailing differences between the four migrant groups. From the data, we were able to get enough dependent and control variables to compare the use of GP and ER between age groups and the differences in the morbidity burden among SSA migrants groups.

The other main methodological issues pertaining to this study relate to the reliability and validity of the register data. Reliability relates to the extent to which an assessment tool produces a consistent result, while validity is how well a test measures what it is intended to measure. Although the number of consultations is highly reliable and valid, the burden of disease is probably underreported in our study given that HELFO claims are only used for administrative purposes and often only include one of several diagnoses. However, they were

suitable for comparing groups, as was our purpose. The Norwegian registry data undergo rigorous quality control methods.

#### **5.4.2 Methodological issues in qualitative research: Rigour and trustworthiness**

Paper-II and III used qualitative research methods and analyses. The rigour and integrity of the data and the findings of the qualitative methods was ensured by addressing the four-point criteria of trustworthiness proposed by Lincoln and Guba for qualitative research (244). Although Lincoln and Guba's criteria of confirmability, credibility, transferability, and dependability are used to address the trustworthiness of quantitative data (244), many scientists have recognized the usefulness of such criteria in the assessment of the quality of qualitative research and methods. Confirmability is the measure of how well the findings are backed by the data, and it also seeks to address the issue of reliability in quantitative research. To ensure this, all interviews and FGDs were audio-recorded, transcribed, and translated into English when applicable. In addition, all the findings are supported by quotes from a broad range of study participants as indicated in papers II and III and two research team members independently undertook the coding of the transcripts, with excellent inter-coder reliability. Furthermore, to enhance the confirmability of the study, interview data were shared with the respondents for verification, and the discussants for the FGDs went over the main points for verification after the FGDs.

Credibility addresses the issue of internal validity in quantitative research, and it evaluates how well the research findings are supported by the data (244). To ensure this, we adopted two appropriate research methods; in-depth interviews and focus group discussions. We triangulated these two data collection methods to ensure the validity of the study. The results obtained from each of the methods were similar, indicating a reliable indicator of credibility. We also used different categories of research participants.

Transferability is comparable to the concept of external validity or generalization in quantitative research. In essence, this is whether the findings from a study based on a sample can apply beyond the sample and context of the research itself (244). According to Malterud, irrespective of the method used, no study can provide universally transferable findings, although most research aims at producing information to be used beyond the sample setting (187). The study findings suggest that access to healthcare among migrants varies from one context to another. Access and utilization of healthcare depend on a number of context-specific factors, including: migrants' place of origin, legal status of the migrant, duration of stay in the host country, culture,



health beliefs and behaviour, working and living condition, language, health policies in the host country, age, gender, the efficiency of the healthcare system, socio-economic status, barriers to access in host countries, and health needs. However, the information gathered in this study can be used in a related context, because the components from each informant's expressions may be used to gain knowledge applicable to others (187). Finally, dependability is equivalent to reliability in quantitative research, and this is to assess the quality of the integrated processes of data collection, data analysis, and theory generation (244). To achieve this, we used two methods of data collection, and we included a detailed description of the study methodology and interview guides.

With all these measures in place, the rigour and trustworthiness of the qualitative component of the study were greatly improved. Using the qualitative methods and analyses, including IDIs and FGDs, we were able to get in-depth information about the challenges and experiences of SSA migrants in accessing and utilization of the healthcare services in Norway. We were able to address our research questions as to the reason why SSA migrants have limited access and use of healthcare services. Not all subgroups of national and ethnic SSA communities were represented by the sample, but there was substantial diversity among respondents and their country of origin.

## **5.5 Strengths and limitations**

The research study had some strengths and limitations. To our knowledge, this is the first study that describes the patterns, perceptions, and experiences of the SSA migrants separately related to access and use of the Norwegian healthcare system, without combining data with other migrant groups. For the quantitative study, using the register data with nationwide coverage is the main strength in the study, because the data gives us enough numbers for adjusting and categorization of the variables and it minimalizes self-reported bias. For the qualitative aspect, the findings of the research methods point in the same direction, indicating that a saturation point was reached and also showing a strong indicator of the validity and reliability of our findings. Another major strength of the qualitative component of this study lies in the study site. Working in Oslo gave us the possibility to have diverse research participants with different social backgrounds, and from different countries in the SSA region. In addition, the background of the interviewer as an African migrant and as a woman together with the one-to-one interviews encouraged trust, more honest responses. Some participants may avoid complaining about

healthcare professionals and the government in front of the researcher; nevertheless, the impact of this was quite small because a wide range of participant's experiences was covered. In addition, although the sample size in the qualitative studies was small, the insight gained in these studies could be important when considering optimizing healthcare for SSAs in general and specifically for women exposed to FGC.

The register data lack information about patients who used private clinics in PHC, although the Norwegian healthcare system is mostly public, and the GP is the gate-keeper in the PHC. Patients previously referred to a specialist or consulting only in the private clinics will look as if they have not been in contact with PHC (148). In addition, one of the merged databases, HELFO, does not include patient information for the elderly residing in the nursing homes. This may explain the elderly populations' low utilization of the PHC services in paper I. The diagnoses in this study were not extracted from electronic records but based on ICPC-codes registered for administrative claims and these claims include only one diagnosis discounting the number of diseases the patient might present (148). However, the ICPC-codes are reliable and have been recommended for group comparison in primary healthcare, although it may not be useful in estimating disease prevalence (245). One other limitation is that we were unable to interview the healthcare providers, as well as the men or family members of women exposed to FGC. In addition, women known to be circumcised were asked to recruit other women that were exposed to FGC. This was to overcome the challenges of recruitment, especially as this group of women is hard to reach. Hence, some groups of women from the same country of origin were over-represented; thus the possibility of selection bias cannot be ruled out in the study that explores the experiences of women exposed to FGC.

## 6. CONCLUSIONS AND RECOMMENDATIONS

### 6.1 Conclusions

Barriers to access and utilization of healthcare services may not only be a concern to the healthcare system and policymakers in Norway, but they also have a physical and psychological impact on healthcare service users. Access and use of healthcare services are influenced by certain factors like gender, age, racial discrimination, and socio-cultural and environmental challenges. The use of healthcare services is not only different among the host population but also within and between migrant groups in Norway. It is, therefore, important to understand SSA migrant's patterns, perceptions, and factors influencing their use of healthcare services. The findings suggest that based on country of origin, SSA migrants use PHC differently. Specifically, the health needs of SSA are not adequately addressed by the Norwegian healthcare system. We document that healthcare-seeking among SSA migrants is affected in different ways because they face barriers to healthcare-seeking when in and out of the healthcare system. Apart from the challenges and experiences at the patient and family level, we specifically observed that the healthcare system and healthcare services in Africa are notably different from that of Norway, and SSA migrants do not have the necessary information about how to access and use the healthcare system and health services in Norway. However, when SSA migrants finally receive healthcare services, they perceived discrimination or racism discouraging them or demotivating them from using it in the future. This does not only reduce their ability to engage in healthcare and trust the healthcare system, but it also affects their perspectives.

Finally, Norway has established national health policies and procedures to achieve specific healthcare goals. Yet, the ability to access and use the healthcare services among its residents remains challenging, especially among SSA migrants. So, it is therefore still necessary to have an explicit goal for equity in healthcare in Norway. It is required that legislative, social, and educational measures are put in place for proper intervention, so to enhance migrant's ability to access and use the healthcare system. Interventions and policies to improve access to healthcare and address inequalities in healthcare should take into consideration the healthcare effect of racial discrimination, to attain more effective Universal Health Coverage.

## 6.2 Recommendations

Research on access to healthcare among SSA migrants is rare, and it has been argued in other countries that the lack of research on issues to do with SSA health leads to serious health outcomes and ill-health. Issues surrounding the health and healthcare of SSA migrants in Norway should be prioritized. Barriers to accessing and utilization of healthcare services must be put into the context of issues facing SSA migrants as they adapt to their host communities.

### *1) Need for data*

- Developing appropriate data collection methods for SSA migrants can help determine their healthcare needs. In general, further research is necessary to determine how to understand the healthcare needs of subgroups within Africa migrants, as Africans as a whole are diverse and cannot be studied as a single entity.
- Conducting focus group interviews with faith-based organizations and ethnic-based organization members can provide more insight into the specific healthcare needs of registered members. It can also serve as a mechanism to follow-up with participants to obtain detailed answers regarding future research study questions.

### *2) On ensuring and improving SSA migrants' access and use of healthcare services*

- Increasing access to Norwegian training programs can improve language proficiency and reduce perceived feelings of alienation. Confidence in Norwegian speaking skills can improve understanding of medical terminology and communication between physicians and patients.
- There is a need for appropriate measures to be put in place to address racial discrimination, to encourage positive encounters with the healthcare system. These measures should deal with racism and discrimination at different levels, including institutional, interpersonal, or internal. It is vital to confront the problem of prejudice and inequality in the healthcare system. There is a need to avoid segregation and stereotyping of “black” Africans in healthcare settings.
- There is a need for intervention or awareness-raising programmes to encourage more community and family support for FGC healthcare and FGC healthcare.
- The implementation of healthcare policy advocacy for equality in healthcare will be a step in the right direction to facilitate the utilization of healthcare services for optimal use.

### *3) On improving SSA migrants' knowledge for an appropriate decision for healthcare*

- There is a need to engage migrants at all levels of policymaking and co-creation of services for healthcare sustainability, for this may ensure the long-term health and well-being of the migrant population.
- There is a need for education and awareness-raising on the symptoms, preventive measures of mental health, and related illnesses perceived to be common among SSA migrant communities.
- Designing and implementing a community-led healthcare advocacy group can increase awareness of health issues in a culturally acceptable manner and encourage health education and awareness in SSA languages.

### *4) Policymaking and Capacity building*

- Training and recruiting healthcare professionals with migrant backgrounds for a culturally diversified healthcare setting will be valued among the SSA migrants.
- Social services and the police must ensure that home visits are only conducted once a reasonable risk has been identified.
- Policymakers should be informed about racial discrimination and cultural differences, so that it might be given consideration when forming policy, to reach an explicit goal of equity in healthcare in Norway.
- It is of utmost importance for psychological health counselling and sexual health counselling services specifically for FGC be made available. The policy emphasis on de-infibulation, but not for other healthcare services to alleviate mental health issues and counselling. Besides the competence of healthcare providers in de-infibulation, the availability of healthcare services is necessary and should be an important aspect of healthcare provision for those who have been exposed to FGC, especially in the area of mental health. This is because there is an increased risk of various psychological disorders for both children, adult and family to those subjected to FGC.
- It will be essential to include cultural competence and cultural awareness in the healthcare curricula.

### **6.3 Future research**

As demonstrated in the literature discussing access and utilization of healthcare services and African migrants, limited data exist on the pattern and experiences of SSA migrants in host countries. Based on the study findings, measures to address the issues raised should be prioritized for further examination.

- Future research should further the understanding of factors that hinder healthcare, guiding policy development and identifying areas for improvement.
- More qualitative research should attempt to explore how migrants understand their health and health norms, including when they should access healthcare and what type of care to seek.
- Future research could explore the relationship between the factors that the authors have identified and the care provider's perspectives, to further identify areas for improvement.
- Further research could explore an intervention of changing healthcare providers' beliefs on care delivery to "black" African migrants.
- An in-depth analysis could determine the role of male partners in women's uptake of healthcare for FGC, and strategies to improve male partner's involvement in FGC healthcare. This study could involve healthcare providers, women, male partners, and immediate family members as leading participants. The design of the study could be such that interviews should be held with the women alone, care providers alone, male partners alone, family members alone and then later together with their partners. This could identify areas for improvement and intervention to strengthen and encourage male partners and family involvement of women's healthcare for FGC and women's involvement in decision-making for healthcare.

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## APPENDICES

### Appendix I: Supplementary results Supplemental Table Paper I

*Logistic regression of migrants' use of primary healthcare services by sex, age groups, employment and, length of stay*

	Use of General practitioner				Use of Emergency room			
	Somalia OR (95% CI)	Ethiopia OR (95% CI)	Eritrea OR (95% CI)	Gambia OR (95%CI)	Somalia OR (95% CI)	Ethiopia OR (95% CI)	Eritrea OR (95% CI)	Gambia OR (95% CI)
<b>Sex</b>								
Men	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
Women	1.56 (1.47- 1.64)	1.52 (1.36- 1.70)	1.71 (1.51- 1.93)	1.49 (1.23- 1.81)	1.30 (1.21- 1.39)	1.23 (1.06- 1.42)	1.27 (1.05- 1.54)	1.27 (0.98- 1.64)
<b>Age groups (years)</b>								
0-14	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
15-44	1.37 (1.29- 1.46)	1.00 (0.87- 1.15)	0.92 (0.79- 1.07)	1.15 (0.91- 1.46)	0.94 (0.87- 1.02)	0.71 (0.59- 0.86)	0.63 (0.49- 0.80)	1.10 (0.79- 1.53)
45-64	2.06 (1.83- 2.32)	1.27 (1.02- 1.59)	1.51 (1.21- 1.89)	2.15 (1.54- 3.01)	0.90 (0.77- 1.04)	0.58 (0.42- 0.79)	0.70 (0.50- 0.79)	1.10 (0.70- 1.74)
>65	2.00 (1.49- 2.70)	3.66 (1.06-12.60)	1.31 (0.68-2.52)	-	1.09 (0.77- 1.54)	0.49 (0.11- 2.15)	1.23 (0.50- 2.98)	-
<b>Length of stay (years)</b>								
0-6	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
>6	0.60 (0.57- 0.64)	1.00 (0.89- 1.25)	1.19 (1.04- 1.35)	0.77 (0.61- 0.97)	0.85 (0.79- 0.91)	0.87 (0.75- 1.02)	1.02 (0.83- 1.24)	0.55 (0.41-0.74)
<b>Employed immigrants</b>	1.25 (1.21- 1.30)	1.43 (1.29- 1.59)	1.44 (1.29- 1.61)	1.36 (1.17- 1.58)	1.09 (1.05- 1.14)	1.12 (0.99- 1.26)	1.29 (1.12- 1.49)	1.09 (0.91- 1.30)

## ***Additional information in access to Norwegian healthcare***

### **Geographical access**

Geographical accessibility refers to the physical location of healthcare services, climate and a person's ability to receive care at that location. Geographic access to a specialist and a lack of family physicians in their neighbourhood were perceived as critical barriers to receiving care. Accessing primary care in other neighbourhoods appears to be difficult for recent and senior migrants who rely heavily on public transportation. Family physicians located in more distant neighbourhoods were difficult to find. The struggles when trying to locate a hospital when referred for specialist care caused a lot of frustration. Unfamiliarity with map reading to trace directions to the clinics and specialist hospitals further aggravated SSA immigrant's challenges. Map reading was mentioned as something SSA migrants were unfamiliar with, as far back in their home countries. Seniors mentioned of having limited mobility, and the fear of falling discouraged and prevented them from traveling to distant areas to consult with a specialist. This was more mostly common during the winters.

### **Lack of continuity of care**

Some participants felt that the physicians failed to follow up on them as affirmed. Newly delivered mothers expressed frustration with the physicians and the lack of continuity of care, especially those who had the baby through C-section. They worried that they lacked a midwife during the entire pregnancy and revealed that they needed a midwife who would take on the responsibility to follow them up at home for childcare training and procedures. They expressed that, in contrast to their country where women attend maternity clinics for pre and post-natal information, in Norway, they lack information and knowledge on caring for new babies and breastfeeding. Thus, they sought help from their mothers in Africa or from friends and relatives in Norway. They equally complained that they were confused and did not know what to do when their babies were sick, especially as they were not informed by the health system about childcare. Despite appreciating the government for the free pregnancy check-ups and the continuity of follow up by the doctors during the entire pregnancy, they felt disappointed that they were abandoned after having had their babies. Some even went as far in comparing Norway with other European countries, where midwives are assigned to newly delivered mothers to assist them for the first weeks after birth and to each mother on care on new babies. They expressed that they would like to have a midwife throughout their pregnancy and after delivery to assist and educate them on childcare.

## **Appendix II: Data collection tools: Interview and Focus Group Discussion Guides**

### **Key issues explored during FGDs**

1. The perception of the general health, the common health problems and how it is reported for healthcare
2. Experiences and challenges in visiting the general practitioner, emergency room, other healthcare services
3. Reflection on the barriers to accessing the healthcare system and experiences navigating the healthcare system.
4. The issues that make it difficult to access healthcare (e.g. language)
5. The factors that make it easier to seek healthcare
6. The factors that make it difficult to seek healthcare
7. Beliefs in the care (e.g. advice, prescription) offered by the healthcare workers at the health facilities
8. Awareness of healthcare services
9. Access to health information and the general perception of the Norwegian healthcare system

## **Interview guide for access and use of healthcare services (for SSA migrants)**

Date of interview

Participants name: N°:

Hour:

Duration:

Language of the interview:

Place:

Area/address:

### **Socio-demographic characteristics**

Age: Home: Contact:

Religion: Education: Marital status: Number of children: Profession:

Country of origin:

### **Perception of general health and decision to seek help**

- What is the perception of your general health? (researcher wants to ascertain the presence of ill-health)
- How do you feel when you have these health problems/ concerns? What do you do when you have these health problems/ concerns? Do you take care of them at home/ by yourself? Or do you seek help somewhere else?
- Why did you need help? When did you decide to seek help? How did you report them for healthcare?
- Do you know where to seek help for your particular health problems?
- Did you decide to seek help by yourself or did someone else decide it?
- Where have you been first with the health problems?

### **Barriers to access to healthcare**

- When was the last time you visited your GP? Probe: Why did you visit him/her?
- Who attended to you on the day of the visit?
- Did you face any challenges, or had some difficulties in seeking healthcare for health problems?
- What are the issues that make it difficult for you to access healthcare? What were your experiences with healthcare providers? How did you get about the difficulties? (Probe:

Can you tell me more about it? (This was to allow the participants to go in-depth into their challenges if any)

- Did you face a problem or had some difficulties navigating the healthcare system? Can you tell me more about that? (Probe: Researchers' intention was to allow participants to reflect on the barriers to accessing the healthcare system and navigating the healthcare system).
- What are your experiences and challenges in visiting the general practitioner, emergency room, and other healthcare services for your health concerns? Please, can you tell me more about it?
- Can you tell me other factors that make it difficult in seeking healthcare for your health problems?
- Did you have some problems/ experiences that affected you during pregnancy and childbirth? What problems? Can you please tell me more about it? What were your experiences during childbirth?
- What are your beliefs in the care (e.g. advice, support) offered by the healthcare workers at the health facilities?
- What are other worries someone has caused you not to seek help?

