Giving Mothers a Voice:

Development and pretesting of a survey of migrant women's experiences of respect, autonomy in decision-making and mistreatment in maternity care in Iceland

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Gefum mæðrum rödd:

Þróun og forprófun spurningalista um upplifun erlendra kvenna af virðingu, ákvarðanatöku og mismunun í barneignarþjónustu á Íslandi

Edythe L. Mangindin

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Thesis for the degree of Master of Science

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Abstract

Background: In Iceland, immigrants make up 15.6% of the population with the largest group consisting of Polish migrants. There is very limited knowledge on how the healthcare system meets the needs of foreign women receiving maternity care. In addition, the experience of respectful care, autonomy and mistreatment among foreign women within the Icelandic maternity health system has not been described.

Aims: The aim was to develop and pretest a survey about the experiences of childbearing migrant women in Iceland in the areas of respect, autonomy in decision-making and mistreatment in maternity care through standardized instruments.

Methods: The online survey was developed for the Icelandic healthcare system and includes questions about socio-demographics, birth outcomes and the following standardized instruments: Mothers on Respect Index (MORi), Mother's Autonomy in Decision Making (MADM) scale and the Mistreatment by Care Providers in Childbirth Indicators (MCPC). The survey was translated to Polish using forward and backward translation and pretested in both English and Polish. Participants for the pre-testing phase were recruited through purposive and snowball sampling. Requirements included: 1) being a foreign woman; 2) childbirth in Iceland within the past 5 years; and 3) proficiency in English or Polish. Participants were asked to provide written evaluations on the functionality, format, comprehensibility, answer options and response time of the online survey.

Results: Eleven English-speaking and six Polish-speaking participants were recruited. The participants deemed the survey easy to access and understandable. Written evaluation of the questionnaire resulted in minor changes to the survey format, wording and answer options. In the end, the survey included 64 questions. Participants completed the survey in approximately 20 minutes on average.

Conclusion: Results show that this survey can be used to assess migrant women's experiences of Icelandic maternity care and is accessible, understandable and easy to answer in both English and Polish. With this survey, it is possible to collect data that is necessary to understand their experiences and improve services for this vulnerable group.

Key words: Immigrants, maternity care, respect, autonomy, mistreatment

Ágrip

Bakgrunnur: Á Íslandi eru innflytjendur u.þ.b 15,6% íbúa og stærsti hópurinn er pólskur. Lítið er vitað um hvernig heilbrigðiskerfið kemur til móts við barnshafandi konur af erlendum uppruna. Ekkert er vitað um upplifun kvenna af erlendum uppruna um virðingu í umönnun, sjálfræði og mismunun þegar kemur að barneignarþjónustu þessa hóps.

Markmið: Markmiðið var að þróa og forprófa spurningalista um upplifun barnshafandi kvenna af erlendum uppruna á Íslandi með tilliti til virðingar í umönnun, sjálfræðis í ákvarðanatöku og mismunun í barneignaþjónustu með stöðluðum mælitækjum.

Aðferðafræði: Spurningalistinn var aðlagaður íslenskum aðstæðum og fól í sér spurningar um félagslýðfræðilega þætti, fæðingaútkomur og eftirfarandi stöðluð mælitæki: Mothers on Respect Index (MORi), Mother's Autonomy in Decision Making (MADM) og Mistreatment of Care Providers in Childbirth (MCPC). Listinn var þýddur á pólsku og var forprófaður á ensku og pólsku. Þátttakendur voru valdir með tilgangsúrtaki og snjóboltaaðferð með eftirfarandi skilyrðum: 1) kona af erlendum uppruna; 2) barnsburður á Íslandi á síðustu 5 árum; og 3) ensku- eða pólskukunnátta. Þátttakendur voru beðnir um að leggja fram skriflegt mat á virkni, sniði, skilningi, svarmöguleikum og viðbragðstíma spurningalistans.

Niðurstöður: Ellefu enskumælandi og 6 pólskumælandi konur tóku þátt í forprófunni. Skriflegt mat þátttakenda á spurningalistanum leiddi til smávægilegra breytinga á sniði, orðalagi og svarmöguleikum spurningalistans. Í lokin innihélt spurningalistinn 64 spurningar. Svartími þátttakenda var 20 mínútur að meðaltali.

Ályktun: Niðurstöður benda til þess að spurningalistinn sé gagnleg aðferð til að meta reynslu kvenna af erlendum uppruna af barneignarþjónustu á Íslandi og er aðgengilegur, skiljanlegur og auðveldur að svara á ensku og pólsku. Með notkun spurningalistans er hægt að safna gögnum til að skilja upplifun þeirra og bæta þjónustu fyrir þennan viðkvæma hóp.

Lykilorð: innflytjendur, barneignarþjónusta, virðing, sjálfræði, mismunun

Acknowledgments

First of all, I would like to thank my best friend and husband, Valur Arnarson, for his unconditional love and unwavering support. I never, in a million years, thought I would be raising a family in Iceland and working as an Icelandic midwife. “Love recognizes no barriers. It jumps hurdles, leaps fences, penetrates walls to arrive at its destination full of hope.” – Maya Angelou

I am eternally grateful for my two sons, Ari Pablo Valsson and Haukur Ben Valsson, for being my inspiration in everything that I do. Because of you, I realized my dream of becoming a midwife and helping other women as they become mothers.

I would especially like to thank my advisors, Dr. Emma Marie Swift and Dr. Helga Gottfreðsdóttir, for their patience, encouragement, guidance, constructive feedback, invaluable insight and, most of all, belief in me. I have enjoyed working with you on this project, and I hope that this is just the beginning of many more collaborations to come.

I would also like to thank Dr. Helga Gottfreðsdóttir for inviting me to be on her research team studying the birth outcomes and experiences of migrant women in Iceland which is supported by the Rannís Icelandic Center for Research. Furthermore, I would like to express my appreciation to the Jóhanna F. Hrafnfjörð Memorial Fund that supports midwives in continuing education.

Finally, I would like to dedicate this thesis to the foreign women of Iceland, especially those who have faced challenges and barriers as they became mothers far away from their own families. With passion, hard work and empathy, anything is possible.

“The way a culture treats women in birth is a good indicator of how well women and their contributions to society are valued and honored.”

-Ina May Gaskin, *Birth Matters: A Midwife’s Manifesta*

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List of Acronyms and Abbreviations

MADM	Mother's Autonomy in Decision Making
MCPC	Mistreatment by Care Providers in Childbirth
MORi	Mothers on Respect Index
NICE	The National Institute for Health and Care Excellence
QRMCQI	Quality of Respectful Maternity Care Questionnaire
REDCap	Research Electronic Data Capture
RMC	Respectful Maternity Care scale
SPSS	Statistical Package for the Social Sciences
WHO	World Health Organization
WP-RMC	Women's Perception-Respectful Maternity Care

1 Introduction

In the last decade, there has been a rise in migration all over the world as people search for a better future and decide to leave their homes for many reasons, including globalization, urbanization, inequality, conflict, poverty, poor job prospects and climate change. To date, approximately 258 million international migrants make up 3.4% of the global population (WHO, 2019). Although there are many benefits of moving to a new country, migrants are considered to be one of society's vulnerable groups due to difficulties accessing services, language barriers and cultural differences. Even more vulnerable are pregnant women who are recent migrants, asylum seekers or refugees and have difficulty reading or speaking the national language (NICE, 2010). In the Global Strategy for Women's, Children's and Adolescents' Health proposed by the World Health Organization (WHO), global agendas are not only focusing on the survival of women and their babies in the event of labor complications but on women's ability to thrive after childbirth and achieve their full potential for health and life (WHO, 2015).

The World Health Organization standards emphasize that outcomes of high-quality maternity care include experiences of autonomy, respect, dignity, emotional support and a client-led, informed decision-making process (WHO, 2016). In 2018, WHO published intrapartum guidelines for a positive birth experience defined as "one that fulfils or exceeds a woman's prior personal and sociocultural beliefs and expectations, including giving birth to a healthy baby in a clinically and psychologically safe environment with continuity of practical and emotional support from a birth companion(s) and kind, technically competent clinical staff" (WHO, 2018). These guidelines are founded on the assumption that most women trust the physiological process of labor and childbirth and have a sense of autonomy in decision-making, even when obstetric interventions are required or wanted. With an increased emphasis on woman-centered maternity care, providing care for migrant women has become progressively challenging since these women often have different needs when compared to their native counterparts.

A growing number of studies on the experiences and outcomes of migrant women receiving maternity care has been conducted in other countries such as the United States, Canada, Australia, the United Kingdom, Sweden, Switzerland and South Korea (Ahrne et al., 2019; Almeida, Caldas, Ayres-de-Campos, Salcedo-Barrientos, & Dias, 2013; Barkensjö, Greenbrook, Rosenlundh, Ascher, & Elden, 2018; Bawadi & Ahmad, 2017; Carolan & Cassar, 2010; Chu, Park, & Kim, 2017; Crowther & Lau, 2019; Essen et al., 2000; Fisher & Hinchliff, 2013; Hennegan, Redshaw, & Miller, 2014; Higginbottom, Hadziabdic, Yohani, & Paton, 2014; Hoang, Le, & Kilpatrick, 2009; Hoban & Liamputtong, 2013; Lee et al., 2014; Owens, Dandy, & Hancock, 2016; Pelaez, Hendricks, Merry, & Gagnon, 2017; Phillimore, 2016; Reitmanova & Gustafson, 2008; Sami et al., 2019; Schmidt, Fargnoli, Epiney, & Irion, 2018). This topic has not been researched in Iceland. In order to understand the experiences of this group as well as identify areas of improvement, research needs to be conducted specifically looking at outcomes of high-quality care such as experiences of respect, autonomy, decision-making and dignity.

1.1 Background

In this section, immigration in Iceland will be discussed along with the Icelandic maternity system. Then, experiences of migrant women receiving maternity care as well as the experiences of healthcare professionals providing care will be presented.

1.1.1 Immigration in Iceland

Over the past two decades, the immigrant population in Iceland has grown drastically. According to the Statistical Institute of Iceland (2017), an immigrant, also known as a first-generation immigrant, is defined as "an individual born abroad to parents who were also born abroad, as well as both of his or her grandparents". Figure 1 shows the number of immigrants living in Iceland from 2000 to 2019. In 2000, the Icelandic population consisted of 279,958 inhabitants with immigrants making up only 2.6% of the population or 7,255 residents. Today, Iceland has a population of 364,134 with the most recent statistics showing that immigrants now make up 15.6% of the population, which is equivalent to over 56,000 residents (Statistics Iceland, 2020).

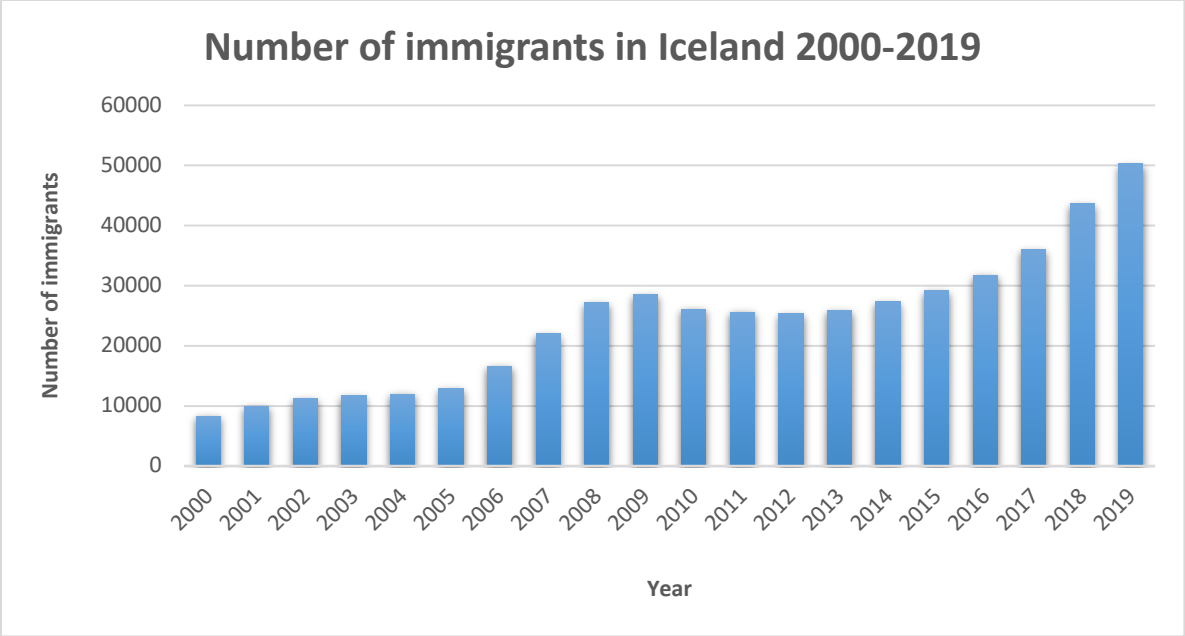

Figure 1. Number of immigrants in Iceland, 2000-2019. Data from Statistics Iceland (2020).

The composition of the immigrant population in Iceland has changed over the last decades. Until the 1990s, Iceland was a homogenous society with a large number of immigrants coming from other Nordic countries. In 1996, 30% of all immigrants were from Denmark, Sweden, Norway and Finland (Figure 2), but today, this percentage has decreased to 4% (Figure 3) (Statistics Iceland, 2020).