### **Perception of healthcare**

- What is it that you liked about the care?
- What didn't you like?
- What can be done to improve care? [if you have to add/remove, what would you want to add/remove /modify?]
- Would you say it was easy for you to communicate with the doctor?
- Reasons for your answer.....
- Did the healthcare system meet your needs?
- Is the Norwegian healthcare different from that at home?
- Are you expecting more or less of what you were getting back at home?

### **Health information**

- Which healthcare service do you visit when you are sick?
- Are you aware of healthcare services that offer care for the kind of your health problems?
- Did you require health information about the health condition?
- How do you access health information pertaining to your health concerns?
- How/where did you get the health information?
- Why didn't you get information or advice about the health problem?
- Do you have sufficient information to manage your health problems?
- What are the other healthcare services you know that offered care for your health needs?
- How did you get to know the healthcare services?
- Do you know the kind of services they offer?

## **Guide for FGC healthcare (for women)**

### **Perception of general health and decision to seek help for FGC**

- What is the perception of your general health? (researcher wants to ascertain the presence of ill-health)
- Do you have any health issues caused by female genital cutting? Or do you have some health issues which are caused by female genital cutting?
- What are your common health problems that are caused by female genital cutting?
- How do you feel when you have these health problems/ concerns? What do you do when you have these health problems/ concerns? Do you take care of them at home/ by yourself? Or do you seek help somewhere else?
- Why did you need help? When did you decide to seek help? How did you report them for healthcare?
- Do you know where to seek help for your particular health problems?
- Did you decide to seek help by yourself or did someone else decide it?
- Where have you been first with the health problems?

### **Barriers to access to healthcare for female genital cutting**

- Would you ever consult a doctor or other healthcare workers for female genital cutting health needs? Why?
- Have you been to the hospital or any other healthcare services for your health problems?
- Who attended to you on the day of the visit?
- Did you face any challenges, or had some difficulties in seeking healthcare for the health problems caused by female genital cutting?
- What are the issues (relating to female genital cutting) that make it difficult for you to access healthcare? What were your experiences with healthcare providers? How did you get about the difficulties? (Probe: Can you tell me more about it? (This was to allow the women to go in-depth into their challenges if any)
- Did you face a problem or had some difficulties navigating the healthcare system? Can you tell me more about that? (Probe: Researchers' intention was to allow the women to reflect on the barriers to accessing the healthcare system and navigating the healthcare system).
- What are your experiences and challenges in visiting the general practitioner, emergency room, and other healthcare services for your health concerns caused by female genital mutilation? Please, can you tell me more about it?
- Can you tell me other factors that make it difficult in seeking healthcare for female genital cutting?
- Did you have some problems during pregnancy and childbirth caused by female genital cutting? What problems? Can you please tell me more about it? What were your experiences during childbirth?
- What are your beliefs in the care (e.g. advice, support) offered by the healthcare workers at the health facilities?

- What are other worries someone has caused you, not to seek help?

#### **Family involvement in healthcare**

- What is the level of approval/disapproval within your family to seek care for female genital cutting?
- Do you think your family would approve you seeking help for your health needs caused by female genital cutting?
- Who accompanied you to see the care professionals? Was your husband with you or any member of your family? What were your experiences in healthcare settings? Can you tell me more about it?

#### **Knowledge of FGC health consequences**

- Do you know or have an idea of the health consequences of female genital cutting?
- Do you think there is a relationship between female genital mutilation and psychological issues? Why?
- Do you think there is a relationship between female genital mutilation and sexual issues? Why?
- How common do you have sexual health problems caused by female genital cutting?
- How easy would you feel about consulting on sexual health issues?
- What are other worries FGC has caused you?

#### **The general perception of the Norwegian healthcare system**

- Does the Norwegian health system meet your health needs?
- What would you have changed in the Norwegian healthcare system?
- What do you like about the Norwegian health system? Or what are the factors that make you want to seek care for your health problems?



## Discussion guidelines about perceptions in healthcare and access to healthcare

### Information of discussant

Group	Interviewee's country of origin	Language use in discussion	Gender and numbers of participants	Interviewer's notes

Main theme	Sub-theme
Perception of general health/ well-being	<ul style="list-style-type: none"> <li>• What are your common health problems and how do you report them for healthcare?</li> <li>• What are your health concerns?</li> </ul>
Perception of the Norwegian healthcare system	<ul style="list-style-type: none"> <li>• Does the Norwegian health system meet your health needs?</li> <li>• What would you have changed in the Norwegian healthcare system?</li> <li>• What do you like about the Norwegian health system?</li> </ul>
Enablers in seeking healthcare	<ul style="list-style-type: none"> <li>• What are the factors that make it easier for you to seek healthcare?</li> <li>• What are the factors that make it difficult to seek healthcare?</li> </ul>
Barriers to access to healthcare	<ul style="list-style-type: none"> <li>• What are the issues that make it difficult for you to access healthcare (e.g. language)?</li> <li>• What are your beliefs in the care (e.g. advice, prescription) offered by the healthcare workers at the healthcare facilities?</li> </ul>

## **Appendix III: Information Leaflet and Informed Consent Documentation**

### **Request for participation in the research project**

#### **Access and Utilization of Norwegian Healthcare Services among sub-Saharan African Migrants**

##### **Background and Purpose**

This is a request for you to participate in a research study that intends to examine the factors that influence sub-Saharan Africans ability to access and use the Norwegian healthcare system. This research study is part of the research project “Access and utilization of healthcare services among immigrants from sub-Saharan African (SSA) in Norway,” in the framework of my Ph.D. at the University of Oslo (UiO). The purpose of this research study is to gather indicators both obstructing and enabling access and utilization of healthcare services. There is the possibility of these indicators to predispose immigrants to unmet health needs; delays in receiving appropriate care; inability to get preventive services and hospitalizations that could have been prevented. The knowledge about the enablers and barriers to access to healthcare experienced among migrants is important in generating solutions to healthcare access and ultimately addressing their health needs. You have been contacted because you migrated from Africa or because your parents came from Africa.

##### **What does participation in the project imply?**

Your participation in this study will consist of an interview or focus group discussion, lasting approximately one hour. Before you decide, you need to understand the information about this study and what it involves. Please, take the time to read the following information or get the information explained to you. Listen carefully and feel free to ask if there is anything that you do not understand. Ask and it will be explained to you until you are satisfied. If you make up your mind to join in the study, you will need to sign or thumbprint a consent form saying you agree to be in the study. You will be given a copy. Please, note that it is your choice to take part and you can stop taking part in this study at any time if you wish.

##### **What will happen to the information about you?**

The interview will be audio recorded. The data that are registered about you will be used in accordance with the purpose of the study as described in the section above. All personal data as your age, name, and country of origin will be treated confidentially. All the data will be processed without the name, personal number or other recognizable types of information. It will not be possible to identify you in the scientific articles. The name of the research participant will be anonymized.

Data will be stored in a computer with password access. Only authorized project personnel will have access to the data. The project is scheduled for completion by 2019. The accumulated information will be deleted 3 years after completion of my Ph.D. study programme.

**Voluntary participation**

Participation in this study is voluntary. You can withdraw your consent to participate in the study at any time and without stating any particular reason. This will not have any consequences on you. If you wish to participate, sign the declaration of consent at the end of this form. If you agree to participate at this time, you may, later on, withdraw your consent without you being affected in any way.

If you wish to participate in the study, you are entitled to have access to what information is registered about you. You are further entitled to correct any mistake in the information we have registered.

If you later wish to withdraw your consent from the study, you are entitled to demand that the collected data are deleted, unless the data have already been incorporated in analyses or used in scientific publications.

**Other relevant information**

For any additional information about the study, or if you have questions, queries or concerns about the study, you can contact Vivian Mbanya on +4796996022. You can also contact Bernadette Kumar on +4799640321

The study has been notified to the Data Protection Official for Research, NSD - Norwegian Centre for Research Data (53374/3/AMS) and ethical clearance has been obtained from REK-Regionale Komiteer for Medisinsk og Helsefaglig Forshningsetikk (2016/799/REK vest).

# Information and consent form

Hi, my name is .....

We are working for the project *Migrants' access to and utilization of health services*. This project is carried out by the Institute of Health and Society, Faculty of Medicine, University of Oslo. The purpose of the project is to investigate the enablers and barriers among sub-Saharan Africans in Norway in access to the Norwegian healthcare system. The results of this study will help in the development of programs that will facilitate and improve access to and utilization of primary healthcare services. The Regional Committees for Medical and Health Research Ethics has approved this project. **The method in the project is an interview, individual and/or in a focus group.**

By participating in this project you can help us understand the attitudes, perceptions, and experiences among sub-Saharan African migrants with the Norwegian healthcare services and how to better attain equity in the provision of healthcare.

Please feel free to give open and correct information. Any information you give us will be treated confidentially and you can withdraw from the project at any time without giving a reason.

We will write an article where all information will be anonymized so that no one can know who has answered the questions. You can choose where and when we can talk.

Are you willing to participate in this project and be interviewed?

Yes

No

Do you prefer to be interviewed individually or to participate in a focus group?

## Informations- og samtykkebrev

Hei, jeg heter .....

Vi jobber for prosjektet *Migranternes tilgang til og bruk av helsetjenester*. Dette prosjektet gjennomføres ved Institutt for helse og samfunn, Det medisinske fakultet, Universitetet i Oslo.

Formålet med prosjektet er å utforske hva som fremmer eller hindrer tilgang til det norske helsevesen blant sub-Sahara afrikanere i Norge. Resultater fra dette prosjekt vil bidra til utviklingen av programmer som forenkler og forbedrer tilgang til og bruk av helsetjenesten. Regional komité for etikk og medisin har godkjent prosjektet. **Metoden som vil bli brukt i prosjektet er intervju, individuelt eller i fokusgruppe.**

Ved å delta i dette prosjektet kan du hjelpe oss å forstå holdninger, oppfatninger og erfaringer blant sub-Sahara afrikanere i å få helsehjelp i Norge og hvordan man bedre kan oppnå likeverdighet i helsehjelp.

Føl deg fri til å svare åpent og ærlig på spørsmålene. Du kan avslutte intervjuet når som helst uten å gi noen grunn. All informasjon du gir oss vil bli behandlet konfidensielt.

Vi skal skrive en artikkel og all informasjon vil bli anonymisert så ingen kan vite hvem som har svart. Du kan velge når og hvor vi kan snakke sammen.

Vil du delta i prosjektet og bli intervjuet?

Ja

Nei

Ønsker du å bli intervjuet individuelt eller være med i fokusgruppediskusjon?

## **Appendix IV: Regulatory/Ethical Approvals**

## Appendix IV: Regulatory/ Ethics Approvals



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Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK vest	Camilla Gjerstad	55978499	05.09.2016	2016/799/REK vest
			Deres dato:	
			25.07.2016	

Vår referanse må oppgis ved alle henvendelser

Bernadette Nirmal Kumar  
Nasjonalt kompetanseenhet for minoritetshelse (NAKMI)  
Ullevål sykehus

### 2016/799 Tilgang til og bruk av helsetjenester blant innvandrere fra Afrika sør for Sahara i Norge

**Ansvarlig institusjon:** Universitetet i Oslo  
**Prosjektleder:** Bernadette Nirmal Kumar

Vi viser til din tilbakemelding 25.07.2016 samt epost fra medarbeider Vivian N. Mbanya 11.08.2016. Tilbakemelding/epost ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK vest) i møtet 18.08.2016. Vurderingen er gjort med hjemmel i helsepersonelloven § 29.

#### Prosjektomtale

*Studien vil undersøke hvordan innvandrere fra Afrika sør for Sahara bruker primærhelsetjenester i Norge. Det søkes om å benytte opplysninger fra en forskningsfil i prosjektet «2009/1747 Innvandrerhelse i Norge» der data er koblet fra ulike registre. REK har innvilget dispensasjon fra taushetsplikt i dette prosjektet.*

#### Tidligere saksbehandling

I brev av 22.06.16 ber REK vest om tilbakemelding på følgende:

- Prosjektleder må angi hvilke variabler og registre som inngår i datafilen, og forklare hvorfor de ulike variablene er relevante og nødvendige for å oppnå forskningsformålet.
- Prosjektleder må begrunne hvorfor det søkes om fritak fra samtykke fra personene som opplysningene gjelder.
- Dersom REK innvilger dispensasjon, må prosjektleder legge opp til at dispensasjonen er tidsbegrenset og at data må slettes eller anonymiseres ved prosjektslutt, dvs. 31.01.19.

#### Tilbakemelding

Det fremgår av tilbakemeldingen at kun tre variable fra forskningsfilen i prosjekt «2009/1747 Innvandrerhelse i Norge» vil bli benyttet i den nye studien. De tre variablene vil være: «Fødeland», «Antall besøk hos allmennlege» og «Antall besøk på legevakt.» Variablene vil bli utlevert til studenten fra prosjektleder Diaz i prosjektet 2009/1747, uten at studenten får tilgang til den opprinnelige filen eller til koblingsnøkkel i studien. Diaz er også medarbeider i den nye studien.

Komiteen har i første behandling av saken definert studien som helsetjenesteforskning, som faller utenfor virkeområdet til helseforskningsloven (§ 2 og 4a). REK vil derfor bare ta stilling til dispensasjonsspørsmålet (helsepersonelloven § 29) når det gjelder gjenbruk av omsøkte data fra forskningsfilen fra prosjektet 2009/1747. Prosjektleder er enig med REK om at resten av studien (inkludert den kvalitative delen) må bli vurdert av personvernombudet.

---

**Besøksadresse:**  
Armauer Hansens Hus (AHH),  
Tverrløy Nord, 2 etasje, Rom  
281, Haukelandsveien 28

**Telefon:** 55975000  
**E-post:** rek-vest@uib.no  
**Web:** <http://helseforskning.etikkom.no/>

All post og e-post som inngår i saksbehandlingen, bes adressert til REK vest og ikke til enkelte personer

Kindly address all mail and e-mails to the Regional Ethics Committee, REK vest, not to individual staff

*Vurdering av tilbakemeldingen*

Tilbakemeldingen besvarer komiteens spørsmål og merknader. Det er kun snakk om gjenbruk av tre variabler fra forskningsfilen. Variablene anses som lite sensitive og utleveres til studien uten at studenten får tilgang til filen eller koblingsnøkkelen. Rasjonale for studien er redegjort for, og opplysningene om fødeland samt antall besøk hos fastlege og legevakt er relevante for å besvare forskningsspørsmålet i studien. REK vest har derfor ingen innvendinger til at de omsøkte variablene benyttes i studien.

REK vest legger til grunn at studiedata/koblingsnøkkel vil bli slettet eller anonymisert senest ved prosjektslutt, dvs. 31.01.19.

**Vedtak**

*REK vest godkjenner bruk av opplysningene i prosjektet i samsvar med forelagt søknad og tilbakemelding. Vurderingen er gjort med hjemmel i helsepersonelloven § 29.*

*Klageadgang*

Du kan klage på komiteens vedtak, jf. forvaltningsloven § 28 flg. Klagen sendes til REK vest. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK vest, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Med vennlig hilsen

Ansgar Berg  
Prof. Dr.med  
Komitéleder

Camilla Gjerstad  
kontorsjef

**Kopi til:** postmottak@admin.uio.no



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<b>Region:</b>	<b>Saksbehandler:</b>	<b>Telefon:</b>	<b>Vår dato:</b>	<b>Vår referanse:</b>
REK vest	Camilla Gjerstad	55978499	31.05.2019	2016/799/REK vest
			<b>Deres dato:</b>	
			29.05.2019	

Vår referanse må oppgis ved alle henvendelser

Bernadette N Kumar  
Enhet for Migrasjonshelse - Område Helsetjeneste

### **2016/799 Tilgang til og bruk av helsetjenester blant innvandrere fra Afrika sør for Sahara i Norge**

**Forskningsansvarlig:** Universitetet i Oslo  
**Prosjektleder:** Bernadette Nirmal Kumar

Vi viser til søknad om prosjektendring datert 29.05.2019 for ovennevnte forskningsprosjekt. Søknaden er behandlet av REK vest ved sekretariatet på fullmakt, med hjemmel i helseforskningsloven § 11.

#### *Prosjektendring*

Det søkes om endring av prosjektslutt. Ny prosjektslutt vil være 30.04.2020. Det er publisert to artikler og tredje er innsendt. Arbeidet har blitt forsinket. Det søkes nå om forlengelse for å fullføre det som allerede er vurdert og godkjent av REK.

#### *Vurdering*

REK vest har vurdert endringsøknaden og har ingen merknader.

#### **Vedtak**

*REK vest godkjenner prosjektendringen i samsvar med søknaden, med hjemmel i helseforskningsloven § 11.*

#### *Klageadgang*

Du kan klage på komiteens vedtak, jf. helseforskningsloven § 10 og forvaltningsloven § 28 flg. Klagen sendes til REK vest. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK vest, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Med vennlig hilsen

Camilla Gjerstad  
rådgiver

**Kopi til:** [postmottak@uio.no](mailto:postmottak@uio.no)

Bernadette Kumar  
Institutt for helse og samfunn Universitetet i Oslo  
Postboks 1130 Blindern  
0318 OSLO

Vår dato: 18.05.2017

Vår ref: 53374 / 3 / AMS

Deres dato:

Deres ref:

## TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 01.03.2017. Meldingen gjelder prosjektet:

53374	<i>Access and Utilization of Healthcare services among sub-Saharan African Immigrants in Norway</i>
Behandlingsansvarlig	Universitetet i Oslo, ved institusjonens øverste leder
Daglig ansvarlig	Bernadette Kumar
Student	Vivian Mbanya

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilrår at prosjektet gjennomføres.

Personvernombudets tilråding forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, ombudets kommentarer samt personopplysningsloven og helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, [http://www.nsd.uib.no/personvernombud/meld\\_prosjekt/meld\\_endringer.html](http://www.nsd.uib.no/personvernombud/meld_prosjekt/meld_endringer.html). Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, <http://pvo.nsd.no/prosjekt>.

Personvernombudet vil ved prosjektets avslutning, 31.05.2019, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

Kjersti Haugstvedt

Anne-Mette Somby

Kontaktperson: Anne-Mette Somby tlf: 55 58 24 10

*Dokumentet er elektronisk produsert og godkjent ved NSDs rutiner for elektronisk godkjenning.*

[English text below](#)

## BEKREFTELSE PÅ ENDRING

Vi viser til statusmelding mottatt: 07.10.2019.