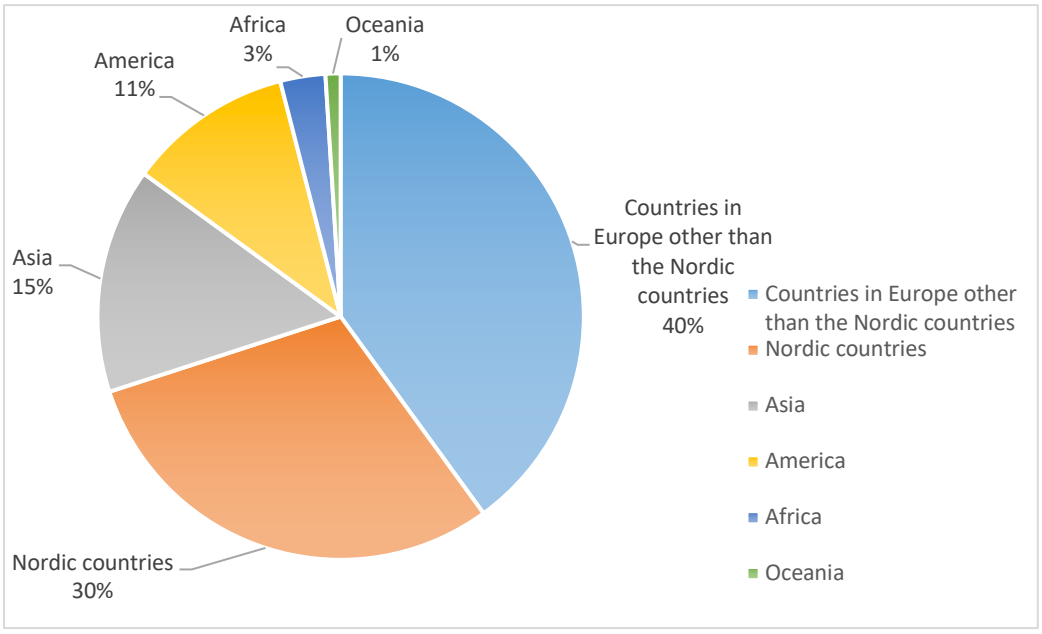

Figure 2. Immigrants in Iceland by country of birth January 1st, 1996. Data from Statistics Iceland (2020).

Note: Percentages also include Icelanders who were born in other Nordic countries.

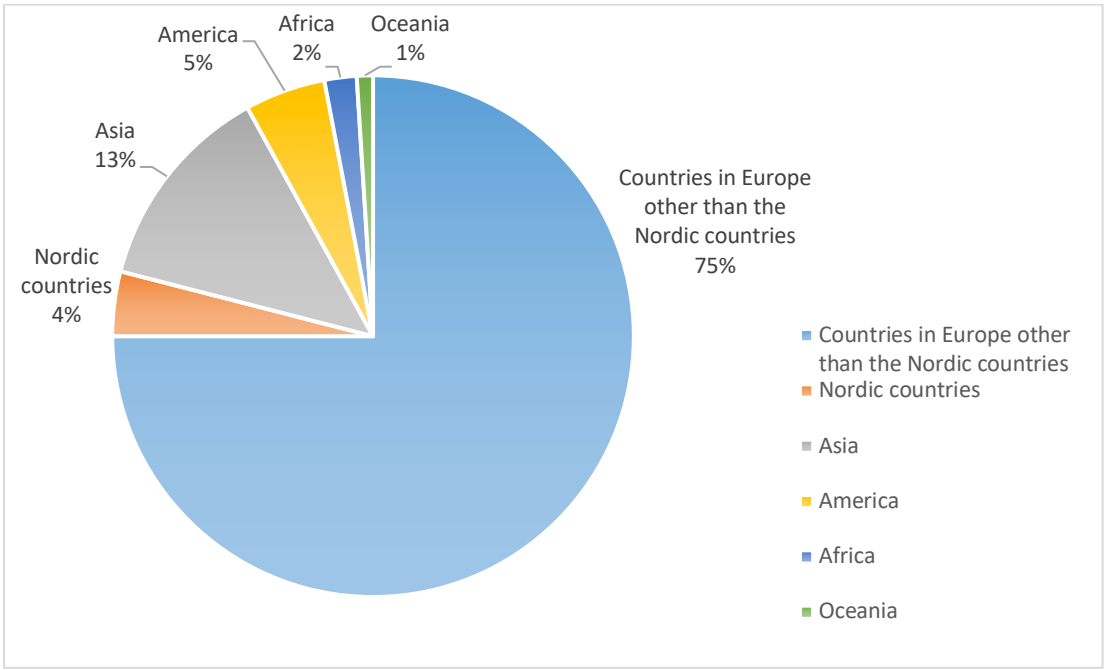

Figure 3. Immigrants in Iceland by country of birth January 1st, 2019. Data from Statistics Iceland (2020).

Note: Percentages also include Icelanders who were born in other Nordic countries.

The reason for these changes in the composition of the immigrant population in such a short amount of time was likely the enlargement of the European Economic Area and the free movement of persons within the European Economic Area (Icelandic Ministry of Foreign Affairs, n.d.). This resulted in an influx of immigrants coming from Eastern Europe. Currently, individuals from 180 countries reside

in Iceland (Statistics Iceland, 2020), and they have different backgrounds, languages, cultures, values and attitudes. The background of immigrants is, therefore, very diverse. Today, the three largest groups of immigrants in Iceland are from Poland, Lithuania and the Philippines. According to the Statistical Institute of Iceland (2020), the Polish population alone makes up 40% of all immigrants in Iceland or approximately 20,000 inhabitants. There are over 22,000 female immigrants living in Iceland with Polish females make up 35% of all female immigrants followed by Filipino (6.2%) and Lithuanian (4.9%) (Figure 4). According to the Polish Embassy, reports show that Polish women living in Iceland have a fertility rate of 2.62 children per woman which is much higher when compared to the fertility rate of Polish women living in Poland which is 1.5 children per woman (Yaghi, 2019). In comparison, the average fertility rate in Iceland is 1.71 children per woman (Jónasdóttir & Eiríksdóttir, 2019).