Personvernombudet har nå registrert ny dato for prosjektslutt 31.12.2019.

Det legges til grunn at prosjektopplegget for øvrig er uendret.  
Ved ny prosjektslutt vil vi rette en ny statushenvendelse.

Hvis det blir aktuelt med ytterligere forlengelse, gjør vi oppmerksom på at utvalget vanligvis må informeres ved forlengelse på mer enn ett år utover det de tidligere har blitt informert om.

Ta gjerne kontakt dersom du har spørsmål.

Vennlig hilsen,  
Håkon Jørgen Tranvåg - Tlf: 55 58 20 43  
[Hakon.Tranvag@nsd.no](mailto:Hakon.Tranvag@nsd.no)  
Personvernombudet for forskning,  
NSD – Norsk senter for forskningsdata AS  
Tlf. direkte: (+47) 55 58 21 17 (tast 1)

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## AFFIRMATION

Referring to status report received 07.10.2019.

The Data Protection Official has registered that the project period has been extended until 31.12.2019.

We presuppose that the project otherwise remains unchanged.

Please note that in case of further extensions, the data subjects should usually receive new information if the total extension exceeds a year beyond what they previously have received information about.

Do not hesitate to contact us if you have any questions.

Best regards,  
Håkon Jørgen Tranvåg - Phone number: 55 58 20 43  
[Hakon.Tranvag@nsd.no](mailto:Hakon.Tranvag@nsd.no)  
the Data Protection Official for Research,  
Norwegian Centre for Research Data  
Phone number (switchboard): (+47) 55 58 21 17 (enter 1)



# PAPER I



RESEARCH ARTICLE

Open Access



# Differences in primary health care use among sub-Saharan African immigrants in Norway: a register-based study

Esperanza Diaz<sup>1,2</sup>, Vivian N. Mbanya<sup>3\*</sup>, Abdi A. Gele<sup>2,4</sup> and Bernadette Kumar<sup>2,3</sup>

## Abstract

**Background:** Immigrants' utilization of primary health care (PHC) services differs from that of the host populations. However, immigrants are often classified in broad groups by continent of origin, and the heterogeneity within the same continent may hide variation in use among immigrant groups at a national level. Differences in utilization of PHC between sub-Saharan African immigrants have not received much attention.

**Methods:** Registry-based study using merged data from the National Population Register and the Norwegian Health Economics Administration. African immigrants and their descendants registered in Norway in 2008 (36,366 persons) were included in this study. Using  $\chi^2$  test and logistic regression models, we assessed the differences in the use of PHC, including general practitioner (GP) and emergency room (ER) services, and the distribution of morbidity burden for immigrants from Somalia, Ethiopia, Eritrea, and Gambia. For the analyses, we used the number of visits and medical diagnoses from each consultation registered by the physician.

**Result:** Among the total studied population, 66.1% visited PHC within 1 year. The diagnoses registered were similar for all four immigrants groups, regardless of country of origin. Compared to immigrants from Somalia, the age and sex adjusted odds ratios (OR) for use of GP were significantly lower for Ethiopians (OR 0.91; 0.86–0.97), Eritreans (OR 0.85; 0.79–0.91), and Gambians (OR 0.88; 0.80–0.97). Similarly, we also observed lower use of ER among Ethiopians (OR 0.88; 0.81–0.95), Eritreans (OR 0.56; 0.51–0.62) and Gambians (OR 0.81; 0.71–0.92). However, immigrants from Somalia reduced their use of PHC with longer duration of stay in Norway. Differences between groups persisted after further adjustment for employment status.

**Conclusion:** Despite the similarities in diagnoses among the sub-Saharan African immigrant groups in Norway, their use of PHC services differs by country of origin and length of stay. It is important to assess the reasons for the differences in these groups to identify barriers and facilitators to access to healthcare for future interventions.

**Keywords:** Emigrants and immigrants, Sub-Saharan Africa, Norway, Primary health care

## Background

Migration to Europe has increased substantially in the twenty-first century because of economic, political and social factors. In 2010, an estimated 72.6 million migrants lived in the European region, with migrants constituting 8.7% of the total European population [1]. Migrants represent 13.4% of the total population in Norway in 2016, with an additional 2.9% Norwegian-born to immigrant parents.

The influx of African migrants to Norway is on the rise, with African-born immigrant population representing 2.2% of the Norwegian population [2]. Somalis are the fourth largest migrant group in Norway, with a population of 41,453 immigrants, while immigrants from Eritrea (23,618) and Ethiopia (10,387) are among the fastest growing migrant groups in Norway. Ghana (2702), Nigeria (2348) and Gambia (1762) are also countries with an increasing immigrant population in Norway [3].

Providing equitable health care services to immigrants remains a challenge to the health care systems. In Norway, the National Health Services are decentralized,

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Full list of author information is available at the end of the article



with municipalities providing primary health care (PHC). The Norwegian General Practitioners (GP) are the backbone of the PHC and Emergency rooms (ER) are also staffed by GPs out of hours. All immigrants with legal residence permit and asylum seekers are entitled to the same health services as Norwegian-born [4].

The extent of use of GP and ER among immigrants may vary depending on their health care needs, health care seeking behaviours, the organization of health care in their home country, practical barriers to access in the host country, health literacy, migrant's status, education level and other socioeconomic factors [5–13]. Diverse combinations of these push and pull-factors might influence the use of health care services by immigrants in Norway in different ways.

Immigrants from Africa are often considered a single group because of their geographical location, similar lifestyles, and health problems. Furthermore, in Norway, immigrants from Africa are often grouped with Asian and Latin Americans into a single immigrant population [14–17]. However, the relationship between cultural/social norms and health care utilization patterns seem to differ between nations [18–20]. Prior to migration, sub-Saharan African (SSA) immigrants lived in countries with systems of more self-referral, higher user fees and generally low utilization of health services [21]. Nevertheless, variations in cultural and social norms, prevalence of disease, genetic admixture and health system access in their countries of origin have been described [22–25]. Also, although most immigrants from these countries are refugees, they have different educational and socioeconomic profiles [26]. Thus, once in Norway, their response to a different lifestyle and different health system might vary through different strategies to cope with communication problems, cultural differences, difficulties in their interaction with health systems and providers, and other challenges [10, 27–29].

For these reasons, the heterogeneity among immigrants from Africa should be addressed in order to detect eventual differences among groups and to be able to provide adequate responses to the differing health needs. In this study we aimed to compare the patterns of morbidity burden and the use of PHC services, including GP and ER services, among four of the largest groups of immigrants from SSA countries living in Norway.

## Methods

### Setting and data source

This study includes information from two national Norwegian registers: the National Population Register (NPR) and the Norwegian Health Economics Administration Database (HELFO). These registries were linked by personal identification numbers assigned to all Norwegian

citizens and legal immigrants staying in Norway for 6 months or longer. This identification number entitles individuals to access to health care services similarly for immigrants and Norwegians.

Immigrants and their descendants from Somalia, Ethiopia, Eritrea and Gambia registered in Norway in 2008 ( $n = 36,366$  individuals), were included in the study. Other SSA immigrant populations in Norway could not be included in the study because the groups were very small. Both first generation immigrants defined as persons born abroad to both parents from abroad and persons born in Norway, with at least one parent from the four selected SSA countries (2nd generation immigrants) were included in the study. Other combinations, like adopted children for the SSA countries, although seldom, were also included in the study to capture disparities among groups.

From the NPR, we obtained socio-demographic variables, including sex, age, marital status, urban or rural settlement, personal income in Norway (in Norwegian crowns), employment status, country of origin, and length of stay in Norway. Age was categorized into four groups for some analyses and length of stay dichotomized by 6 years since registration in Norway. Reason for migration (labour, refugee, family reunification and other reasons) was available only for those who migrated to Norway after 1990.

The HELFO-database contains administrative claims for all patient contacts within the public PHC services including consultations with GPs and ER services. From this register, we obtained information on the number of visits to GPs and ER for each individual in 2008. We used information from consultations both as dichotomous 'yes or no' and as numerical variables. Each consultation claim contains at least one medical diagnosis based on the International Classification of Primary Care (ICPC-2) registered by the physician. These ICPC-2 diagnoses were grouped according to the Major Expanded Diagnostic Clusters (MEDC) of the Johns Hopkins University Adjusted Clinical Groups (ACG<sup>®</sup>) Case-Mix System [30]. The ACG methodology assigns ICPC-2 codes found in claims to one of 27 MEDCs. As broad groupings of diagnosis codes, MEDCs help to remove differences in coding behaviour between practitioners. The ACG System is validated and widely used for research purposes [31].

### Statistical analysis

Descriptive analyses were conducted for socioeconomic variables, use of PHC and MEDCs for the four selected countries. Subject characteristics are presented as means (standard deviation) or percentages for the variables of interest. We then analysed health service use and morbidity burden by age group, gender, and country of origin. Chi-square test and analyses of variance (ANOVA)



were used for categorical and continuous variables, respectively, to compare the distribution and differences among immigrants from the four countries. Last, logistic regression analyses were conducted for the outcome dichotomic variables 'use of the GP' and 'use of ER' to estimate odds ratios (OR) and 95% confidence intervals (CI) for the different countries of origin, using Somalia as a reference. Several models were conducted and results are presented for the unadjusted analyses and the two other models that better explained the use of PHC, one adjusting for age categorized in four groups and gender and the second one for gender, age categorized, and employment status. As interactions were detected between length of stay and country of origin, logistic regression analyses conducted for each of the countries separately and including the length of stay in Norway as an additional variable in the model are presented as a supplementary table. The SPSS 20.0 software package was used for statistical analyses.

## Results

### Demographic characteristic

Table 1 shows the number of subjects, the distribution of the study variables, and the frequency of use of PHC according to the immigrants' country of origin. The study population comprised of 36,366 SSA immigrants legally registered in 2008 in Norway. Women formed 47% of the studied population and children under 15 years of age were 38.1%. Most immigrants lived in urban areas. Immigrants from Somalia were youngest, the least likely to earn an income and had the highest proportion of unmarried individuals. The mean stay for SSA immigrants was 7.6 years in Norway. With the exception of the Gambian (1.0% refugees), for whom reason for migration was seldom registered, the majority of immigrants were registered as refugees and family reunification. Less than 1.0% in all the groups was labour migrants. Once living in Norway, the proportion of employed SSA immigrants was higher among Ethiopians, Eritreans, and Gambians compared to Somalis.

### Use of health care services

A total of 66.1% of all immigrant groups visited either the GP or the ER in 2008, with annual means (standard deviations) of GP and ER visits of 2.42 (3.38), and 0.24 (0.68), respectively (Table 1). The proportion of each immigrant group who used PHC services by age group is presented in Table 2. The use of GP increased with age in all the four countries. Use of GP was similar for the four countries by age group, except for young adults (15–44 years) from Somalia, who used the GP more than those from the other SSA immigrants groups. For all countries, children (0–14 years) and the elderly (over 65 years) used the ER more than the other age groups

(15–64 years). Generally, Somalis were over-represented in all age groups at the ER, while Eritreans had the lowest user rates.

In binary logistic regression analyses, immigrants from Ethiopia, Eritrea and Gambia had significantly lower odds ratios of use of both GP and the ER in 2008 compared to Somalis in unadjusted and adjusted models with the exception of unadjusted analyses of GP use for Gambia (Table 3). Effect modifications between the country of origin and length of stay were however, observed when we included the length of stay in the model (Additional file 1). After adjustment for sex, age and employment status, immigrants from Somalia and Gambia significantly reduced their use of both GP and ER services after 6 years living in Norway while those from Eritrea increased their use of GP but not of ER and Ethiopians did not change their use of PHC with length of stay.

### Diagnoses

Figure 1 represents the proportion of immigrants from each country with at least one MEDC registered in 2008. The most common diagnostic groups among SSA immigrants included musculoskeletal, general signs and symptoms, ear-nose-throat and respiratory related diagnoses. Generally, small differences in diagnoses among immigrants according to the country of origin were detected. Somali immigrants more often than Ethiopian, Eritrean, and Gambian had diagnoses related to ear-nose-throat (19.7% vs 15.7%, 14.8% and 15.0%, respectively); general signs and symptoms (17.8% vs 15.9%, 15.6% and 16.0%, respectively), and respiratory (14.0% vs 11.6%, 10.0% and 11.6%, respectively). Immigrants from Gambia had more often musculoskeletal problems (23.4% vs 20.5–21.2% of all the other groups, respectively).

## Discussion

### Summary of main findings

Our study confirms differences in the use of PHC services across the major four SSA immigrant groups in Norway. Immigrants from Somalia used the PHC services, especially ER services, more than the Ethiopian, Eritrean, and Gambian, although all had relatively similar diagnoses when in contact with the PHC.

In other European countries as well as in Norway, studies have reported differences in the use of PHC across different immigrant populations compared to natives [14, 32, 33]. Overall, our study reports lower mean number of annual visits to the GP but higher to the ER compared to what have previously been reported for immigrants from low income countries in a similar health survey comparing immigrant groups with natives in Norway [34]. As hypothesized previously, differences in the findings could be explained by

**Table 1** Characteristics of the study subjects

Variables	Overall	Somalian	Ethiopian	Eritrean	Gambian	P-value
N	36,366	24,253	5631	4483	1999	
Age distribution, %						
0–14	38.1	41.2	34.1	28.5	33.7	<0.001
15–44	52.2	50.8	56.0	56.1	49.9	<0.001
45–64	8.8	7.0	9.6	14.5	16.2	<0.001
≥ 64	0.8	0.9	0.4	0.9	0.2	<0.001
Age, mean (SD)	22.8 (16.0)	21.5 (15.8)	24.0 (15.5)	27.3 (16.7)	25.0 (16.5)	
Women, %	47.0	47.0	46.5	48.7	44.4	0.11
Urban settlement, %	83.3	81.9	86.6	82.6	92.0	<0.001
Marital status, %:						
Unmarried	64.4	65.0	63.1	63.7	61.4	<0.001
Married	24.5	23.8	27.7	27.0	19.2	<0.001
Others (divorced, separated or widow)	11.1	11.2	9.2	9.3	19.4	<0.001
Income, mean [Norwegian crownes]	75,827	53,731	126,980	118,213	104,721	<0.001
Employment status, %						
Outside work force	67.9	73.3	55.3	58.7	58.5	<0.001
Employed	26.0	19.9	40.9	38.0	35.8	<0.001
Self-employed	0.7	0.6	0.8	0.7	1.9	<0.001
Unemployed	3.3	4.0	1.9	1.7	2.4	<0.001
Social welfare beneficiaries	1.8	2.2	1.0	0.9	1.4	<0.001
Immigrants, reasons of migration, %:						
Labour	0.1	0.1	0.4	0.1	0.4	<0.001
Refugee	35.3	37.9	29.7	43.4	1.0	<0.001
Family reunification	25.1	28.8	19.7	11.5	25.6	<0.001
Others	2.2	0.9	7.5	1.5	3.4	<0.001
Reason not specified	37.3	32.3	42.7	43.5	69.6	<0.001
Length of stay in Norway, mean (SD)	7.63 (7.15)	6.61 (5.39)	8.51 (9.07)	9.33 (9.71)	13.74 (8.77)	<0.001
Immigrants background, %						
Immigrant	69.0	71.2	64.4	71.8	48.6	<0.001
Born in Norway with immigrant parent	23.3	26.3	14.2	20.4	18.7	<0.001
Born out of Norway with one parent a Norwegian	0.3	0.0	1.5	0.4	0.3	<0.001
Born in Norway with one parent a Norwegian	5.1	2.4	7.1	5.0	32.4	<0.001
Born out of Norway with both parent Norwegian	2.3	0.0	12.8	2.4	0.0	<0.001
Norwegian nationality, %	56.5	54.2	58.2	55.4	81.5	<0.001
Use of health care services, mean (SD)						
Number of consultations with GP in 2008	2.42 (3.38)	2.48 (3.41)	2.29 (3.30)	2.33 (3.45)	2.14 (3.01)	<0.001
Number of consultations at ER in 2008	0.24 (0.67)	0.27 (0.72)	0.22 (0.61)	0.14 (0.48)	0.19 (0.53)	<0.001

the pooling of heterogeneous immigrant populations in the same group in the referred study, in which immigrants were classified according to World Bank income categories. Accordingly, another study on ER use using register data from Norway from 2008 showed that immigrants from Somalia more often attended the ER compared to native Norwegians [35].

Somalis in our study used the PHC services more than other SSA immigrants; approximately 15–20% more for GP services and 15–45% more ER after adjustment for age, gender and employment status. Because of the nature of our study, we cannot explain the reasons for the differences in the use of PHC. The higher frequency of PHC use among Somalis compared to the other SSA

**Table 2** Proportion of use of primary health care services across immigrants' countries of origin by age group

	Somalia (N = 24,253)	Ethiopia (N = 5631)	Eritrea (N = 4483)	Gambia (N = 1999)	Total (N = 36,366)	P value
General practitioner, %						
Age range: 0–14	58.8	57.4	57.2	55.5	58.3	0.208
15–44	66.8	64.5	61.6	62.7	65.5	<0.001
45–64	71.1	68.1	72.3	73.1	71.4	0.293
≥65	71.8	85.0	63.4	100	71.9	0.193
Total:	63.9	62.5	61.9	62.0	63.3	0.016
Emergency room, %						
Age range: 0–14	17.8	18.4	12.5	15.0	17.3	<0.001
15–44	17.5	15.0	9.8	15.2	15.2	<0.001
45–64	15.9	11.7	10.6	13.0	13.0	0.003
≥65	18.5	10.0	14.6	0.0	17.1	0.567
Total:	17.5	15.8	10.7	14.8	16.3	<0.001

immigrant groups might be appropriate if it reflects a higher burden of disease. However, once in contact with the PHC, the distribution of the MEDCs in the four SSA groups presented more similarities than differences, suggesting other additional reasons to explain differences in use. The three most common diagnoses reported among all the immigrant populations irrespective of the country of origin were musculoskeletal, general signs and symptoms and ear, nose and throat morbidities, with the latter being most common among Somalis, probably due to the higher proportion of children. However, when

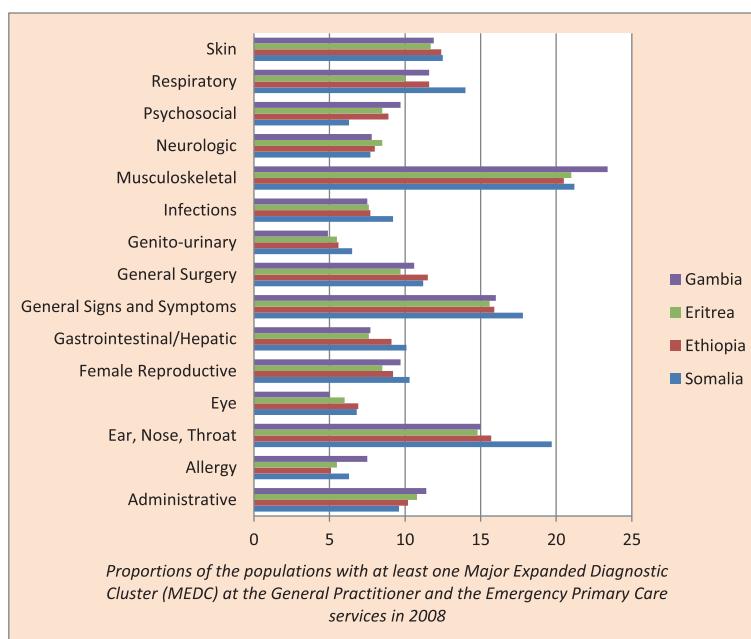
compared to native Norwegians, earlier studies have pointed to an overrepresentation of non-specific diagnoses and consultations at night among Somalis at the ER [35]. In contrast to our study, studies in other countries show that immigrants from SSA have a worse health profile compared to other immigrant groups in the same country and as well as the native population [36, 37].

Differences among countries in our study could be explained by the characteristic of the populations, which include the diverse immigrant background of the groups. As more immigrants from Ethiopia, Eritrea, and Gambia

**Table 3** Use of General Practitioner and Emergency Room services by immigrants' country of origin. Logistic regression analyses with Somalia as the reference group

	Use of GP (yes/no)			Use of ER (yes/no)		
	OR (95% CI)	P-value	Nagelkerke R <sup>2</sup>	OR (95% CI)	Nagelkerke R <sup>2</sup>	P-value
Model 1						
Somalia	1		0.017	1	0.007	
Ethiopia	0.94 (0.88–0.99)	0.048		0.88 (0.81–0.95)		0.002
Eritrea	0.92 (0.86–0.98)	0.012		0.56 (0.51–0.62)		
Gambia	0.92 (0.84–1.01)	0.095		0.81 (0.71–0.92)		0.002
Model 2						
Somalia	1		0.025	1	0.011	
Ethiopia	0.91 (0.86–0.97)	0.004		0.89 (0.82–0.96)		0.005
Eritrea	0.85 (0.79–0.91)	<0.001		0.57 (0.51–0.63)		<0.001
Gambia	0.88 (0.80–0.97)	0.010		0.83 (0.73–0.94)		0.005
Model 3						
Somalia	1		0.050	1	0.014	
Ethiopia	0.83 (0.78–0.88)	<0.001		0.85 (0.79–0.93)		<0.001
Eritrea	0.80 (0.74–0.85)	<0.001		0.55 (0.50–0.61)		<0.001
Gambia	0.83 (0.75–0.91)	<0.001		0.80 (0.70–0.91)		0.001

Model 1: unadjusted; Model 2: adjusted for gender and age categorized into four groups (0–14, 15–44; 45–64 and 65+ years of age); Model 3: adjusted for gender, age categorized into four groups (0–14, 15–44; 45–64 and 65+ years of age) and employment status  
OR Odds ratio, 95% confidence interval



**Fig. 1** Proportions of the populations with at least one Major Expanded Diagnostic Cluster (MEDC) at the General Practitioner and the Emergency Primary Care services in 2008

had at least one Norwegian parent, they probably encountered less communication challenges and had higher knowledge regarding health care services. Socioeconomic status, with Somalis having the lowest income in Norway, could also partially play a role, although our adjusted model including employment status still showed dissimilarities among groups. Variation in the use of PHC in our study might also be explained by differences in unmet health care needs, formal and informal information about how to access PHC or satisfaction with the health system organization in terms of patients/providers interaction, waiting time to get an appointment or convenience of hours of service. Other individual factors like health literacy, fear of stigma or differences in acculturation and combination of stress related to pre-migration and migration experiences can be differentially distributed between groups [10, 20, 38, 39].

The length of stay is often used as a proxy for acculturation to the new country, and in our study was differentially related to PHC use for the four countries of origin. Duration of stay in immigrants' host countries tends to improve immigrants' knowledge of the health care system, language skills and consequently improves utilization of health care services [40]. On the other hand, although immigrants tend to be healthier when they arrive at a new country, which is known as the healthy immigrant effect, their health worsens with time in the new country quicker than the host population [41, 42]. Previous studies show therefore a general increase in the use of health services after some years in the new country

[16, 43]. In our study, however, the pattern seems to be reversed for immigrants from Somalia and Gambia. These results should further be studied qualitatively to better understand the underlying causes.

#### Strengths and limitations of the study

Using register data with nationwide coverage is the main strength of our study, as it gives us enough numbers to be able to disaggregate SSA into country of origin. The use of administrative data minimalizes self-reported bias. In addition, several socioeconomic and migration-related characteristics were available giving us the possibility of adjusting for the variables that better explained the use of PHC, although many factors related to health and health care use remains unmeasured and some variables, like reason for migration, were not specified in a sufficient number of participants to be included in the models. Our study had, however, also limitations. Firstly, our data lack information about patients using private clinics in PHC. Although the Norwegian health care system is mostly public and base on a gate-keeper function of the GP, patients already referred to the specialist or attending only private clinics will appear as if they have not been in contact with PHC. Secondly, our HELFO-database does not include patient's information for elderly residing in the nursing homes, which may explain part of the elderly populations' low utilization of the PHC services. Last, the diagnoses in our study were based on ICPC-codes registered for administrative claims and not extracted from electronic records.

Generally, these claims include only one diagnose disregarding the number of diseases the patient might present and therefore cannot be used for estimating actual prevalences of diseases. However, the ICPC- codes have far been used and recommended to be an adequate and reliable classification system for comparison of groups in primary health care [44].

## Conclusion

Although Somalis, Ethiopia, Eritrea and the Gambians have a similar distribution of diagnosis, differences exist in their use of GP and ER, with immigrants from Somalia using the PHC system more often than the other groups. However, immigrants from Somalia seem to reduce their use of PHC with a longer duration of stay in Norway. Differences among immigrants from the four sub-Saharan countries should be further explored in order to inform policy makers to attain equity in the provision of PHC.

## Additional file

**Additional file 1:** Logistic regression of migrants' use of primary health care services by sex, age groups, employment and, length of stay. The supplemental table shows the results of the logistic regressions of immigrant's from different sub-Saharan African countries (Somalia, Ethiopia, Eritrea and Gambia) and the use of the general practitioner and the emergency room by sex, different age groups, those employed and the immigrants' length of stay in Norway. (DOCX 15 kb)

## Abbreviations

ACG: Adjusted clinical groups; ENT: Ear nose throat; ER: Emergency room; GP: General practitioner; HELFO: Norwegian health economics administrative database; ICPC: International classification of primary care; MEDC: Major expanded diagnostic clusters; NPR: National population registry; OR: Odds ratio; PHC: Primary health care; SD: Standard deviation; SSA: Sub-Saharan Africa; WHO: World Health Organization

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## Availability of data and materials

The datasets generated and/or analysed during the current study are not publicly available because it is a Norwegian National Registry data, under the management of the Department of Global Public Health and Primary Care, University of Bergen, but are available from the first author on reasonable request.

## Authors' contributions

ED: designed the study and conducted the analyses, VM: Wrote and revised the paper. ED, VM, AG, BK: edited and approved the final manuscript.

## Ethics approval and consent to participate

This study is part of the main study "Immigrant health in Norway", and was approved by the Norwegian Regional Committee for Medical and Health Research Ethics (2016/799/REK Vest), which waived the need for a written patient consent because, the study was based on national Norwegian registers.

## Consent for publication

Not applicable.

## Competing interests

The authors declare that they have no competing interest.

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## PAPER II





RESEARCH

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# Access to Norwegian healthcare system – challenges for sub-Saharan African immigrants

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## Abstract

**Background:** Immigrants face barriers in accessing healthcare services in high-income countries. Inequalities in health and access to healthcare services among immigrants have been previously investigated. However, little is known on the sub-Saharan African immigrants' (SSA) access to the Norwegian healthcare system.

**Methods:** The study had a qualitative research design. We used the snowball technique to recruit participants from networks including faith-based organizations and cultural groups. Forty-seven qualitative in-depth interview and two focus group discussions with immigrants from sub-Saharan African were conducted from October 2017 to July 2018 in Oslo and its environs. Interviews were conducted in Norwegian, English or French, audio-recorded and transcribed verbatim into English. The analysis was based on a thematic approach, using NVivo software. Interview data were analyzed searching for themes and sub-themes that emerged inductively from the interviews.

**Results:** Our findings reveal barriers in two main categories when accessing the Norwegian healthcare services. The first category includes difficulties before accessing the healthcare system (information access, preference for doctors with an immigrant background, financial barriers, long waiting time and family and job responsibility). The second category includes difficulties experienced within the system (comprehension/expression and language, the *black elephant* in the room and dissatisfaction with healthcare providers).

**Conclusion:** Healthcare is not equally accessible to all Norwegian residents. This ultimately leads to avoidance of the healthcare system by those most in need. Lack of seeking healthcare services by immigrants from Sub Saharan Africa may have significant implications for the long-term health of this group of immigrants. Therefore measures to address the issues raised should be prioritized and further examined.

**Keywords:** Sub-Saharan Africa, Immigrants, Norway, Access to healthcare services, Challenges

## Background

Sub-Saharan African (SSA) consists of regions economically classified as low-income countries and having some of the worse human development and health indices in the world [1, 2]. Due to the economic situations and political instabilities in some regions of SSA, people tend to migrate to other parts of the world, amounting to 4.15 million sub-Saharan African migrants in Europe in 2017 [3]. The first waves of SSA immigrants migrated to Norway in the 70s, and presently, 916,625 immigrants

and Norwegian-born to immigrant parents constitute part of the total population, with 112,786 from 55 countries in SSA. [4]. Oslo has become home for 27.8% of them and has a number of established cultural networks.

Upon arrival, many migrants have better self-reported health compared to the general host, a phenomenon known as “healthy migrant effect” [5, 6]. However, after a period in the host countries the “healthy migrant effect” may wear off, and the health of many immigrants eventually worsen [5]. Recently, immigrant’s disparities in health and access to healthcare services have attracted increased attention in high-income countries [5]. The relationship between cultural and social norms and health care utilization patterns seem to differ between sending

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and receiving nations [7–9], and there is an ongoing debate whether immigrants benefit equally from services as the non-immigrant [8].

Access to health care services is often one of the indicators of equity in health care provision [10]. Providing health care on equal terms has become a challenge for the health care system all over the world [11–14]. Some individuals do not achieve this fairness because of their social position or other socially determined factors, which in essence negatively affect their health and quality of life in general [15]. Equity in accessing healthcare is a central objective of many health care systems and has been an important buttress of the Norwegian National Health Service. Reducing inequity in health between socioeconomic groups in Norway is the state's priority, with targets set at local and national levels [16].

The Norwegian health care system is founded on the principles of universal access, decentralization and free choice of provider [17]. It is financed by taxation with minor out-of-pocket payments (co-payments). The Norwegian General Practitioners (GP) are the backbone of primary healthcare (PHC) and gatekeepers for secondary care. All immigrants with a legal residence permit and asylum seekers are entitled to the same health services as Norwegian-born [16].

However, the extent of use of health services among immigrants may vary depending on their health care needs, health care seeking behaviors, the organization of health care in their home country, practical barriers to access in the host country, health literacy, migrant's status, education level and other socioeconomic factors [15, 18–25]. Examining issues of accessibility to healthcare among immigrants including understanding their experiences in accessing health care, is essential to improving their health.

Immigrants in Norway and other high-income countries have been described to face barriers to accessing healthcare services [5, 26]. Lack of access to healthcare services by immigrants represents a concern for the host countries and the delay in accessing healthcare services may lead to late diagnosis, delayed treatment, and morbidity [27, 28]. Social and economic deprivation has been linked to higher burden and greater risk of disease among some immigrant groups from low-income countries in Norway [4, 29] and other high-income countries [13]. A number of studies among migrants and ethnic minorities have revealed important barriers in healthcare access [30–32]. However, while many quantitative studies explore issues of access among immigrant [33–39], a gap still remains, especially in understanding the immigrants' experiences to healthcare, as this may be relevant among SSA immigrants.

Existing quantitative studies in Norway have reported findings on the extent of the variation in health care

service utilization and the incidence of disease event between various immigrant groups, without giving insights into immigrant's perceptions [40–42]. Africa immigrants are often examined as a single group, because of their geographic zone, related lifestyles, and health problems. In addition, studies in Norway often grouped African immigrants with immigrants from other regions of the world, in assessing the use of healthcare services [40–45]. Meanwhile, certain factors may have a differential effect on health care utilization between population groups [8, 9], especially as SSA immigrants are confronted with issues of low socio-economic status, language difficulties, coupled with having different cultural beliefs and boundless trust in traditional medicine [46–49]. In addition, this population is different in that, as "blacks", they often experienced racial discrimination in most walks of life [39, 50, 51] and treated as second class citizens [52].

It is important for the population to get the right services at the right time to ensure and promote better health outcomes. Understanding the accessibility to healthcare among the immigrant population is essential and timely as a guiding phase in improving their health, and knowing their experiences in access to healthcare may be a great step for effective disease management/intervention for better health outcomes. Despite the growing numbers of SSA African immigrants in Norway, little is known about their experiences of accessing healthcare, which is key in generating solutions to enhance healthcare access. This paper, therefore, presents the findings of a qualitative study exploring the experiences of SSA immigrants, to accessing the Norwegian healthcare services.

## Methods

A qualitative research design was chosen to have a detailed understanding of immigrants' experiences and reflections and individuals' objectivity with the Norwegian healthcare system.

### Participants, recruitment and data collection

In the recruitment process, we used the snowball technique, where we first identified different informants in a number of established cultural networks including faith-based organizations and cultural groups. The identified informants later recruited their peers. Immigrants from SSA were identified and were informed about the research study and the immigrants and their descendants from SSA countries as described previously [37], with legal residence, at least 18 years of age and willing to participate were included in the study. This study was conducted from October 2017 to July 2018.

The participants were informed of the study objectives through an information letter. They gave both written

and verbal consent to participate, and appointments were taken at their conveniences. Because the participants were from many different backgrounds and had different experiences, we included many informants, in order to explore the themes we had and stopped after data saturation.

The primary mode of data collection involved in-depth interviews (IDI) and focus group discussion (FGD), conducted by the first author. These two methods offered the participants the opportunity to share detailed information about their experiences and opinions [53, 54] to healthcare access. We chose these two methods in order to have a better understanding of participant's experiences both at an individual level and within a group.

The IDIs were conducted in English, Norwegian, or French by the first author. During three of the IDI, a research assistant translated into Somali and Arabic. English and Norwegian were used in the group discussions. Of the 50 participants recruited for the IDI, 47 completed the IDI. The IDIs lasted 45 to 75 min. Two FGD were held with nine participants per group. The FGDs included people from different social background and different SSA countries. The FGDs lasted for 90 to 105 min. The participants held the FGDs and the IDIs at a location of their choice.

The interviews started with questions to gather the general characteristic of the participants. Then, participants were asked to reflect on the barriers to accessing the healthcare system and experiences navigating the healthcare system. The interviews focused on the visits to the general practitioner, emergency room, other healthcare services visited, cognizance of healthcare services, access to health information and the general perception of the healthcare system. After piloting the topic guide for the focus group, with six participants, the research team met to review early transcripts and adjust the topic guide to better capture participants' perspectives. Because the modifications of the topic guide were minimal, we went back and interview the six participants on the topic we adjusted, so, we included the pilot interviews in the final analysis.

This research study is part of the research project "Access and utilization of healthcare services among immigrants from sub-Saharan African living in Norway", approved by the Norwegian Regional Committee for Medical and Health Research Ethics (2016/799/REK Vest) and the Norwegian Social Science Data Services (NSD).

#### **Data analysis**

All interviews and FGDs were audio-recorded and transcribed verbatim into English. As an exploratory study, the research did not attempt to test existing theories on barriers to healthcare for immigrants. To

ensure trustworthiness, field notes were maintained to document the interviewer's perceptions and interpretations during each interview. Data were analyzed for themes and patterns, and the themes and sub-themes that emerged from the data [55, 56]. An initial working coding scheme was generated from a consecutive review of the transcripts. Then, with the working coding scheme, we coded a second set of transcripts and revised the theme until no new theme was identified. The codes were later grouped into each theme, and the relationships among the themes were interpreted. The first author conducted the first analysis; and as a method of triangulation, the second author read the transcripts and provided the additional viewpoint of the analysis and the interpretation. NVivo 11 software was used for data management and analysis.

## **Results**

### **Characteristics of participants**

Table 1 gives the demographics of the participants for the IDI. Five women and four men participated in the first FGD, while seven women and 2 men were in the second FGD. Participants were mainly migrants from 14 SSA countries, both men and women, aged 18 years and older, with a combination of Muslim and Christian. The majority were between the ages 30–50 years and more than half of the participants, had up to secondary school education. Almost all of the participants were employed and some had attended a professional course and were either assisting in the kindergarten or working in the nursing homes. Some owned private businesses as cosmetic/Afro shops or a restaurant. The rest of the participants were working in a Cleaning company and some unemployed. More than half of the participants migrated to Norway between the late 90s and early 2000 and the main reasons for migration were to seek asylum and family reunification.

The reasons for seeking health care services and experiences for different healthcare services visited varied among the participants. Participants faced barriers to system access, healthcare providers and navigations related to their needs for multiple services. The barriers were in two categories: difficulties prior to accessing the healthcare system, and difficulties experienced once in contact with the system (Table 2). The findings reveal categories of accessibility barriers of concern to the participants. Contextual and societal factors hindered their efforts to seeking healthcare. Here, we present the specific concerns raised by participants as they relate to each of the categories. Verbatim quotes have been selected from the IDIs and FGDs to apprehend the perceptions, and experiences shared by the participants with respect to access to the Norwegian healthcare system.