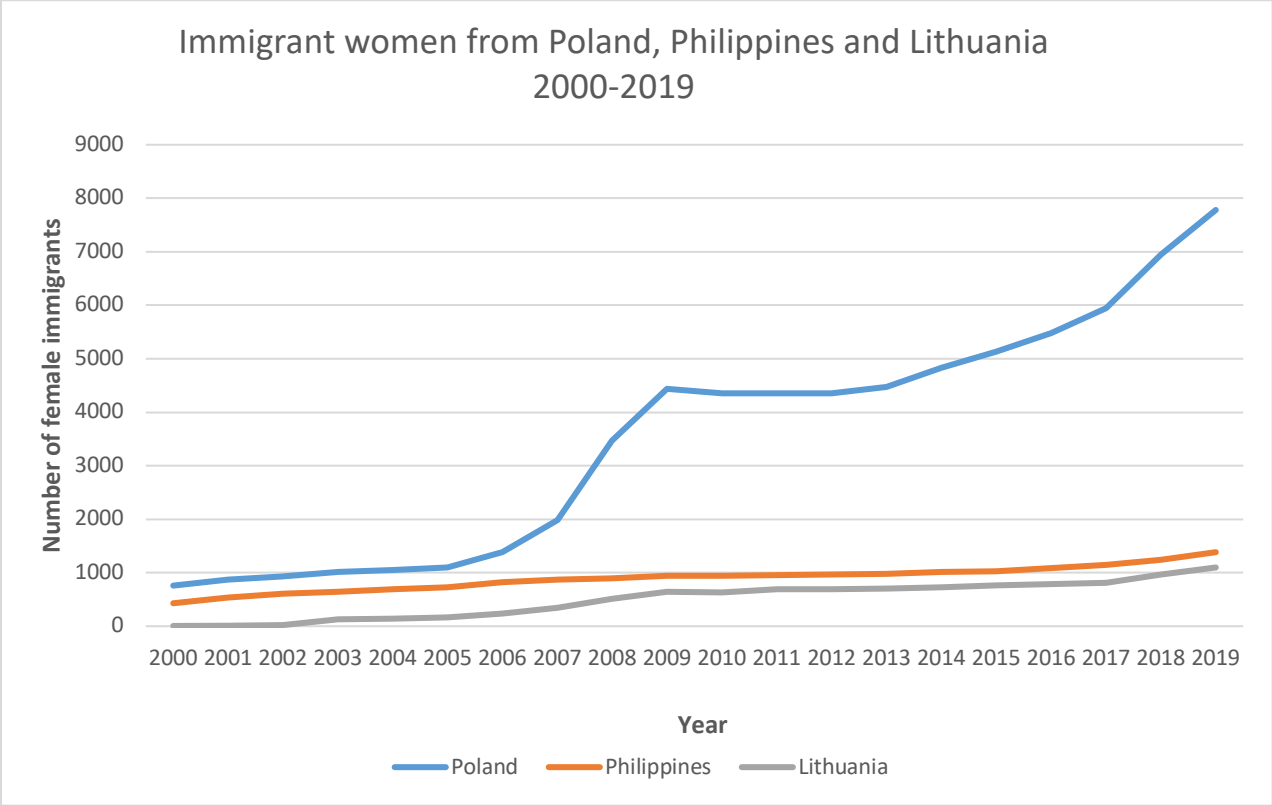

Figure 4. Number of female immigrants from Poland, Philippines and Lithuania residing in Iceland 2000-2019. Data from Statistics Iceland (2020).

There are many reasons people migrate to Iceland. Most come in search of better long-term or short-term living conditions. Many people intend to stay for a few years to study at the universities or work as professionals, while others migrate on the basis of family reunification, according to Article 13 of Act no. 96/2002 on foreigners (Icelandic Directorate of Immigration, n.d.). Some immigrants come to Iceland because of food shortages, economic conditions or armed conflict in their homeland, such as refugees and asylum seekers (Icelandic Human Rights Office, n.d.).

Many immigrants successfully adjust to Icelandic culture and actively participate in society while others face challenges such as the language barrier. In a survey of 800 immigrants conducted in 2009 by the Department of Social Sciences at the University of Iceland (Icelandic: Félagsvísindastofnun Háskóla Íslands) and the Multicultural Center (Icelandic: Fjölmenningarsetur), approximately 80% of respondents were content living in Iceland, and 60% considered themselves to have successfully adapted to Icelandic society. Nonetheless, some immigrants report struggling with learning Icelandic. About 40% of respondents had a good understanding of Icelandic while 33% had a very poor understanding of the language. Only one-third of respondents was able to speak Icelandic well, while 40% had difficultly speaking the language, and more than half of the respondents found it difficult to learn. Only 27% of the respondents had used interpreter services, and 19% of respondents did not trust interpreters to adhere to the confidentiality agreement. At medical appointments, respondents who had someone other than a professional interpreter interpret for them most commonly used their spouse/partner (37%) or a friend (39%). Immigrants also report difficulties in the job market. Almost half of the respondents had worked in a job where their education and experience had not been fully utilized due to either inadequate Icelandic language skills (54%) or not being hired for a job that they were qualified for (23%). Over 70% did not even try to get their education evaluated after moving to Iceland (Jónsdóttir, Harðardóttir & Garðarsdóttir, 2009).

According to a report from the Icelandic Ministry of Social Affairs (2005), most of the immigrants in Western Europe's most prosperous countries are working the worst paid and most unconventional jobs, and this includes Iceland. In modern times, globalization facilitates the migration of people while communication technology and improved transportation increase along with international trade. These conditions encourage young people to travel between countries for the purpose of education or work. A large proportion of immigrants in Iceland have tertiary education and have one or more university degrees. In a report by the Ministry of Welfare in 2019, there continues to be barriers preventing many immigrants with higher education from working within the public sector (Wilson & Aðalbjarnadóttir, 2019). These barriers include inadequate Icelandic language skills along with unfavorable laws, policies and practices. Over 40% of immigrant job seekers are denied employment within the public sector. The report showed that Iceland lags behind other Nordic countries when it comes to adopting positive action measures aimed at employing more immigrants in the public sector and addressing the lack of transparency and risk of discrimination in the hiring process.

According to an analysis on pay gap by background (Statistics Iceland, 2019), the average of income of immigrants is 8% lower than the average income of native Icelanders after correcting for gender, age, education, family status, residency and employment-related factors. The results showed that the pay gap varies between occupations. For example, the pay gap is 10% in janitorial or cafeteria jobs, 11% in assembly line jobs and 8% in childcare positions. Furthermore, accounts suggest that immigrants generally benefit less from their education than native Icelanders. The results show that immigrants have lower earnings on average than native Icelanders with the same education, or a conditional pay gap between 11% and 15%. There is also a pay gap among immigrants. For example, immigrants born in Nordic countries have a higher income than immigrants born in other countries, with immigrants from Asia having the lowest pay, or 7% lower on average.

1.1.2 Icelandic maternity care system

In Iceland, pregnant women receive maternity care services free of charge after legal residence in Iceland for a minimum of six months. Antenatal care services aim to promote the health of the mother and child with professional care, support and training (Icelandic Ministry of Welfare, n.d.). Midwives are the primary healthcare professionals who provide antenatal care in collaboration with obstetricians and other specialists if needed. Healthy pregnant women with no pregnancy complications attend prenatal check-ups at their local healthcare center, but women with pregnancy complications are treated at Landspítali University Hospital or Akureyri Hospital. Prenatal check-ups begin between the 8th and 12th week of pregnancy, and first-time mothers are recommended to attend 10 check-ups throughout pregnancy while women who have already had a child are recommended to attend 7 check-ups (Icelandic Directorate of Health, 2008). At around the 20th week of pregnancy, women are offered an ultrasound, and if the pregnancy has any risks or complications, ultrasounds can be performed earlier and more frequently along with further tests. Courses in childbirth preparation and breastfeeding are available in Icelandic and English for expecting parents in the capital area. During the first 10 days after childbirth in most parts of the country, a homecare midwife will provide postpartum services free of charge to the woman.