**Table 1** Demographic characteristics of in-depth interview participants

	Total (%)
Total population	47 (100)
Gender	
Women	26 (55.3)
Men	44.7 (21)
Age distribution	
18–30	15.0 (7)
31–40	28.0 (13)
41–50	45.0 (21)
51–60	8.5 (4)
≥ 60	4.1 (2)
Country of origin	
Somalia	23.4 (11)
Sudan	17.0 (8)
Nigeria	10.6 (5)
Cameroon	8.5 (4)
Ethiopia	6.4 (3)
Ghana	6.4 (3)
Senegal	6.4 (3)
Eritrea	4.3 (2)
Uganda	4.3 (2)
Gambia	4.3 (2)
Liberia	2.1 (1)
Congo	2.1 (1)
Burundi	2.1 (1)
Tanzania	2.1 (1)
Social status	
Married	78.7 (37)
Single	17.0 (8)
Divorce	2.1 (1)
Undisclosed	2.1 (1)
Education	
No formal education	12.8 (6)
Primary	6.4 (3)
Secondary	36.2 (17)
High school	29.8 (14)
University	23.4 (11)
Employment status	
Employed	74.5 (35)
Unemployed	19.1 (9)
Retired	4.3 (2)
Undisclosed	2.1 (1)
Years living in Norway	
Born in Norway	2.1 (1)
≤ 10 years	36.2 (17)
11–20 years	46.8 (22)
≥ 20 years	17.0 (8)

**Table 2** Presentation of themes and sub-themes

Themes	Sub-themes
Difficulties before accessing the healthcare system	<ul style="list-style-type: none"> <li>• Information accessibility</li> <li>• Preference for doctors with an immigrant background</li> <li>• Financial barrier</li> <li>• Long waiting time</li> <li>• Family and Job responsibility</li> </ul>
Difficulties when in the healthcare system	<ul style="list-style-type: none"> <li>• Comprehension/expression and language</li> <li>• The “Black Elephant in the room”</li> <li>• Dissatisfaction with healthcare providers</li> </ul>

### Difficulties before accessing the healthcare system

#### Information accessibility

The participants were aware of the existence of the GP, emergency room and the referral scheme, but were unaware of preventive and mental health services and counseling. In addition to the lack of knowledge about the availability of the existing healthcare services, those with psychological problems for example substance abuse, trauma (missing their children collected by the child protective services) did not know where to seek help and they were unaware that they could be referred to see specialist for their psychological problems. Participants did not know the right kind of services that should be used when different health needs arose. Had the participants had this information's it would have guided them for appropriate health decisions.

*“I don't know if they are available and where to get them. Sometimes I go about reading through the net and asking people if they know if a particular health service does exist in Oslo. I am really lost in terms of knowing and navigating the Norwegian healthcare system.” (FGD, group 2)*

*“I have not been to the hospital for depression because I do not know if the service is here in Oslo and even if it is here where can I find it. It is very difficult to know where mental health services are in Oslo. I don't know where to start finding the hospital [ ... ].” (Interview, participant C7)*

Health information available only in Norwegian at certain health facilities further intensified the problem. Some participants complained that they lack health-related information in their language and perhaps in English. Participants expressed they sought information from relatives, Google and other online sites for answers to their health needs.

*“Everyone struggle to get information from the left or right, either by asking friends who are health professionals or read from Google.” (Interview, participant D10)*

Regarding the accessible information, participants emphasized that the government pay much attention to cancer prevention, and less to sicknesses believed to be common among the African immigrants in the community, including vitamin D and iron deficiency, hypertension and diabetes. They requested the government should inform them of the preventive measures of the ailments said to be common in the community.

*"To get information about health is difficult. I only get information about cancer but not for HIV, high blood and diabetes. They are also very dangerous diseases. The government should also send us a letter about them. I also need information about vitamin D and iron. Many of my friends are suffering from a lack of vitamin D and iron. The government should tell us why many black people are facing that problem [...]"* (Interview, participant A8)

*"My father finds it difficult getting health information on diabetes. We only hear from friends or people who have lived here for a long time."* (FGD, group 1)

Many participants felt that the physicians place more values on medications than advice on disease prevention.

#### **Preference for doctors with an immigrant background**

Many participants felt that the immigrant doctors trained in or out of Norway would be an ideal solution to their accessibility problems. Although most immigrants will prefer doctors with an immigrant background, their top priority was immigrant doctors from Africa. Their preference stemmed from the respect, attention, and treatment they perceived to get. Their disappointment and frustration with doctors with non-immigrant background urge them to seek alternatives to the official public system.

*"I get respect from my doctor [the immigrant doctor] and he is very friendly to my family. I am very satisfied with him. He cares for me and refers me to a specialist. He does a lot of investigation on me [...]. He visits us at home and we can call him whenever we want and can go at any time to see him [...]. He has never refused to see us on the same day. He will look [physical examination] at us and take his time to know about the start of the sickness."* (Interview, participant A5)

*"If my children are sick I don't go to a Norwegian doctor [non-immigrant background], I just call my Sudanese friend who is a doctor here and things will go very fast."* (FGD, group 1)

*"I prefer going to see a private doctor, especially those from Nigeria."* (Interview, participant E1)

*"I really will prefer a foreign doctor especially one from Africa."* (Interview, participant B6)

Although few participants had Norwegian doctors, they were very convinced that a physician with the same ethnic background would understand them better than the Norwegian doctors would. Majority of the participants changed their family doctors to an immigrant doctor and it was discussed hotly that the government should employ doctors and specialist from their region of origin.

#### **Financial barrier**

Economic affordability is in relation to the direct cost of receiving healthcare services. The participants lacked the understanding of their entitlement to free healthcare. Being entitled to free healthcare is confusing to many, and the issue of co-payment for doctor's visit is a source of distress. Although healthcare is subsidized, almost all the participants wanted free healthcare. Some participants prayed not to get sick because they could not afford the co-payment. They expressed the patient's co-payment for a doctor's visit be let off. Dental care and physiotherapy were perceived to be expensive and unaffordable.

*"The dental care services here are unaffordable. One needs to look for alternative treatment when needing dental care. Some Africans take the bus and go to the Czech Republic for dental care."* (FGD, group 2)

*"Physiotherapy is expensive for me. Some days I do not go, I skip until I can afford it. It cost me a lot just for single physiotherapy treatment."* (Interview, participant E7)

Our findings revealed that because of the cost of healthcare, immigrants may either forgo treatment, may travel abroad to nearby countries for cheaper treatment, may seek alternative traditional treatments or may wait to seek care during their next trip to Africa.

*"... The healthcare in Turkey is cheaper than that of Norway. So, if my illness is serious I go to Turkey and if it is not that serious I consult with a private doctor ... the money will pay for healthcare in Turkey is almost the same as the money we pay in Norway for consultations and laboratory fees."* (Interview, participant A4)

*“The treatment for dental care is very expensive. ... I cannot visit the dentist because it is expensive. I use some herbs on the hole in my teeth to relieve the pains. I am waiting for my next trip to Ghana so that I can visit a dentist for treatment and filling.” (Interview, participant A7)*

### Long waiting time

Long waiting time was a repeated theme in all the interviews. Many participants expressed dissatisfaction with the long waiting times for doctors' appointments, referral, at the emergency room and some public services, due to bureaucracy procedures.

*“They take a long time in diagnosis. The results of my test took a long time. I was without treatment until when I got the result of the test from the laboratory [ ... ]. It can take about 5 to 6 months to see a specialist in this country.” (FGD, group 2)*

*“The emergency room may have many patients to attend to and waiting for treatment can be a big problem.” (Interview, participant D8)*

Participants discussed that certain conditions would have been avoided if they sought care earlier. They expressed that long waiting time prolongs the process of obtaining treatment and sometimes can be life-threatening. They believed that referral to a specialist was too long for a wait and some boycotted to the private sector or traveled abroad for treatment. Migrants were aware of the delay in treatment, caused by bureaucratic procedures of the public health system and this caused frustration and feelings of discrimination and exclusion.

*“Here [Norway] waiting for a long time to get an appointment can lead to the death of a patient.” (Interview, participant B7)*

*“It took a long time for my wife to get ultrasound [ ... ]. I was so afraid of complication. People going in for an ultrasound, MRI, and x-ray always complained of having a long time to wait before the procedures.” (Interview, participant A8)*

*“The nurses in the front desk told me that my doctor could not see me until after 2 weeks because she has many patients [ ... ] I was spitting out blood.” (Interview, participant C1)*

### Family and job responsibility

Culturally, most African believes in “holding each other's back” or assisting/being there for each other. Family responsibility and job security were prioritized to health-care seeking.

*“Family responsibility as household chores and sometimes our jobs are a barrier to access to healthcare. You know as Africans, we still maintain our responsibility in caring for the family. Our family comes first before ourselves ... our family comes first.” (Interview, participant D6)*

*“I am a single mother and I have to only attend hospital appointment when my children are at school. When they are at home, especially during the holiday I cannot attend an appointment because there is no one to take care of them.” (FGD, group 2)*

According to most of the participants, financial constraints mean limitation to an entire family. Missing a job means starving or somewhat not taking care of several family members in their countries. It was expressed that the employer did not hinder care, but may indirectly have an impact.

*“I fear to lose my job because my boss is also complaining that I am taking leave all the time. I am afraid that one day he may say I should stop working and how will I take care of my family back in Africa.” (Interview, participant A10)*

*“ Our job is our life and the life of those back at home, so we cannot leave our job for simple hospital treatment for body pains.” (FGD, group 2)*

For the reason that some participants were into cleaning and newspaper/packages delivery services, some could barely find the time to meet up with GP appointments, because of work intensity or exhaustion from their jobs. But, they ensured their children did not miss any hospital appointments.

*“Sometimes I barely find time for the appointment, because of the nature of my job. I start very early to distribute or take parcels to various destinations. [ ... ] Either I forget to go to the appointment or I cannot find time to attend because of work.” (Interview, participant D2)*

### Difficulties when in the healthcare system Comprehension/expression and language

Communication or expression difficulties represent a significant barrier to receiving appropriate healthcare. It was a recurrent theme in all the interviews and affected all aspects of the healthcare, from accessing, understanding health-related information to receive the right diagnosis and treatment. Participants expressed apprehension regarding their ability to convey their health concerns in Norwegian, the physician's inability to comprehend their health concerns as well as their capability to interpret medical directions provided by the physicians. Some participants expressed that because of the communication barrier or because of the lack of comprehension for both the patients and the doctors, they spend a lot of time trying to get their symptoms through to the health professional. Although the State takes financial responsibility for interpreters in the health sectors, the majority of the participants are unaware and do not take advantage of this offer, but rather rely on their basic knowledge of Norwegian.

*"With a non-immigrant doctor, he will ask you the same question more than two times. I do not know if they do not understand the Norwegian I speak, or they do not understand the symptom. I cannot tell if it is my accent or if they do not understand what I am saying. Sometimes I feel very embarrassed. They ask and ask and ask. Maybe our accent is difficult to understand. I speak in Norwegian, yet the doctor will ask that I repeat myself."* (FGD, group 1)

*"It takes a long time for them to understand me. I do not speak good Norwegian. The doctor understand English but I do not understand English and when I speak little Norwegian they too do not understand. I have to repeat myself over and over [...]"* (Interview, participant D5)

In addition of taking time in expressing themselves in the best language possible, some participants could not discuss in detail their symptom to the doctors, because the doctors were always in a rush to attend to the next patient. They bothered that health information's at the health services and the chemists are inscribe only in Norwegian.

*"Every information's in the hospital or on medication packages are written in Norwegian and it makes things very difficult for us. I know that educated people do not suffer, but for those who can barely speak nor understand the language is a very big challenge."* (FGD, group 1)

*"Medications instructions are labeled in Norwegian and how can we follow the instructions written on the leaflets."* (Interview, participant A9)

### The "Black Elephant in the room"

Many participants felt discouraged because they perceived the care providers did not seem interested in them. They felt ignored and being treated as second-class citizens. They believed the care providers paid less attention to them than they did to other patients of a different race

*"They pretend not to understand you [someone] and they ignore your presence and concentrate on different patients that are white."* (Interview, participant A4)

Some participants also felt the care providers were scrutinizing them. Those that experienced this said they were so certain not to consult with the same doctors in the future.

*"[...] she will ask me many questions concerning my private life, like what brought me to this country and why don't I go back to Uganda and find a better job."* (Interview, participant D9)

*"Sometimes when I go to my doctor, he immediately asks the questions: what are you sick of? What do you want? Did you come for sick leave? The first thing when they see me, they think I am there for sick leave."* (FGD, group 1)

Most of the participants were equally worried about why HIV test was often among the list of laboratory test check. According to the participants, it was obvious they were being suspected of having infectious diseases, which were affirmed by the facial expression and actions of the healthcare providers.

*"I was surprised that my doctor told me it is good that I do not have HIV and that I should take care of contacting it and if I want to do further test, I can do that after 6 months. What is the problem with these guys [doctors]!. Is it HIV test I went for!. I was so angry that I wanted to explode but for a fact, I respected myself. Can they do that to a Norwegian?"* (Interview, Participant D3)

*"One day I had anemia and when I went to the hospital, the doctor listed a very long list of test for me to do, including HIV."* (Interview, participant C4)

In a particular case, a nurse was said to double her gloves before collecting the participants' blood. Another participant reported that the nurse gazed into her eyes before wearing her gloves. It was all perceived as not wanting to have direct skin contact with them or avoiding contamination.

*"You need to see them [nurses] when they want to physically examine an African child. Some do double their gloves and the expression on their faces shows they are avoiding to have direct contact with the child." (Interview, participant D3)*

*"One day I was in the hospital and I was the next to give my blood for a blood test, the nurse that was collecting the blood was not wearing gloves. I saw it because I was right at the door and she asked me to give her some minute to finish with the patient in the room. When she finished collecting the blood and it was my turn, she gazes at me straight in the eyes and immediately pick up her gloves and wore them before collecting my blood." (FGD, group 2)*

It is worth emphasizing that the recurrent inclusion of HIV test among other test and the use of double gloves were highly perceived as suspecting them of being contagious. Most believed that they were being discriminated because they were black and from Africa. Participants perceived this to be disrespectful, unfriendly and an idea that has been preconceived of Africans. They felt neglected and isolated and supposed the healthcare providers preferred talking to patients of different ethnic background and race.

*"The nurse that was supposed to perform the dialysis was ignoring me during the process and was paying attention to the Norwegian guy that was on the other bed. We were two but she was only asking the other guy how he was feeling while ignoring me." (Interview, participant D7)*

*"The doctors treat the African differently. We are not always greeted in a friendly manner as compared [...] the people are always biased towards Africans. They treat us different and they talk to other white people with respect, but with us, they are very rigid. They do not smile and only send us to do the test or prescribed medications. No physical examination." (Interview, participant D2)*

#### **Dissatisfaction with care providers**

Expectation regarding treatment was hotly perceived and discussed. Many participants described their frustration because of incorrect diagnoses and inappropriate treatments. One participant described being misdiagnosed of cancer, and she believed this was because of improper diagnostic procedures.

*"I had swollen throat last year and went to see the doctor and he asked for series of test to be carried out and finally after some time, he said I have no problem and I was given pain medication. The problem and the pains continued and I went back to him he called some other doctors in and they examined my neck and they were murmuring and after some minutes they said I have to see a specialist for he has to examine me for cancerous cells. It took another 3 weeks and they said I still have to go for further test. My husband said I should travel to Germany to see a Nigeria doctor and I did, it took just a single examination and the result came out to be a problem of the thyroid." (Interview, participant B6)*

The participants' skepticism of the care provider's skills and subsequently the treatment they received emanate from the repeatability of treatment regimens, hospital revisits and lack of sufficient time to express their symptoms to doctors' understanding.

*"When I had a kidney problem, the doctor did not give me the right medication. They tested me with a lot of medication and the case was getting worse. It actually took them about 8 months before they started the real treatment." (FGD, group1)*

*"The baby was sick and I took him to see the doctor [...]. The doctor could not diagnose what was wrong with the baby. The baby's health was not improving so I had to visit and revisit the hospital for the third time." (Interview, participant B6)*

Many participants expressed that in contrast to their home country, physicians in Norway do not do a physical examination, but rather rely on a description of the patient's symptoms in making an initial diagnosis.

*"The doctor in the "legevakt" [emergency room] never touched me [physical examination]. They only allow you to speak but they can never touch you. I was asked to go and rest and take water and eat well. When I got back home the problem continues and it became chronic [...]." (Interview, participants A5)*



Participants expect the routine examination of vital signs as they experienced in their countries, where, patient's pulse and temperature are checked during every consultation. They expressed that the doctors in their home countries hold patient's hand, check the blood pressure, temperature and check the eyelids for signs of blood deficiency. They were distressed that the doctors in Norway focus more on their computers to write down what the patients tell them. Their expectation is for the physician to make a diagnosis based on physical examination. Participants felt that Norwegian doctors spend less time with them. Short and hasty consultation with the physician led to disappointment, lack of confidence in the physician and distrust in the healthcare system.

Participants were worried that the doctor does not trust their words. The myths of drug trials as habitual in Africa prompted some participants to be skeptical of the prescribed drugs, to be for "drug testing" or "experimental drugs".

*"I do not trust the doctors here. I am always afraid that they are testing drugs on us and may use us for experiments. I am very careful when taking the medication. I also call someone to read all the things written on the medications to confirm before taking the medication."* (FGD, group 1)

The participants expressed that they are not trusted enough to be given sufficient sick leave to address their health issues. They voiced that no matter the severity of their ill health, they wouldn't be given more than 5 days of sick leave. This caused tension between the doctors and the patients and eventually boycott. They felt as if the physicians were more concerned with the financial loss of the Norwegian Labour and Welfare Administration (NAV) scheme than their health needs.

## Discussion

Providing health care on equal terms has become a challenge for the health care systems around the world [5, 11, 12, 14, 57, 58]. This study highlights that SSA immigrant's in Norway face challenges in accessing healthcare services both prior to accessing the healthcare services and when in contact with the healthcare system. Our data demonstrate that utilization of healthcare is not only influenced by affordability but also by lack of information about the existence and adequate use of healthcare services when the need arises. Similar to other studies, non-proficiency in the host country language and low health literacy impede immigrants from accessing healthcare [59, 60]. Our study highlighted the need for easily understandable information in English and other relevant languages, on the Norwegian healthcare system to be made available, specifically about

disease and preventive measures for appropriate health decisions.