According to the most recent Icelandic Birth Report, in 2017 there were 4,019 births in Iceland, and the fertility rate was 1.7 children per woman (Jónasdóttir & Eiríksdóttir, 2019). Over 74% of all births took place at Landspítali University Hospital in Reykjavík, while 2% were homebirths. Over the last decade there has been a decrease in births in the rural health care institutions. Nationwide, the cesarean section rate was 16.2%, specifically 11.4% at Akureyri Hospital and 18.2% at Landspítali University Hospital. The infant mortality rate was very low at 1.97/1,000 live births, and there was no reported maternal death. In Iceland, as in other Nordic countries, breastfeeding is the cultural norm (Símonardóttir, 2016). Among infants born in Iceland between 2004 and 2008, approximately 98% started to breastfeed and 74% were breastfeeding at 6 months (Icelandic Directorate of Health, 2012). More recent statistics about breastfeeding rates in Iceland are currently not available.

1.1.3 Migrant women's experiences of maternity care and motherhood

For many women, moving to a new country and experiencing pregnancy and childbirth can bring on personal changes. In a qualitative study, Bawadi and Ahmad (2017) proposed the main theme "Displacement and reformation of self" when describing Arabic women's experiences of becoming a mother in the United Kingdom, and these women talked about freedom from their cultural restraints as they moved from a state of dependence to independence. Becoming a mother in a new country brought about new values and expectations (Crowther & Lau, 2019) as well as new opportunities (Owens et al., 2016).

A growing number of studies shed light on the many barriers and challenges that migrant women face when accessing maternity care (Fair et al., 2020). In a study by Chu and colleagues (2017), researchers interviewed first-time migrant mothers in South Korea who described their experiences as "Coming to a crisis." This referred to the fact that participants had difficulty coping with cultural differences, the immigrant environment, mixed feelings about expectations and fear of childbirth. In other

studies, women have also described further challenges regarding language barriers such as lack of information in different languages, decreased level of health literacy and unavailability of interpreter services (Crowther & Lau, 2019; Phillimore, 2016; Sami et al., 2019). Furthermore, Barkensjö et al. (2018) suggest that if migrant women perceive neglectful behavior from healthcare professionals in clinical encounters, feelings of anxiety and fear intensify. In addition, some migrant women experience difficulties with transportation leading to problems attending antenatal visits (Phillimore, 2016).

Research also shows social support is an important issue for childbearing migrant women. Lack of social support is a common challenge that many of these women experience during pregnancy, in childbirth and after childbirth (Owens et al., 2016; Sami et al., 2019). During this time in their lives, relationships are of great importance (Crowther & Lau, 2019). In one study, migrant women expressed that it was crucial to strengthen the family unity and to be able to depend on others as they take on the role of being a mother in a new country (Chu et al., 2017). For instance, Arabic women living in the United Kingdom experience an emerging dominance of the nuclear family over extended family which causes changes in the social structures within their own families (Bawadi & Ahmad, 2017). In Arabic countries, members of an extended family are often together during their free time, and men are required to participate in social events of neighbors, relatives and friends. However, life in the United Kingdom released the Arabic husbands from these social commitments giving them more time with their wives and children.

Despite the many barriers and challenges that migrant women experience, studies have also reported positive aspects of maternity care services including availability of services (Sami et al., 2019), holistic services (Owens et al., 2016), positive communication with healthcare professionals (Barkensjö et al., 2018) and the ability to obtain information about maternity services and healthcare systems (Owens et al., 2016). Interestingly, if healthcare professionals displayed trustworthiness and provided informed, culturally sensitive and flexible care along with knowledge of social networks and events aimed at migrant women, the expecting mothers felt acknowledged and empowered through these positive clinical encounters (Barkensjö et al., 2018).

In Iceland, only one study has been conducted about migrant women's experiences in maternity care. Jónsdóttir and colleagues (2011) interviewed migrant women about their experiences with the maternity healthcare system. In this qualitative study, the concept of cultural competence and the ideology of service leadership laid the foundation of the interviews with seven migrant women taken before, during and after childbirth in Iceland. The women reported difficulties accessing information about maternity and social services; however, personal client education, continuity of care from midwives and the use of professional interpreters played a key role in ensuring that these migrant women were well-informed. Overall, the participants experienced positive interactions and communication with their healthcare providers, but they also perceived limited cultural competence of healthcare staff, prejudice and mistreatment. Lastly, participants reported a lack of social support, feelings of loneliness and a sense of homesickness. Although the women were generally satisfied with their care providers' manner, they reported a need for improvement in accessible information, client education, formal communication services and support around childbirth (Jónsdóttir, Gunnarsdóttir, & Ólafsdóttir, 2011).

1.1.4 Healthcare professionals' experiences of providing care for migrant women

Healthcare professionals experience challenges when providing care for migrant women and their families. Attempting to understand the experiences of women in this vulnerable group can be demanding. Many studies suggest that language barriers are a very common challenge that healthcare professionals encounter (Ahrne et al., 2019; Crowther & Lau, 2019; Lyberg, Viken, Haruna, & Severinsson, 2012; Pelaez et al., 2017; Yelland et al., 2016). Insufficient communication between healthcare provider and woman can lead to failure to meet the woman's needs and expectations, resulting in low-quality maternity care services (Origlia-Ikhilor et al., 2019; Pelaez et al., 2017). Although healthcare professionals utilize interpreter services to address language barriers, they can encounter challenges in negotiating the use of these services when spouses, family members or friends insist on interpreting, even though professional services are available at no cost to the woman (Lyberg et al., 2012; Yelland et al., 2016).

For midwives, providing individualized woman-centered care can be difficult due to limited insight into migrant women's context, lack of partner involvement and varying levels of health literacy (Ahrne et al., 2019). In a qualitative study by Lyberg and colleagues (2012) about Norwegian midwives' experiences of providing care for childbearing migrant women, midwives reported having to manage and support educational, relational and cultural diversity in maternity care. In Norway, the largest groups of non-Western migrants come from Pakistan, Vietnam, Iraq, Somalia, Bosnia-Herzegovina and Poland. Norwegian midwives faced several difficulties and concerns when caring for migrant women. Because many migrant women viewed pregnancy as a natural part of life, they were not very concerned about their own health and were not interested in too much information from healthcare professionals. Providing culturally sensitive care was challenging because of different subcultures within a culture in addition to varying levels of education. Midwives often needed to support migrant women through emotional pain stemming from social isolation, depression, grief, a feeling of loss and a neglect for their own health. Also, migrant women were considered to require special attention during pregnancy because they were more likely to give birth to children with low birth weight, illness or disabilities compared to Norwegian women. Migrant women in Norway also to having a higher risk of miscarriage and stillbirth. Furthermore, women from Eastern Europe had a tendency to request a cesarean section (Lyberg et al., 2012).