In addition, the direct cost of healthcare was cited as a barrier to healthcare services and reimbursement bureaucratic procedures was said to be complicated. Even though the Norwegian government ensured health insurance coverage and financed the healthcare system, the out of pocket expense is considered to be high, for those with economic hardship and this affects access to primary healthcare. Researches have shown how lack of sufficient finances significantly affects access to healthcare, both for the immigrants and the non-immigrants [61]. Demographic characteristics, most especially low income have also been shown to play an important role in persisting disparities in access, despite the presence of health insurance coverage [62]. Our findings revealed that lack of sufficient finances or income might force SSA immigrants to seek alternative or self-treatment, and may mean that most SSA immigrants in Norway might not be able to make payments for high-cost procedures such as eye and dental care and physiotherapy.

Furthermore, health professional support to the SSA immigrants is of great importance for a positive encounter with healthcare. Immigrants' preference for immigrant doctors is partly a consequence of participants perceiving the Norwegian health professional show less respect and interest in them. Similar to our study, other researches highlighted that immigrants have been distraught because health professional show no interest in them [63], spend less time with them during the consultation [64] and professionals are often in a rush to attend to other patients [65]. It is of importance for the health professional to support SSA immigrants, especially when in contact with the health care system, for reason that they are from countries with complex health issues and most of them might have migrated from countries with political instability and cultural practices, which might have subjected them to physical and mental health-related issues.

Other factors were also reported in this study regarding difficulties attending appointments, including long waiting time and family and job responsibility. Long waiting time is not unique to the immigrant [66, 67]. Long waiting time has led to patients' dissatisfaction with health care and death of patients [67, 68]. If countries with limited means can achieve the virtual absence of waiting lists, then what excuse can there be for countries such as Ireland, the UK, Sweden or Norway to keep having waiting list problems?. However, reducing patients wait time may contribute to better health outcome [69] and should be a priority for the Norwegian health care. Family and job responsibility were emphasized to influence immigrants access to healthcare particularly

among married immigrants and those with children, who perceived conflict between their own care and to the care for their family and protecting their jobs.

In addition to challenges faced before accessing the healthcare system, immigrants experiences while in the healthcare system were also enumerated. Similar to other research [30, 32], communication between the health professionals and immigrants is important, and that insufficient language knowledge acts as a barrier. Communication difficulties affected SSA immigrants' ability to interact with the healthcare system once in contact with the system. The use of interpreters during consultation would be of an advantage in reducing communication barriers. Immigrants have significant difficulties with health literacy and can accordingly be challenge by intercultural communication barriers when accessing healthcare and making sense of the related health information. This could lead to misguidance and subsequently health errors and health problems. Health literacy has clearly shown to have an impact on health decisions [70]. These difficulties compromised the quality of care on a number of levels such as discouraging SSA immigrants from accessing care, making it difficult to describe symptoms and disease prevention. Language difficulties among non-western ethnic minorities in Norway accounted for dissatisfaction with the physician and lower attendance in health surveys [71]. The efficacy of care, which included interpersonal communication and clinical effectiveness, could be linked to an extent to language problems. It is important that the immigrants should have proper and effective communication with the care providers and English as a second language instruction have been shown to improve health outcome [72].

Perceptions of discrimination and negative stereotypes from health providers emerged as a barrier to access. This reflects similar findings, where, other research has shown that black patients and low socio-economic status influences physicians' perceptions and attitudes towards patients, and that physician's view patients from ethnic minorities and of low-economic status more negatively than the white patients and patients with high economic status [73, 74]. The participants felt the health professionals were judgmental because they were black. Asking participants to do HIV test, the use of double gloves and gazing straight into the participant's eyes before health professionals wore their gloves could be a sign that the care professionals were afraid of contamination. The speculation could be that, since the immigrants migrated from areas of high endemic of infectious diseases, they might be carriers. But the question is, why did those born in Norway also experience this? Participants' perception of being a black and the paradox

of relating "African with infectious diseases" could be the reason of health professional attitudes towards them, or it could be the idiomatic expression "Black elephant in the room" which has caused a lot of frustration and controversy among the black community and this has often been overlooked in codified social interactions [75]. Health professional putting an extra pair of gloves during a hospital visit [58] has been shown. Discrimination and mistreatment because of skin colour, race, ethnicity, name, country of birth, language or religion background have been propounded as drivers of racial/ethnic inequities in healthcare [76, 77]. The negative impacts of racism on physical and psychological health are well verified, mostly focusing on measures of individual personal experiences of racism [77–79]. Racial discrimination experienced within the healthcare setting may affect how people perceive the healthcare system, how they engage with health services and care providers, as well as the patterns and quality of their healthcare access [80, 81]. Experiences of racism may potentially influence patient satisfaction, levels of trust, and perceived quality of healthcare interactions, and consequently may influence their future patterns of health service use [81, 82].

Our participants perceived health professionals with immigrant backgrounds and private healthcare providers are more willing to listen, talk and explain things to them. They expressed that discrimination and miscommunication were more frequent in the public sectors. This may be related to the fact that physicians' practices are known to be influenced by healthcare remuneration scheme with doctors spending less time with fee-for-services patients [83, 84]. Although our research does not directly reflect on delivery of quality of care, our findings suggest that negative stereotypes and lack of cultural awareness may inadvertently lead to inequalities in the quality of care among SSA immigrants, compared to the rest of the population. Culturally appropriate healthcare development could possibly address these factors [85].

Participant's expressed dissatisfaction with the healthcare providers. The perceived unskillfulness of the health professional may possibly stem from the cultural differences with that of the host country, and this might have impelled the immigrants to prefer consulting with immigrant doctors. A previously reported [85], culturally appropriate care may be crucial to address cultural differences concerning diagnosis, symptomology and the understanding of the health investigation system in Norway. Although cultural appropriateness alone may not be sufficient for reducing healthcare disproportions, it nonetheless remains one of the most significant implements in addressing health disparities in society [86]. Finally, distrust of the healthcare providers and

the healthcare system, in general, raised a lot of skepticism, especially as participants were worried about the issue of “drugs testing”. The issue of “drug testing” may have been conceived prior to migration. However, health care providers can build trust by being transparent about the decision underlying the treatment and perhaps being more explicit in explaining why a physical examination may not be required could be helpful. A similar study in the Netherlands among Ghanaians revealed that participants perceived the drugs prescribed to them were for “test prescriptions” [31]. Similar to other studies, participants equally felt that some health workers were more concerned with the financial benefits of the state, rather than an issue concerning their health [87].

From a theoretical perspective, the finding of this study adds records to the capability perspective in healthcare research. Although the literature on healthcare research is broad, it does not take into consideration Africans immigrants from the sub of the Sahara. The findings of this study bridge the knowledge gap of SSA immigrant’s access and use of the Norwegian healthcare system. It provides a better understanding of how SSA immigrants access and use healthcare services in Norway. As asserted by some analysts, only when the health needs of immigrants are addressed, would the host countries be able to support the health of the country as a whole [88]. The study findings may contribute to generating solutions for a positive encounter with the healthcare services for better health outcome and general wellbeing of SSA immigrants.

### Conclusions and recommendations

This study makes it clear that while the Norwegian healthcare system is founded on the belief of universal coverage, healthcare is not necessarily equally accessible to all Norwegian residents. Despite having a well-funded system marginalized SSA immigrant group are faced with multiple barriers before they reach out for care and when they are in the healthcare system. This ultimately results in avoidance of the healthcare system by those most in need and that may have significant implications for the long-term health of SSA immigrants in Norway.

This represents an important area of future investigation of the issues raised and factors identified in our study. Future research must further the understanding of these factors that hinder health, should guide policy development and identify areas for improvement. More qualitative research should attempt to explore how migrants understand their health and health norms including the time they should access healthcare and what type of healthcare. Future research should look at bringing together and advancing both epidemiological and qualitative findings.

As the rate of immigrants in Norway and high-income countries are on a rise [4], and as the structure of the immigrant population become increasingly diversify, more immigrant may find that their access to medically necessary services is compromised. This will indicate the need for a healthcare system and healthcare policies that are more sensitive and responsive to the increasing diversity of the Norwegian population. It will require health policy to move beyond multicultural rhetoric.

### Abbreviations

FGD: Focus group discussion; GP: General practitioner; IDI: In-depth interview; NAV: Norwegian Labour and Welfare Administration; NSD: Norwegian Social Science Data Services; SSA: Sub-Sahara Africa.

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### Authors’ contributions

VM, LT: conducted the analyses. VM: drafted and revised the manuscript. VM, LT, AG, ED, BK: edited and approved the final manuscript.

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### Availability of data and materials

The datasets generated and/or analyzed during the current study are not publicly available due to confidential reasons. The datasets are under the management of the University of Oslo, but are available from the corresponding author on reasonable request.

### Ethics approval and consent to participate

This study is part of the project “Access and use of health care services among immigrants from sub-Saharan African in Norway” ethically approved by the Norwegian Regional Committee for Medical and Health Research Ethics (2016/799/REK vest). Informed consent was obtained from all participants.

### Consent for publication

Not applicable.

### Competing interests

The authors declare that they have no competing interest.

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# PAPER III





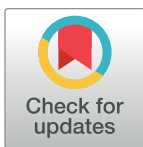
## RESEARCH ARTICLE

# Barriers to access to the Norwegian healthcare system among sub-Saharan African immigrant women exposed to female genital cutting

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**Data Availability Statement:** All relevant data are within the manuscript, except for the participant's addresses, contact information and Norwegian personal numbers. There is ethical restriction on the data to release the addresses, personal numbers and the contact information, imposed by the Norwegian Social Science Data Services and the Norwegian Regional Committee for Medical and Health Research Ethics. However, if the personal information is needed, then contact: NSD – Norsk senter for forskningsdata AS Harald Hårfagres gate 29 N-5007 Bergen Norway

## Abstract

### Introduction

Millions of women and girls have been exposed to female genital cutting (FGC). The practice of FGC extends beyond countries in Africa and Asia in which it is traditionally practiced. Women living with FGC in Norway have been reported to be in need of healthcare, but there is evidence of suboptimal use of healthcare services among this group, and we lack the women's perspective about this problem. This study aims to explore the experiences and perceptions hindering access and use of the Norwegian healthcare system among sub-Saharan African (SSA) immigrant women exposed to FGC.

### Method

This qualitative research was conducted using purposive and snowball sampling to recruit thirteen SSA immigrant women in Norway previously exposed to FGC. Interviews were conducted from October 2017 to July 2018. The Interpretative Phenomenological Analysis method was used.

### Results

The findings indicate that women experience barriers both in reaching out to the healthcare system and within the healthcare system. Barriers prior to contact with the healthcare system include lack of information, husband and family influence on healthcare, and avoiding disclosing health problems. Barriers within the healthcare system include care providers with insufficient knowledge and poor attitudes of care providers.

### Conclusion

This study reveals multiple barriers to healthcare access that co-exist and overlap. This indicates that SSA immigrant women are 'left behind' in being able to access and use the

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Norwegian healthcare system. Therefore, appropriate interventions to improve access to healthcare should be considered in order to reach Universal Health Coverage, thus having a positive impact on the health of these women. Equitable healthcare should be reflected in policy and practice.

## Introduction

Migration to Norway has grown in the past two decades, particularly with immigrants from sub-Saharan Africa (SSA) [1]. Presently, 112,786 immigrants and their descendants from SSA countries constitute part of the total Norwegian population [1]. The Norwegian healthcare system is a tax-based system embedded with the principles of solidarity and equity [2]. The Norwegian General Practitioners (GP) are the backbone of primary healthcare; they are responsible for all initial assessment, investigation, and treatment of patients. They also are responsible for referring patients to specialist care [2].

All asylum seekers and immigrants with a legal residence permit are entitled to the same health services as Norwegian-born patients. Immigrants exposed to female genital cutting (FGC) are also entitled to receive the required healthcare and free treatment in health matters related to FGC [3]. The practice of FGC “comprises all procedures involving partial or total removal of the external female genitalia for no medical reason” [4]. Following FGC, women reportedly suffer from short term and long-term health risks as a consequence of the procedure. Some of these health risks includes pain, hemorrhage, infection, urinary retention and injury to the urethra, wound healing problems, problems with menstruation, sexual problems, psychological consequences, increased difficulties in labor and delivery, shock, human immunodeficiency virus (HIV), and death of the neonate and the women [5–10].

Some studies in Norway and abroad have shown the association between FGC and adverse obstetric outcomes, including episiotomy, prolonged labor, obstetric tears/lacerations, and difficult labor/dystocia [11]. However, some studies also indicated no association [12]. Following FGC, women can reportedly suffer from post-traumatic stress disorder, depression, loss of trust, and permanent lifetime tissue damage [8]. Four (Type I, II, III, and IV) forms of FGC exist and classified based on how the practice was done on an individual. The practice of FGC not only affects the lives of girls and women in the countries in which it is traditionally practiced, but it also affects the lives of girls and women living as immigrants in high-income countries [13]. According to the Norwegian Directorate of Immigration (UDI), many immigrant girls and women from FGC practicing countries may have undergone FGC upon arrival in Norway [14]. Presently in 2019, Norway has 47276 immigrant women from sub-Saharan African FGC practicing countries [15]. In 2013, 44,467 such female immigrants were residing in Norway, and half of them were estimated to have been subjected to type III (also known as infibulation the most severe form) of FGC prior to migration [16, 17]. In Norway, these women are offered reconstructive surgery—called de-infibulation—to alleviate some of the complications resulting from infibulation [18].

Based on literature and the official Norwegian policies (<https://www.udi.no>), those exposed to FGC and living in Norway, are required to receive information about the legislation that prohibits the practice, the health consequences, and healthcare-related to FGC. Women have the right to contact their general practitioner, midwife/nurses at the local medical center or school nurse. They can also contact the women’s or children’s clinic at their local hospital [3]. A GP must refer women to these specialized services. However, the question is, do these women receive and know where to get this information?

Despite having a good welfare system and measures [19], providing equitable healthcare services to immigrants remains a challenge to the healthcare systems in Norway, probably because of its multiethnic/cultural population [15]. SSA immigrants in Norway, reportedly face challenges, including system barriers and personal experiences that impede their access to healthcare [20]. Many factors reportedly influence health and health inequalities within a population. Inequities in access to healthcare exist, and access to healthcare is considered a social determinant of health [21]. Barriers to accessing healthcare—including the lack of cultural competence of healthcare professionals—are some significant factors that cause inequities in healthcare [21]. Social determinants of health could refer to social and economic factors within the broader determinants of health [22], or the experiences of historical trauma, discrimination, and racism, which may affect certain groups of people within a population to influence health and be responsible for healthcare inequities [23–26]. Addressing social determinants of health can improve health and reduce disparities in health and healthcare [22].

In understanding how different social factors do interact to influence health and health inequities, intersectionality has increasingly been applied in health system research, especially to understand and respond to health disparities. “Intersectionality is a research approach that helps researchers to deepen their understanding of inequity through better reflecting on the complexity of the real world [27]. “It promotes an understanding of human beings as shaped by the interaction of different social categories as race, ethnicity, migration, gender, class, in varied ways to disadvantage different people depending on their characteristics and contexts [27].” These interactions occur within framework of connected systems and structures of law, policies, governments, religion, and institutions [27]. The intersectionality concept provides a more specific form of pinpointing inequalities, in developing intervention approaches, and in ensuring results are relevant within particular communities [28]. With the thoughtfulness of the concept of intersectionality, it would be appropriate to understand whether certain predisposing factors among SSA immigrant women exposed to FGC influence their ability to access and use healthcare services in Norway. Factors such as women circumcision status, being a black African, being a woman, originating from regions with different cultural attitudes, and believing in traditional African healing practices can influence healthcare-seeking behaviors. These factors can significantly put women at a distinct disadvantage within Norwegian society. Additionally, FGC practices are rooted in culturally sophisticated traditions that influence the practice, so, it may require an ethical and culturally sensitive health and social service provision.

While Norwegian healthcare providers’ experiences have been reported, including lack of knowledge about infibulation with women living with FGC [18], the experiences of SSA women exposed to FGC with the Norwegian healthcare system has not been adequately investigated. Additionally, in Norway, existing evidence on women’s and care providers’ experiences around FGC mostly orients towards maternity care delivery, with less attention dedicated to healthcare delivery in other settings or for other problems, as emotional and psychosocial well-being and barriers to healthcare [29, 30]. This study aims to explore the experiences and barriers impeding circumcised SSA immigrant women’s access and use of the Norwegian healthcare system, both for maternity care and non-maternal healthcare needs.

## Materials and methods

### Participants and procedure

This research study used qualitative methods to collect data. Interpretative phenomenological analysis (IPA) was used to provide a detailed examination of participants’ experiences [31]. The IPA approach is suitable for understanding immigrant women’s subjective experiences and perceptions regarding factors that hinder their access and use of the Norwegian healthcare

system. Participants in this study were immigrant women exposed to FGC from sub-Saharan Africa, living in Norway. Purposive and snowball sampling techniques were used in the recruitment process. Immigrants and their descendants from SSA countries, as described previously [32], were identified through several established cultural networks, including faith-based organizations and cultural groups. Those identified were informed of the research objectives. The sub-Saharan immigrants with legal residence, at least 18 years of age, and willing to participate were included in the study. The identified participants also referred us to other women. Each new referral was explored, and thus, a total of 13 participants were identified. This study was conducted from October 2017 to July 2018.

### Characteristics of women

Participants were mainly migrants from different SSA countries (Sudan, Sierra Leon, Somalia, Liberia, Mali, Nigeria, Eritrea, and Senegal), with a combination of Muslims and Christians. Most of the women were between the ages of 20–50 years, and half of the participants had up to secondary school education, with some having attended professional courses. Most of the participants were employed; in kindergartens, nursing homes, cleaning companies, and a few owned private businesses or small shops. Some were unemployed. All participants had lived in Norway between 6 months and 12 years. The main reasons for migration were to seek asylum and family reunification. Among the 13 women, four were unmarried, but two of them had children. The rest of the women were married and had children.

### Data collection

Through an information letter, all participants were informed of the study objectives and details, giving them the possibility to reflect upon their participation without undue stress and pressure. All participants gave both written and verbal consent to participate. Once the participants accepted, initial contact was made, and the researcher kept in touch until the agreed appointment date. In order to ensure cultural sensitivity, there was a need for the term “female genital mutilation” to be replaced with “female genital cutting” in the interview guide. The term genital mutilation was not acceptable by most women, so this study used the term female genital cutting.

The women who agreed to participate in the study were interviewed in Norwegian or English. This took place in their home or selected time and place of their choice and convenience. Data were collected through a semi-structured interview, using an interview guide developed by the lead author. For most of the participants, the interview started with open-ended questions. Participants were asked to reflect on their perceptions, and experiences of the factors that hinder their access and use of the healthcare services for FGC related-health needs. The interview guide covered topics that focused on their visits to the GP, other healthcare services visited, knowledge of FGC healthcare services, access to FGC health information, and the general perception of the healthcare system. The guide remained flexible, allowing the participants to highlight additional issues of concern to them. The guide allowed the exploration of unanticipated themes. Field notes were maintained documenting the interviewer’s perceptions and interpretations during each interview to ensure trustworthiness. The duration of the interviews lasted for 45 to 75 minutes. All the interviews were audio-recorded with consent. Participants were told they could withdraw from the study at any time without justification and were assured of anonymity in the publication of data. The women were not paid for their participation but were provided refreshments. None of the participants withdrew from the study.

### **Ethical consideration**

All participants gave their consent before the commencement of the interview. Participants were also informed that the data would be used for publications and conference presentations and were assured that data would be anonymous. The Norwegian Regional Committee for Medical and Health Research Ethics (2016/799/REK Vest) and the Norwegian Social Science Data Services (NSD) approved this research study.

### **Data analysis**

The analysis included all participants and utilized different stages of the IPA framework [33]. It began with carefully reading each transcript for familiarity with its content. Each participants' perspective was examined carefully for a unique context, based on the principles of the IPA idiographic approach, which aims to explore in-depth experiences, in particular, barriers to access and use of the healthcare services for FGC health-related problems. Secondly, line-by-line coding was applied, focusing on each participant's concerns. Thirdly, accounts were cross-examined by searching for repetition. Based on the in-depth analysis of a single participant, emergent subjects were grouped based on interrelations between words and thoughts. Super-ordinate themes from all the transcripts were compiled, and connections between emergent themes were identified. The themes were grouped based on the conceptual similarities to highlight important aspects of the participant's account. Super-ordinate themes were then developed based on emergent themes across transcripts (Table 1).

### **Results**

All of the women in the current study experienced circumcision before migrating to Norway. Some of these women were in doubt about the type of FGC performed on them, while others knew they were stitched entirely (type III). The reasons for FGC and those who circumcised the women were different for each individual. Women in the girl's family (grandmother, mother & aunt) and a friend in one case initiated the process of FGC. In most cases, older women or traditional birth attendants performed FGC. The findings revealed that all participants in this study had undergone FGC before migration.

All the women had some health problems related to FGC. These included recurrent infections, bleeding, general pain, painful menstruation, loss of libido, sexual dissatisfaction, abrasion during intercourse, urine retention, reduction in sexual desire, psychological distress, and trauma. However, the women were unsure if FGC was the primary cause of painful menstruation, loss of libido, sexual dissatisfaction, and trauma.

### **Barriers prior to accessing the healthcare system**

#### **Lack of information**

Most of the participants in this study stated that they were not familiar with the Norwegian healthcare system besides the primary healthcare and the GP, and this hindered their ability to navigate and access the health system. Apart from the GP, the women were unaware of services that offer FGC care and were uncertain whether to make appointments with the GP for FGC health-related problems. The women did not know that they could receive a referral to a specialist for psychosexual and psychological health needs and counseling. The women voiced expectation of being informed by the health system or government about the services available for FGC healthcare and the kind of treatment offered at the healthcare services.

**Table 1. Main themes and sub-themes.**

Main themes	sub-themes	
1. Barriers prior to accessing the healthcare system	Lack of information	<ul style="list-style-type: none"> <li>• did not know where to find information about services provided for FGC</li> <li>• unaware of the consequences of FGC</li> </ul>
	Husbands and family influence on healthcare	<ul style="list-style-type: none"> <li>• husband and family members won't allow women to take a personal decision on healthcare</li> <li>• power imbalance</li> <li>• cannot complain when there is pain or bleeding during sex</li> <li>• cannot complain to avoid separation or divorce</li> <li>• cannot complain to avoid rejection by family</li> <li>• fear of disrespect of husband and family</li> <li>• feel unhappy but cannot complain</li> <li>• feel angry but cannot complain</li> <li>• frustrated but cannot complain</li> </ul>
2. Barriers in the healthcare system	Avoiding disclosing health problems	<ul style="list-style-type: none"> <li>• ashamed</li> <li>• fear of being judged by care providers</li> <li>• fear of flashback</li> <li>• shy</li> </ul>
	Care providers insufficient knowledge	<ul style="list-style-type: none"> <li>• unfamiliar about FGC case</li> <li>• care provider acknowledge lack of training</li> <li>• unable to help women</li> <li>• care provider does not know types of circumcision</li> </ul>
	The poor attitudes of care providers	<ul style="list-style-type: none"> <li>• disrespect</li> <li>• interrogation</li> <li>• no confidentiality</li> <li>• GP murmuring with other care providers</li> <li>• suspect patient of committing a crime</li> <li>• call child protective services on women to screen women's children at school</li> <li>• call police on women for questioning</li> <li>• asking intruding question</li> <li>• glanced at women with suspicion</li> <li>• doubt women</li> <li>• women feel ridiculed and humiliated</li> </ul>

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*“No one is telling us where we can find help for female genital cutting. They only tell the children in school, but not those that are not in schools. In the hospitals, there is nothing written about female genital cutting care and where to find help. I read on the UDI page that we should report any case and that we can visit women's clinics for help, without giving the description and details of the women's clinic. Before moving here, I was in England, and there we could walk straight into U.K's National FGC center and talk about our health issues for FGC. It is not the same here.”*

*(Ngozi, interview transcript)*

Participants expected to be told of other services in addition to the GP. Women with psychological problems related to FGC did not know where to seek help and were unaware that they could receive a referral to see a specialist for their psychological problems.

*“I have this problem that is troubling me inside. I cannot tell someone because I don't know if it is a sickness or not. Because I suffer from sexual dissatisfaction, where can I go to seek help and to explain to for advice? This is causing me to be depressed and traumatized. I have not been to the hospital for my problem because I do not know if the service for trauma and depression is here in Oslo, and even if it is here, where can I find it. It is very difficult to know*

*where mental health services are in Oslo. I don't know where to start finding the hospital [ . . . ]”*

*(Fatou, interview transcript)*

However, some of these women have heard about de-infibulation when asked. The participants said they need detail information about the women's clinic that is stated on the directorate of immigration webpage and about the availability of other services for FGC.

To some participants, a lack of health information about healthcare services for FGC was frustrating.

*“[ . . . ]Because I do not know where to get information about female genital cutting, it is very frustrating [ . . . ]”*

*(Helen, interview transcript)*

### **Husband and family influence on healthcare**

Besides the scarcity of information, women stressed the relevance of their family as the main barrier to reaching out to healthcare services. Some women in this study professed that their family members influenced their decision-making in seeking healthcare for FGC health needs, especially de-infibulation. Women in this study did not seek de-infibulation for varied reasons. First, women reported that their husbands wanted to open the “vaginal passage” naturally. The participants stated that their men believe that they will eventually open up their wives’ “vaginal passage” in due time and that if their wives seek help, especially for de-infibulation, it will make them less of a man. This idea was common among the Sudanese and Somali women, who reported that their husbands prevented them from seeking healthcare as stated that their husbands long to widen the “vaginal passage” by themselves.

*“I am really suffering because during sex. It is very painful, and I will have severe bleeding. I cannot go to see the doctor because he will be very angry that I am insulting him of not being able to open me up. He sometimes says that a man should be strong enough and be able to open. If he cannot open, then he is considered as not being a “man.” He says that I should persevere.”*

*(Akifa, interview transcript)*

The second reason reported was in fear of separation, divorce, or rejection by members of their families. Some participants said it was hard to seek help because they were afraid of domestic violence, divorce, and economic deprivation. Some of the women were frustrated and unhappy due to pain and bleeding during sexual intercourse but could not complain to their husbands for fear of rejection.

*“The bleeding happened more than once during sexual intercourse. Every time he is about to penetrate, he pushes hard forward, and because of that continuous pushing of the penis, maybe he did damage the very sensitive tissue. I experience a lot of pain and infection. I dislike sex because, after 2 to 3 days when he comes back for sex, I experience more pain and even more than the first time [ . . . ] Up to now it is still paining me, and I am very upset about it. I even suggested to him for us to seek medical attention. He refused, just to prove that he is a man [ . . . ] He refuses to put lubrication cream, and he pushes and pushes as if I am not a human being. I cannot complain because he may become angry and call for separation.”*

*(Mariatu, interview transcript)*

Apart from the fear of separation and rejection, some women did not want de-infibulation as an option as women were disgruntled with the outcome and they expressed that after reconstruction (de-infibulation), the appearance of the vulva may not be pleasing to their partners. Women who had undergone de-infibulation procedures reported losing potential suitors. Women stated that men absconded from being betrothed to them because of the appearance of the vulva following reconstruction (de-infibulation). For others, their husband prefers to have sex when the vaginal passage is narrow.

*“My husband insisted that I must not go to the doctor without his consent because he likes to have sex when it is tight” [ . . . ], I cannot refuse to comply.”*

*(Sara, interview transcript)*

Some women could not complain because they were respecting the tradition. However, the tradition some are referring to is expected of them by their family and the community.

*“[ . . . ] Despite the pains and bleeding, I cannot complain because according to our culture he has the right over my body. The bible also says so. And for him being the sole provider to the family and for fear of losing my marriage, I cannot refuse to comply.”*

*(Sara, interview transcript)*

According to some women, communication between them and their spouses was poor in matters relating to their health. A few women professed that they could not enforce preferences in sexual situations, to show respect to their husbands. Some women stated that when their spouses did not allow them to seek healthcare, they felt that their spouses were not concerned about their pains.

*“[ . . . ]. He [husband] does not care when it concerns my health and even if I speak he [husband] does not take me seriously, so I keep quiet and stay alone at my corner because I don't want to disrespect him since he is my husband and father to [ . . . ].”*

*(Nora, interview transcript)*

*“[ . . . ]. My sickness is my burden, not his [husband] own. He minds his business and [ . . . ] [then comes a “sigh” sound].”*

*(Aamina, interview transcript)*

### **Avoiding disclosing health problems**

Some women refused to seek help, voicing a need to avoid disclosing health issues to the care providers or talking to others about their feelings. Their refusal was due to fear— fear of blame and judgment by the care providers, fear of disobeying and rejection from family, and fear of flashbacks caused by FGC. Most of them were also shy and ashamed to disclose their health issues, especially those with psychosexual problems.

*“This is inhuman because I am sick of the continuous pain and bleeding. I feel ashamed to discuss this with the doctor. They may laugh at me because it sounds disgusting that my husband wants to open it up by himself.”*



(Mariatu, interview transcript)

*“I have a lot of pain during intercourse because I was completely stitched up. They [those who perform the circumcision] did not cut everything, but they sewed and left only a small hole that my smallest finger cannot get into my vagina. I feel uncomfortable, especially when in the public toilet because people standing out of the toilet door cannot hear the sound of my urine. I feel they [those standing outside the toilet] automatically know that I am circumcised. This has caused me to have a phobia of urine retention. How can I explain this to the doctor? I feel very shameful to discuss this with a medical professional.”*

(Aamina, interview transcript)

Women suffering from sexual dissatisfaction, and recurrent urinary infections were ashamed and shy to disclose to the care providers. In addition to the general shame of disclosing sexual dissatisfaction to the GP, shyness, fear, and stigma attached to FGC deterred women from presenting complaints for their gynecological issues and for urinary tract infections. Women who were suffering from a repeated urinary infection, though unaware of the primary cause, expressed that they were feeling shy and stigmatized to talk about it to the care providers.

*“[. . .] All the time infection, infection [. . .] how can I tell the doctor. I am ashamed to tell anyone. This is causing me to have a stigma. I cannot tell anyone, and I cannot go to the hospital, all because of infection, infection [repeated] all the time. I am tired of this infection in this [pointing to the vaginal area].”*

(Aamina, interview transcript)

Some women complained that recurrent infection occurs with sexual intercourse, and the abrasion caused during sexual intercourse tends to cause itching and swelling around the genitals. Some stated that seeking healthcare meant exposing their FGC. Despite the good intention of de-infibulation to allow intercourse and to facilitate childbirth, some women refused de-infibulation, in fear that their vulva will look unpleasant following reconstruction (de-infibulation).

*“I am so worried that I may not find the right husband or boyfriend. Each time we are together, and they realized that I am circumcised, they will go and never return, not even a call. To me, it seems as if Somali men are interested in women who are not circumcised. This is very traumatizing because I cannot bring back my original private parts [sexual organ]. I blame my parents.”*

(Habiba, interview transcript)

Those women who had been de-infibulated were worried that they might not find suitors of their choice, and they said to have accepted de-infibulation because of the advantages it can offer. Two of the women, previously refugees in Sweden, had undergone de-infibulation in Sweden. The women said their boyfriends left them because the women's sexual organs looked ugly and “abnormal.” The women regretted having undergone the repair (de-infibulation). According to the two women, their friends encouraged them to do the procedure. The two women professed that they did it because their friends told them that following the repair, they would have no health concerns with reproductive health and emotional distress.

*“[...] when I came to Norway, my friend was rushing to be open [de-infibulation] and one of my friends encouraged me to do that because it will ease the pains and the emotional or psychological distress. I was so happy to be re-opened. Once I got married, it was two years past, and my husband started cheating on me [...] he finally left me for one of my friends. He told my relatives that my vulva is ugly, and the flesh is hanging everywhere. Until date, I feel very disturb and angry with myself for doing it. When I walk around my community and among people from my country, I am ashamed. Maybe he [husband] told some people.”*

*(Titi, interview transcript)*

Some women were afraid to seek care or disclose health problems, as they feared that family and members of the community would gossip about them undergoing de-infibulation.

*“Once I tell my mum or someone that I am going in for repair [de-infibulation], they will talk about me. They will gossip around that I am no longer a virgin because the doctor will insert things [referring to medical instruments] into my private part. Because of the gossip, men may refuse to marry me. One is expected to marry while still a virgin.”*

*(Akifa, interview transcript)*

Avoidance of healthcare was also due to fear of judgment or blame for something others did to them. Some participants said the care providers asked them some intrusive questions.

*“I need a hospital where I can visit without being judged. Everyone [population] is judging me for having been circumcised. This is something [FGC] I was not aware of. I am now the victim [...]. When I told a white doctor that I was in the clinic to seek help because of my health problems caused by circumcision [...]. The way he looked at me, I felt stigmatized [...].”*

*(Astou, interview transcript)*

## Barriers in the healthcare system

### Lack of FGC knowledge among care providers

The participants perceived that the healthcare providers were unfamiliar about FGC cases, especially those who experienced challenges during delivery. Women also supposed that healthcare providers might be lacking training, as the women professed that healthcare providers were busy looking into books and computers before treatment. However, some participants professed that some health providers did acknowledge that they lacked training and were unfamiliar with FGC cases. Some of the women felt that clinic staffs (at the maternity setting) lack the skills and experience during childbirth of women exposed to FGC. Three women talked of traumatic experience during childbirth and the doctors and nurses not knowing what to do. This experience caused them embarrassment, fear, and more stress.

*“When I was about having my number 5 child [...] the child was not coming out. In the “birth room” [delivery room], there was a serious problem in the birth room” because the doctors and the nurses were running there and there, walking and talking to themselves as if some serious problem is happening to me or the baby. The doctor and nurses were reading in a book and asking me questions at the same time. I was very afraid and stressed because I thought I was about to die. It was embarrassing.”*

(Aamina, interview transcript)

Participants expressed that healthcare professionals seem to be lacking confidence because they constantly read from a book before asking questions relating to their FGC condition.

*“I do believe that the doctors here [Norway] know nothing about FGC because when you are talking to them, they will be focusing on a book before asking you questions. I was in the hospital for pains and bleeding from genital tissue damage; the doctor was busy looking up stuff from a book and working on his computer. Finally, I left his office unsatisfied.”*

(Akifa, interview transcript)

Again, some women professed that healthcare providers acknowledged not being familiar with FGC cases. In this regard, healthcare professionals, as attested by some women, were regarded as not being a potential source of support.

*“I asked him some questions, and he did not understand what I was saying. I asked him if he knew “pharaonic” circumcision. Because I wanted to explain to him [. . .]. He said he was not aware and was not familiar with circumcision cases. I was disappointed and discouraged to revisit the hospital. He was unable to help me, so why should I waste my time to consult again.”*

(Astou, interview transcript)

*“During my menstrual cycle, the blood does not flow easily. It clots in the vagina and when I go to the toilet, I see a big lump of blood. I sometimes get an abscess. This is called in Arabic “khiraj”. When I went to see the doctor, he told me that he does not know what I am talking about and he has never treated a case of FGC during his professional practice [. . .].”*

(Mariatu, interview transcript)

### The poor attitudes of the care providers

For some women, care providers are more concerned about the criminalization of the practice than their healthcare needs. Women perceived care providers' attitudes are limiting healthcare access; because most of the women said they did not seek care to avoid excessive questioning from healthcare providers. The women said that they were being interrogated and were considered “suspects” by the care providers. Women perceived this as disrespectful. The women complained that healthcare providers questioned them about their intentions of subjecting their children to FGC, and about their traveling plans to Africa.

*“[. . .]. When I finally visited my doctor [. . .]. I realized that she was interested to know if my children were circumcised and if I intended to travel with them to Africa. She was not interested in my health needs. When I realized that she was not paying attention to what brought me to the hospital, I immediately left the hospital.”*

(Lissa, interview transcript)

Women also complained that the care providers glanced at them with suspicion, and they felt ridiculed. The women stated that some of the questions raised conflicts between them and the care providers, thus leading to tension, mistrust, and poor relationships with the care

providers. The women felt that this had a profound effect on the way women viewed their interactions with the GPs. Most of the women felt that the questioning from care providers might be adding to their “worries” caused by FGC.

*“The doctors in Norway do not support but instead add to the worries of women with circumcision. Before I used to visit the hospital for circumcision health problems, but I stopped [. . .] I do it my own way, and I manage it with my own medicine [referring to traditional treatment].”*

*(Fatiya, interview transcript)*

Two women expressed that during one of their visits to the GP, the GP interrogated them about their holiday back to their home countries. On the same day of the GP visit, the police and the social workers came to their houses for questioning and to check whether their children had been circumcised. The women perceived this as being disrespected by the GP.