The approach that midwives use to balance women's individual needs with the perceived requirement to adhere to standard protocol can greatly influence the challenges migrant women face (Pelaez et al., 2017). For many healthcare professionals, it is difficult to provide high-quality maternity care because of systematic barriers such as difficulties accessing services, lack of resources, strict routines of care and unsupportive structures for parent education (Ahrne et al., 2019; Pelaez et al., 2017).

1.2 Concepts and language

The following four sections will explore concepts and language that are essential in assessing migrant women's experiences of maternity care. First, the theoretical framework of intersectionality will be discussed. Then, respectful maternity care and autonomy in decision-making during pregnancy, childbirth and in the postpartum period will be explained. Lastly, mistreatment by care providers in childbirth will be defined.

1.2.1 Intersectionality

Intersectionality is defined as "the interconnected nature of social categorizations such as race, class and gender as they apply to a given individual or group, regarded as creating overlapping and interdependent systems of discrimination or disadvantage" ("Intersectionality," 2015). In the United States in 1989, Kimberlé Crenshaw, a civil rights activist and legal scholar, explored different ways in which gender and race intersected in creating representational, structural and political aspects of violence against women of color (Crenshaw, 1990). Before the beginning of the intersectionality movement, identity politics often ignored differences within groups, and discussions about feminism and anti-racism did not recognize intersectional identities such as women of color (Crenshaw, 1990). The contemporary feminism movement focused mainly on the rights of middle- and upper-class white women, and the anti-racism movement focused primarily on African-American men. In both of these movements, African-American women were often left behind. Crenshaw created the term "intersectionality" and applied the framework to emphasize how "social movements and advocacy around violence against women ignored the vulnerabilities of women of color, especially those from immigrant and socially disadvantaged communities" (Carbado, Crenshaw, Mays, & Tomlinson, 2013). She argued that in situations where race, gender and class come together, such as in the experiences of abused women of color, interventions based exclusively on the experiences of women of a certain race or background will inadequately assist women who face different challenges due to class or race (Crenshaw, 1990).

Today, intersectionality has expanded beyond race and gender in the United States, and the framework has been used internationally to explore ethnicity, nationality, citizenship, socioeconomic status, politics and physical ability (Carbado et al., 2013). It is increasingly associated with quantitative and statistical methods since it can aid in understanding and interpreting the individual and combined effects of various categories in a given context (Atewologun, 2018). Researchers can apply the intersectional framework to strengthen analytical methods and explain how heterogeneous members of a specific group, such as women, might experience situations differently depending on their ethnicity, class, sexual orientation and/or other social complications (Atewologun, 2018). Awareness of these differences enhances insight into issues of inequality in organizations or institutions, therefore increasing the likelihood of social change.

1.2.2 Respectful maternity care

According to the World Health Organization (2018), respectful maternity care refers to "care organized for and provided to all women in a manner that maintains their dignity, privacy and confidentiality,

ensures freedom from harm and mistreatment, and enables informed choice and continuous support during labor and childbirth." Globally, studies have shown that women share similar perspectives of respectful maternity care. Shakibazadeh and colleagues (2018) suggest a conceptualization of respectful maternity care based on the review 67 primary qualitative studies from 32 countries. Using a combination of inductive and deductive approaches, researchers identified the following 12 domains of respectful maternity care:

1. Being free from harm and mistreatment;
2. Maintaining privacy and confidentiality;
3. Preserving the woman's dignity;
4. Prospective provision of information and seeking of informed consent;
5. Ensuring continuous access to family and community support;
6. Enhancing quality of physical environment and resources;
7. Providing equitable maternity care;
8. Engaging with effective communication;
9. Respecting women's choices that strengthen their capabilities to give birth;
10. Availability of competent and motivated human resources;
11. Provision of efficient and effective care; and
12. Continuity of care.

Research has also shown that midwives define respectful maternity care in a similar way. Butler, Fullerton and Aman (2020) conducted a Delphi survey of 895 participants from 90 member countries of the International Confederation of Midwives (ICM). Participants consisted of midwifery educators and clinicians from low-, medium- and high-income countries. One hundred and fifteen survey items were in agreement with the twelve domains of respectful maternity care listed above. The philosophy of respectful maternity care has been integrated into the knowledge, skills and professionalism that are fundamental in midwifery practice across ICM countries. This demonstrates the high value of respectful maternity care within the core of midwifery practice. Midwives consider respectful care as: providing care with empathy by establishing a friendly relationship and being with the woman; woman-centered care by keeping the woman safe and participating in decision-making; and protecting rights through safeguarding dignity and giving equal care (Moridi, Pazandeh, Hajian, & Potrata, 2020).

Currently there are four questionnaires that aim to assess respectful maternity care.To assess maternity care in Ethiopian public health facilities, Sheferaw, Mengesha and Wase (2016) developed a 15-item Respectful Maternity Care (RMC) scale based on qualitative and quantitative data consisting of four components: friendly care, abuse-free care, timely care and discrimination-free care. In Iran, Taavoni, Goldani, Gooran and Haghani (2018) developed the Quality of Respectful Maternity Care Questionnaire (QRMCQI) with 59 items measuring women's experiences during labor, childbirth and postpartum based on seven categories by the White Ribbon Alliance, an organization that aims to decrease maternal and newborn deaths globally. Another research team in Iran, Ayoubi and colleagues (2020) also developed a questionnaire called the Women's Perception-Respectful Maternity Care (WP-RMC) which has 19 items that measures women's care experiences during labor and childbirth in the

areas of comfort, participatory care and mistreatment. In Canada, Vedam and colleagues (2017) developed the Mothers on Respect Index (MORi) which is a 14-item scale assessing respectful maternity care based on interactions between women and their healthcare providers. The MORi scale has been used in surveys measuring quality, safety and human rights in childbirth in Canada (Vedam, Stoll, Rubashkin, et al., 2017). In the United States, the MORi scale has been used to research inequity and mistreatment among diverse populations, including women of color and women with low socioeconomic status (Vedam, Stoll, Taiwo, et al., 2019).

1.2.3 Autonomy in decision-making in maternity care

In patient-centered care, autonomy is defined as the "recognition of the undeniable right of a legally competent person to accept or decline medical care or intervention" (Beauchamp & Childress, 2009). When a woman has the autonomy to make decisions about her maternity care, it is important that she is making an informed choice when she accepts or declines care or interventions. Informed choice is the "deliberative process by which an individual makes a decision for or against a proposed intervention based upon good knowledge and understanding with little or no decisional conflict and consistent with the individual's values" (Lewis, Hill, & Chitty, 2017). If a woman accepts care or an intervention in maternity services, she is considered to have given her informed consent if her "intentional and voluntary authorization of a medical intervention has been given through a process in which a healthcare provider discloses information regarding the risks and benefits of the proposed intervention" (Beauchamp & Childress, 2009).