*“I realized that each time I leave the hospital, workers from the child protective services would come after my children. They [child protective service officers] go to their school to check them, and they will come to my house to question me. I realized that the doctors are trying to implicate me by calling the child protective services to take my children from me. When I do not visit the doctor, I have my peace. We [with husband] decided that it is better to stay away from the hospital because the doctors and nurses are acting as the police.”*

*(Fatou, interview transcript)*

Confidentiality was an issue for some of the women, as it also led to conflict and stress, especially when the clinic staff asked intrusive questions that other patients could overhear. The women further complained that they were being “showcased” to medical students for study practice because they said students come around with papers and books during healthcare.

*“I rather stay with my problems than going to the hospital to see the doctor. When I go to the doctor, I come back unhappy [. . .] they speak loud so that other staff will know that I am circumcised, and people stare at me as if I have committed a big crime. They murmur and call other officers to come and see me. They come around with papers and pen to learn on my body [. . .].”*

*(Nora, interview transcript)*

The women raised other issues as their children were taken from school for a medical check-up to determine if they were circumcised. Our participants said they would not like to speak to the healthcare providers about their health problems because they feel confidentiality is no longer guaranteed. The women stated that the doctors are causing them to have more fear, stress, and discomfort, and women expressed the doctors are more concerned with the criminal aspect of FGC while disregarding their well-being.

*“The doctors are creating a big problem because people go to the doctors as a place of trust and confidentiality, but if they doubt us again and again [. . .] why should I go to the doctors if I do not trust him or her anymore. This is really huge damage to the women, and sadly, it is happening. The doctors are not supporting us in any way; rather, they are looking for someone to report to the police.”*

*(Habiba, interview transcript)*

Women perceived that health providers are victimizing women exposed to FGC, perhaps because of the overwhelming attention of its illegality.

*“[. . .] She [midwife] asked me many questions. She was making as if I have committed a crime [. . .].”*

*(Lissa, interview transcript)*

All of the women expressed feelings of judgment for having undergone FGC. The women expressed that this practice was performed based on the decisions of others and without their consent. The women felt ridiculed by the healthcare providers and the population as if they did this to themselves.

*“Everyone [meaning population] is judging me for having been circumcised [. . .]. [. . .] I felt stigmatized. She [the doctor] glanced at me as being abnormal. I felt ridiculed. This was very annoying and made me unhappy and I had the feeling of emptiness.”*

*(Astou, interview transcript)*

The women considered themselves to be the victims of circumcision and wished to avoid judgment. The women expressed that the doctors and the government feel that because they are circumcised, they might do it to their children. The women complained of undergoing many interrogations. The women believed Norwegian culture criticized them for an act they did not commit. The women said they prefer to stay in pains and isolation, rather than to face fear and humiliation.

*“I am not a criminal and I know that circumcision is bad and I will not dare to circumcise my children. It is time for the Norwegian doctors and the government to change their perception about us especially those from Africa.”*

*(Fatiya, interview transcript)*

*“I will stay at home with my pains [. . .] and it is better than going to the hospital and later come back in fear and disgrace [. . .].”*

*(Helen, interview transcript)*

## Discussion

Our study explored the views of 13 SSA immigrant women exposed to FGC on barriers to healthcare (maternal and non-maternal care), for FGC health needs. This paper specifically highlights the factors that impede women's access and use of the Norwegian healthcare services for FGC healthcare-related needs. SSA women exposed to FGC are facing challenges that impact their ability to seek care for FGC related maternal and non-maternal healthcare needs. Using the concept of intersectionality, we were able to understand the factors that influence SSA circumcised immigrant women's ability to access and use healthcare services in Norway. The findings of the study revealed that women face barriers in and out of healthcare services. Barriers to access to healthcare were classified into two major themes: Barriers prior to accessing the healthcare system, and barriers in the healthcare system.

### Barriers prior to accessing the healthcare system

Lack of information on healthcare services and difficulties in the navigation of the healthcare system may not only be a challenge for women exposed to FGC alone but to other SSA immigrants in Norway [20]. The structure of the healthcare system in Norway could be an issue because most of the women mentioned that they were unfamiliar with the healthcare system in Norway. This might be different from what the participants have previously been exposed to while in Africa, thus making it difficult for them to navigate and use the Norwegian healthcare services. Another possibility is that the information about the healthcare system might be available, but a language barrier or health literacy could be a hindrance to some participants. Some women may not be able to read and comprehend available health information, including the kind of treatments offered at different healthcare services, thus causing a slow in the flow of healthcare information. In addition to lacking healthcare information, women require information on services that provide counseling, for psychological and psychosexual needs. Women in this study reported painful sexual intercourse (dyspareunia) and abrasion during intercourse, and this is higher with type III [34]. Although none of our participants reported having AIDS, theoretically, abrasion of the skin is the risk of transmission of HIV. Sexual intercourse with a circumcised woman is conducive to an exchange of blood, and FGC can correlate with a high incidence of AIDS [34]. Lack of sexual satisfaction and pains during intercourse was perceived to be the prime cause of psychological and psychosexual well-being. Therefore, educating women on the mental health consequences of FGC, and how to address such effects is vital to influence women to seek care for their psychological health needs. FGC can be a traumatic experience that may have both immediate and prolonged negative psychological consequences [11]. The psychosexual and psychological implications of FGC should be a priority to achieve health equity, as seems to be a shared sentiment among circumcised women, as has been reported in Iraq as well as in Kenya. [35, 36]. Importantly, good sexual health is fundamental to an individual's health and happiness, for it could positively impact one's reproductive health and well-being [37]. Having information about the availability of existing healthcare services and about the psychological consequences of FGC could influence a positive encounter with the healthcare system. In this respect, a high health literacy index among circumcised women could increase their ability to obtain, process and understand health information and healthcare services in Norway [38]. While linguistic barriers can hinder access to healthcare, reduce the quality of care, and result in dissatisfaction [39, 40], health literacy as a concept empowers health communication and stimulate understanding of the process of health communication in both clinical and community settings [38].

Husband and family influence over women was one of the main barriers for women to reach out to healthcare, especially for de-infibulation. The basis for women's husband refusing de-infibulation involved the husbands' sexual choice of wanting a narrow "vaginal passage" and willingness to open the "vaginal passage" naturally and as perceived for "husbands sexual enjoyment." "Male sexual enjoyment" reportedly attributed to the continuity of FGC practice, and women in Africa reportedly depend on their husband's consent to seek healthcare, irrespective of their health needs [41]. The family refusal was possibly for cultural reasons. The husband's willingness to open the "vaginal passage" naturally might be that their husbands may either want to face their family with courage, face their friends and community with the pride of fulfilling and accomplishing their marital duties and responsibilities. The "natural way of opening" might be partly responsible for the recurrent infections, bleeding, and pains during sexual intercourse, as also perceived by the women.

Similarly, circumcised Somali women in the UK did not seek de-infibulation but had opted for their husbands to “open” the vaginal way naturally [42]. However, this was the reverse for women in the present study. This result could explain the reason for the unpopularity of de-infibulation among circumcised Somali women in the UK [43].

The participants who refused to undergo de-infibulation in the present study were immigrant women from Somalia and Sudan. It would be essential to look at de-infibulation among circumcised women from these ethnic groups, for family influence may be limiting women wanting to undergo de-infibulation. The result could also explain the reason behind the findings of a previous study on the experiences and management of birth care among women exposed to FGC in Norway, where health providers expressed concern about the birth care of circumcised women because they were mostly infibulation [18]. However, some of the participants seem to be influenced by their culture because it seems like the women themselves consider the natural version of the vulva as not aesthetically optimal. Some women were disgruntled with the outcome of de-infibulation.

Some participants refused to seek healthcare in fear of divorce, separation and family rejection. Women may be afraid of stereotypes of unmarried women, which results in stigmatization and marginalization [44, 45]. SSA African women have reportedly experienced this based on their marital status [46]. Again women in fear of family rejection could very likely be the associated risk and outcomes of family rejections [47]. One of the core fabrics of African customs is ‘respect’ and disrespect—especially of the elderly—and absence of respect is considered a misgiving of the young person [48, 49]. A husband maintains a strong influence as the head of the family [50], and this may be a justification for why some women could not enforce preferences in sexual situations, to show respect to their husbands.

Another factor that hindered healthcare was the fact that women were avoiding to disclose their health problems. Women were either shy or ashamed to reveal health problems, especially those related to sexual needs. As mentioned, they were in two minds between keeping it to themselves and consulting a care provider. This feeling was particularly communicated by women who experienced recurrent urinary infection and those experiencing psychosexual problems like loss of libido and sexual dissatisfaction. Women with FGC are reportedly likely than women without FGC to experience urinary tract infection and pain during intercourse [51]. Our study negates the hypothesis that FGC causes psychosexual problems to circumcised women [36]. Women in our study may refuse to seek care because they may not want information about their FGC status to be public [52]. Another reason might be that many female community members might have experienced similar health complications such that certain FGC related symptoms have become “normalized” and women might find it not relevant to consult a health-care provider [52]. Another reason for not disclosing health issues was in fear of judgment or blamed by the healthcare providers for their circumcision status and being blamed by their community for seeking de-infibulation. For this reason, the community may negatively impact women’s healthcare, especially if the community members gossip after a woman seeks de-infibulation. As perceived, this is also critical for women because when gossip is circulating in the community, they risk the chance of losing potential suitors.

### Barriers in the healthcare system

In addition to barriers prior to accessing healthcare services, women also experienced challenges in the healthcare system that impede them from using healthcare services. Women in our study attested that the criminalization of FGC practice might override their health needs. The participants professed concern that healthcare professionals are more concerned with the

illegality of FGC practices than their health needs. Not only did the women express this concern, but they were also equally worried about their feelings/emotional states.

Most of the women believed that the healthcare system is prejudiced, and according to most of the women, the healthcare providers were asking intrusive and interrogating questions at healthcare. Women perceived this as discrimination, lack of support, and disrespect. According to the women, these questions cause fear, trauma, doubt, mistrust, and becoming a “suspect” and vulnerable. They also said these questions aimed to ridicule them. Healthcare professionals need to be cautious because circumcised women may perceive the questions differently. As documented in other countries, African women exposed to FGC had experienced humiliation and women avoided questions from healthcare providers that triggered recollections [42, 53]. Nevertheless, according to Klein DC (1991), although the feelings associated with humiliation are strongly personal, the process itself exists in the link between the person and “the emotionally relevant human environment” [54].

The women perceived that the personal questions pointed to their race and countries of origin. However, there have been mixed opinions around FGC prevention in the healthcare setting and some circumcised women have argued that FGC prevention is needed in the healthcare setting. Still, it should be done without causing offense [55]. Creating a pleasant atmosphere during healthcare would encourage trust [56], and enable FGC patients to open up the discussion about FGC, and possibly influence revisit to the healthcare services.

Not only did the women had these experiences at the healthcare settings, but the findings also revealed that women had unannounced home visits (after a hospital consultation) by social workers and police. These were perceived to be uncomfortable, fearful, traumatizing, and adding to their worries caused by FGC. The women believed the system did not trust them, and as a result, the women did not trust the system. Such experiences negatively influenced the participants’ ability to access healthcare. However, as mentioned by Fangen K, in her study, many Somali in Norway feel intensely humiliated by the way they are met by public officials [57]. This result may partly explain the women’s feelings in our study when approached by public officials. Impromptu home visits of circumcised women in the UK have also been reported to frightened women and upset girls when interrogated in schools about their traveling plans [55]. Importantly, women in our study professed that they are aware of the laws abiding FGC, and they will not, in any circumstances, subject their children to the practice.

Most countries across the globe (with a few exceptions) recognize FGC as a violation of the human rights of women and girls. Several international rights treaties support the right of physical integrity and freedom from all forms of torture, degrading treatment, and discrimination [58, 59]. In Norway, not only does the government regards the FGC of girls as a crime against children, but it also recognizes FGC as a violation of human rights [60]. In 1995, the Norwegian parliament passed marked laws against FGC, with several measures in place to address and fight FGC. The women in our study are aware of the legal implications of FGC, so emphasizing it during healthcare would not only ruin a patient-care provider relationship, and cause mistrust, but also impact women’s’ subsequent visits to healthcare services. Some authors have documented that the laws and policies preventing FGC in high-income countries might have a negative influence on the abilities to access and use the healthcare system of those affected in the host countries [55].

Further, breach of their privacy and lack of confidentiality in healthcare as perceived by the women impedes the women’s ability to access maternal health services. This breach causes tension and even distrust between the healthcare providers and the women. A breach of confidentiality, according to the women, caused stigma and created an atmosphere of fear and feeling of suspicion. This atmosphere could negatively affect women’s subsequent visits to health centers. According to McCartney, in 2015, disrespecting confidentiality is not the



answer to FGC [61]. Breach of confidentiality utterly destroys patients' trust in health services and stigmatizes patients further [61]. Perceptions of mistrust of care providers from Somali women patients and their families reportedly cause resistance to obstetric interventions [62].

The last but not the least of the factors that impede women's ability to seek care were healthcare providers' awareness and knowledge about FGC. This factor is essential in providing adequate care because women exposed to FGC have professed a greater satisfaction and comfortability in discussing FGC with health workers with prior knowledge of FGC [63, 64]. Not only have healthcare providers acknowledged communication challenges with FGC patients and a lack of formal training or protocols guide for FGC [56], there have been studies that acknowledge poor knowledge regarding different aspects of FGC among healthcare professionals [65]. However, some studies emphasized that healthcare professionals may require the confidence to talk about the subject due to insufficient knowledge, may lack the experience in handling patients with FGC, or may lack understanding of patient culture [53]. For this reason, an understanding of the socio-cultural background surrounding FGC practice is crucial for healthcare providers to improve FGC management [66, 67].

### Strength and limitations

Our study has strengths and limitations. Our qualitative research, as far as we are aware, is the first to describe how SSA African women exposed to FGC experience and perceive healthcare in Norway. An advantage of our research study is that it was planned and designed by a team of immigrant professionals with research experiences in community, public health, and social science. Our team has carried out extensive research on immigrant's health and well-being in Norway. Each team member provided guidance based on his or her professionalism, from the planning phase to the design and data analyses, thus assuring the richness and quality of the data.

The interviewer's background as a female African immigrant created a relaxed atmosphere. The women considered the researcher as one of them, so there was a strong relationship built on trust and mutual respect, and this might have encouraged open and honest responses. It may also be possible that some participants would have downplayed some negative experiences to avoid criticizing their husbands, the healthcare professionals, and the government in front of the researcher. However, as seen from the results, this was relatively small because the participants reported an in-depth range of their experiences from every viewpoint. To overcome the challenges of recruitment—especially as this group of women is hard to reach—friends known to be circumcised were recruited other women exposed to circumcision. Consequently, the variation in the group of women recruited might have been limited.

The insight gained from our study may be valuable when considering optimizing healthcare for sub-Saharan African women exposed to FGC. However, a limitation is not being able to capture any health professionals' viewpoints. Interviewing through triangulation methods would have then been possible. Similarly, it would also be an advantage to interview husbands and men, but this view was beyond the scope of this study.

### Recommendations

The recommendations here originate from what women said and what has been shown in the literature to be significant in improving women's access to healthcare and issues surrounding circumcised women's health. Despite legislation discussing FGC as a violation of human rights, the health needs of those exposed to the practice are overshadowed by the legislation to safeguard FGC practice. Healthcare professionals need to find a way to bridge the void created after FGC, in that healthcare providers must provide excellent support to the women. Patients expect

that all healthcare professionals should identify and report concerns about girls at risk of FGC. However, it is equally crucial that they inspire women and girls to seek healthcare for their FGC related-health problems. Support from healthcare professionals to women exposed to FGC is vital for a positive encounter with healthcare services. Because FGC has been high on the agenda in Norway, these women are fully aware of its ethical and criminal implications. Our study suggests that it would be necessary for healthcare professionals to ensure that a reasonable risk is identified, before contacting the child protective services. Healthcare professionals must be aware that many immigrant women exposed to FGC become fearful and worried when seeking medical care in their host countries [68]. Therefore, creating a good relationship and an environment of trust with the patients would lessen their fear and give room for positive outcomes [68]. It is essential to explore further the issue of criminalization and its impact on women's healthcare since our data may not adequately provide all aspects of the evidence.

It is important to create awareness among women exposed to FGC regarding seeking help for their health needs and where and how to get help through community-based educational programs [63, 68]. Education to women and care providers may be complementary and equally useful to encourage women who are shy or ashamed of presenting their health problems to come forward and seek help. Women exposed to FGC need social support networks for guidance and to provide stability to overcome some of the stigma associated with FGC. Community support may change the views and the perceptions of other community members about FGC. A well-functioning referral system and a good social support network play a key role in encouraging access to healthcare [69]. A good support network reportedly empowers women exposed to FGC to access antenatal and intrapartum services in England [42].

It would be important that healthcare professionals are respectful, non-judgmental, and open-minded when caring for women exposed to FGC. To foster a trusting relationship with women, healthcare providers must have a good understanding of the cultural background surrounding this practice [70]. According to Cindy Little, holistic care given within the context of culture is the most effective [68]. Social and healthcare professionals might need to reinforce their practice to reach an appropriate balance with regards to their legal obligations along with their fundamental responsibility to provide equitable and compassionate care to women.

To facilitate discussion about FGC concerns, care professionals' knowledge and attitudes to FGC—and a positive relationship with the patients—are essential [71]. Assessing care providers for knowledge about FGC is necessary for establishing whether additional training and guidance are required. The absence of specific guidelines may give rise to misunderstandings [72].

## Conclusion

Women exposed to FGC are subject to multiple forms of barriers to getting healthcare in Norway. Women also lack the necessary information, especially about the psychological and psychosexual consequences of FGC, and apart from the GP, they do not know where to seek help in Norway. Mostly, at different points in time, these barriers co-exist independently or interact with one another to impede access and use the Norwegian healthcare system. Importantly, women's concerns and needs are not adequately addressed in the Norwegian healthcare system, leading to a circle of despair and surrendering to the inevitability of their hopeless situation. It is, therefore, important that these issues are adequately addressed by appropriate and relevant training of healthcare professionals and by information provided to the women to improve access to healthcare. Policymakers must address and prevent institutional discrimination issues and race-based inequalities in healthcare in Norway.

## Supporting information

**S1 Text. Interview guide for female genital cutting healthcare.**  
(DOCX)

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