Autonomy in decision-making in maternity care can be complicated by individual, relational, social, cultural and political factors (Noseworthy, Phibbs, & Benn, 2013). Generally, women value the opportunity to be able to actively participate in maternity care planning which involves understanding and applying the best available evidence to their individual situations (Vedam, Stoll, McRae, et al., 2019). If women have enough time to make decisions about their maternity care, their sense of safety increases as well as their ability to determine their best options with or without minimal outside influence (Gee & Corry, 2012). Although encouraging the involvement of women in the decision-making process requires more time from healthcare providers, it can lead to better adherence to women's care plans (Trenaman et al., 2016). In order to minimize risk and maximize integrity in maternity care, women and their healthcare providers must have a relationship built on trust. Research has shown that in longer term relationships, there are higher levels of trust and a better flow of information which encourage a relationship based on shared responsibility and power between the woman and her healthcare provider (Hall, Tomkinson, & Klein, 2012). However, in unexpected situations where birth complications arise, a woman's autonomy may decrease as her vulnerability increases, and in these situations, decision-making is taken over by midwives and/or obstetricians (Noseworthy et al., 2013). In emergency obstetric situations, women have expressed that being able to trust that the midwife and/or obstetrician will make the right decision is important (Noseworthy et al., 2013).

When making important decisions about maternity care, women often experience difficulties understanding the information and evidence that is provided by healthcare professionals. For example, when women are offered labor induction, midwives and obstetricians control how evidence is presented,

and women consequently make their decisions based on what information is provided as well as the recommendations from institutions (Hall et al., 2012). Research also shows that women receive mixed messages in childbirth education which makes informed consent very challenging. For instance, midwives sometimes present information according to institutional policies instead of presenting the evidence, and as a result, women are often not completely informed about pain-relief methods such as the use of water during labor and/or birth or the use of epidural analgesia (Newnham, McKellar, & Pincombe, 2017).

Women also experience difficulties declining monitoring and interventions in a risk-adverse culture (Hall et al., 2012). Although woman-centered care is built on the concepts of partnership and shared responsibility with healthcare professionals in childbirth, some midwives and obstetricians feel that they are ultimately responsible for the important decisions that need to be made (Healy, Humphreys, & Kennedy, 2016). Furthermore, midwives' and obstetricians' perceptions of risk can have an effect on the decisions that women make during labor (Hall et al., 2012).

Shared decision-making is a "deliberative process of active engagement and collaboration between a healthcare provider and individual, which explores the available options of medical interventions for a particular condition, in order to implement a plan based upon the best available evidence and congruent with the individual's preferences values and needs" (Barry & Edgman-Levitan, 2012). If the relationship between the woman and her healthcare provider is based on open communication, collaboration and trust, there is an attentiveness to both the woman's and healthcare provider's integrities; however, if the relationship is characterized by conflict, judgment and defensiveness, there is less integrity which increases the sense of risk (Hall et al., 2012).

Maintaining a sense of control over decisions regarding maternity care is particularly important for women who face difficulties accessing healthcare due to poverty, race, immigration status or other barriers (Higginbottom, Bell, Arsenault, & Pillay, 2012). Socially disadvantaged women often do not feel safe enough to take control of their maternity care or partake in the discussion of their choices due to lack of information and consequences of not conforming to routine procedures (Ebert, Bellchambers, Ferguson, & Browne, 2014).

Currently, there is one instrument that has been developed to assess autonomy in decision-making in maternity care. In Canada, Vedam and colleagues (2017) developed the Mother's Autonomy in Decision Making (MADM) scale which consists of seven items and evaluates women's ability to take the lead when making decisions regarding their maternity care, whether they have enough time to consider their options and whether their choices are respected by healthcare professionals. The MADM scale has been incorporated into surveys assessing quality of maternity care in Canada, the United States and the Netherlands (Feijen-de Jong, van der Pijl, Vedam, Jansen, & Peters, 2019; Vedam, Stoll, Taiwo, et al., 2019; Vedam, Stoll, McRae, et al., 2019). The MADM scale has been used to study various populations including vulnerable groups of women. In the Canadian survey, respondents consisted of over 2,000 women who had experienced at least one pregnancy, and the sample included over 8% of women who were from a vulnerable group, i.e. self-identified as an immigrant or refugee or had a history of incarceration, homelessness or substance abuse (Vedam, Stoll, Martin, et al., 2017). In the American study, researchers used strategies to ensure strong representation of women of color resulting in a

sample consisting of over 15% of women who identified as ‘black’ and 3% who identified as Indigenous which represented the racial makeup of the country (Vedam, Stoll, Taiwo, et al., 2019). In the Netherlands, migrant women and women with low socioeconomic status were underrepresented in the Dutch study; thus, findings could not be confirmed about MADM scores for these groups (Feijen-de Jong et al., 2019).

1.2.4 Mistreatment in childbirth

In a statement by the World Health Organization in 2014, leaders in health care acknowledged that many women all over the world experience neglectful, abusive and disrespectful treatment in childbirth which violates their human rights and their rights to care. Mistreatment in childbirth is a violation of the fundamental rights of women and children and has been researched in both high- and low-income countries. Because of a general lack of agreement about the definition and evaluation of mistreatment of women during childbirth, Bohren and colleagues (2015) carried out a mixed-methods systematic review to develop an evidenced-based typology of the mistreatment of women during childbirth in health facilities worldwide. Using thematic analysis of 65 studies from 34 countries that explored the mistreatment of women during childbirth, researchers identified seven domains: physical abuse; sexual abuse; verbal abuse; stigma and discrimination; failure to meet professional standards of care; poor rapport between women and providers; and health system conditions and constraints (Table 1).

Table 1. WHO Typology of mistreatment of women during childbirth (Bohren et al., 2015).

Third-order themes	Second-order themes	First-order themes
Physical abuse	*Use of force*	*Women beaten, slapped, kicked or pinched during delivery*
	Physical restraint	*Women physically restrained to the bed or gagged during delivery*
Sexual abuse	*Sexual abuse*	*Sexual abuse or rape*
Verbal abuse	*Harsh language*	*Harsh or rude language*
		Judgmental or accusatory comments
	Threats and blaming	*Threats of withholding treatment or poor outcomes*
Stigma and discrimination	*Discrimination based on sociodemographic characteristics*	*Discrimination based on ethnicity/religion*
		Discrimination based on age
		Discrimination based on socioeconomic status
	Discrimination based on medical conditions	*Discrimination based on HIV status*
Failure to meet professional standards of care	*Lack of informed consent and confidentiality*	*Lack of informed consent process*
		Breaches of confidentiality
	Physical examinations and procedures	*Painful vaginal exams*
		Refusal to provide pain relief
		Performance of unconsented surgical operations
	Neglect and abandonment	*Neglect, abandonment or long delays*
		Skilled attendant absent at time of delivery
Poor rapport between women and providers	*Ineffective communication*	*Poor communication*
		Dismissal of women's concerns
		Language and interpretation issues
		Poor staff attitudes
	Lack of supportive care	*Lack of supportive care from health workers*
		Denial or lack of birth companions
	Loss of autonomy	*Women treated as passive participants during childbirth*
		Denial of food, fluids or mobility
		Lack of respect for women's preferred birth positions
		Denial of safe traditional practices
		Objectification of women
		Detainment in facilities
Health system conditions and constraints	*Lack of resources*	*Physical condition of facilities*
		Staffing constraints
		Staffing shortages
		Supply constraints
		Lack of privacy
	Lack of policies	*Lack of redress*
	Facility culture	*Bribery and extortion*
		Unclear fee structures
		Unreasonable requests of women by health workers

Note: The first-order themes are identification criteria describing specific events or instances of mistreatment. The second- and third-order themes further classify these first-order themes into meaningful groups based on common attributes.

The prevalence of mistreatment in childbirth has been largely researched in developing countries. In Ghana, Guinea, Myanmar and Nigeria, one-third of mothers, particularly uneducated younger women, experience some form of physical or verbal abuse, discrimination (Bohren et al., 2019). In India, 28% of women report mistreatment such as violation of privacy, forced birth positions, vaginal examinations without consent, no birth companions and perineal shaving (Sharma, Penn-Kekana, Halder, & Filippi, 2019). In Ethiopia, the prevalence of disrespect and abuse during maternity care and childbirth is over 49% (Kassa & Husen, 2019). In Pakistan, approximately 97% of women experience some form of disrespectful or abusive behavior with non-consented care being the most reported type of mistreatment (Hameed & Avan, 2018).

Mistreatment in childbirth has also been recently researched in the United States. To assess the prevalence of mistreatment in childbirth Vedam and colleagues (2019) developed the Mistreatment by Care Providers in Childbirth (MCPC) indicators based on the aforementioned WHO Typology of Mistreatment by Bohren and colleagues (2015). The MCPC indicators are seven items that ask about physical abuse, verbal abuse, failure to meet professional standards of care, poor rapport with healthcare providers and privacy. In a survey of 2,138 mothers in the United States, over 17% of experienced mistreatment during childbirth, and the most common forms of mistreatment are: loss of autonomy; being shouted at, scolded or threatened; and being ignored, refused or receiving no response to requests for help (Vedam, Stoll, Taiwo, et al., 2019). Women who gave birth in a hospital-setting were more likely to be mistreated compared to women who gave birth at home. Factors that were associated with a lower likelihood of mistreatment were vaginal birth, community birth, a midwife, white skin color, multiparity and age older than 30 years. Women of color with low socioeconomic status were more likely to experience mistreatment compared to white women with low socioeconomic status (Vedam, Stoll, Taiwo, et al., 2019).

1.3 Aims

Currently, research is lacking in the area of migrant women receiving maternity care in Iceland. In order to improve services for this vulnerable and quickly growing population, it is imperative that a survey exploring respect in maternity care, autonomy in decision-making and mistreatment is conducted among women in this group. A study of this kind could also contribute to the current global research on maternal healthcare for migrant women by demonstrating the use of the Mothers on Respect index (MORi), the Mother's Autonomy in Decision Making (MADM) scale and Mistreatment by Care Providers in Childbirth (MCPC) indicators as effective instruments in measuring quality of care in vulnerable populations (Feijen-de Jong et al., 2019; Vedam, Stoll, Martin, et al., 2017; Vedam, Stoll, Rubashkin, et al., 2017; Vedam, Stoll, Taiwo, et al., 2019; Vedam, Stoll, McRae, et al., 2019). The aim of this master's thesis in midwifery is to develop and pretest a survey in English and Polish that assesses the experiences of foreign women who have received maternity care services in Iceland in regard to respect, autonomy in decision-making and mistreatment through the utilization of internationally recognized and standardized instruments.

2 Methods

In this chapter, survey development and international standardized instruments are described in detail followed by a description of the process of translation and back-translation of the survey to Polish. Then, the process of pretesting and written evaluations of the survey will be explained along with the requirements and recruitment methods for participants. Lastly, ethical considerations will be discussed.

2.1 Survey development

The survey was developed to capture client-oriented data on maternity care experiences among women of foreign origin living in Iceland using the MORi, MADM and MCPC instruments (Vedam, Stoll, Martin, et al., 2017; Vedam, Stoll, Rubashkin, et al., 2017). The survey furthermore includes questions about sociodemographic characteristics such as age, relationship status, education, employment, residency status and migration background and birth and neonatal outcomes (Appendices A, B, C and D).

2.1.1 Background questions

In the developmental stage of the survey questions, it was considered important to collect data on sociodemographic characteristics at the time of childbirth, such as age, relationship status, education, employment, residency status and migration background, in order to describe the sample. Sociodemographic questions were placed in the beginning of the survey to ensure a higher response rate for the sociodemographic characteristics of the sample (Polit & Beck, 2017). Questions about age, relationship status, education, birth outcomes and neonatal outcomes were based on information from the Icelandic Birth Register (Icelandic: Fæðingaskrá), information from antenatal records from the Icelandic electronic patient record system *Saga* and items from the original Canadian survey assessing women's experiences of respect and autonomy in decision-making in maternity care (Vedam, Stoll, Martin, et al., 2017; Vedam, Stoll, Rubashkin, et al., 2017; Vedam, Stoll, McRae, et al., 2019).

Questions about income, employment, migration background, residency status and religion were based on information from the National Statistical Institue of Iceland (Icelandic: Hagstofa Íslands) which processes and disseminates data on Icelandic economy and society. This approach in developing the survey questions was taken in order to be able to easily compare information with prior research and population-based data.

Migrant women often encounter challenges in maternity care services due to language barriers, immigrant status, cultural differences in newborn feeding practices and higher rates of neonatal complications (Almeida et al., 2013; Fair et al., 2020; Hennegan et al., 2014; Origlia Ikhilor et al., 2019; Yelland et al., 2016). The prevalence of these challenges in maternity care have not been researched in Iceland. Due to issues with retrieving information from data collection systems and insufficient record-keeping, it has not been possible to research migrant women's birth outcomes and neonatal outcomes in Iceland in relation to factors such as residency status (in particular, refugee or asylum seeker status), number of years residing in Iceland, household income, self-identification as woman of color and language proficiency in Icelandic and/or English. Therefore, it was important to include questions about these factors in the survey.

Women of foreign origin are considered to be a socially vulnerable group who often experiences lack of support, social isolation and depression during pregnancy and childbirth in the new country (Almeida et al., 2013; Barkensjö et al., 2018; Crowther & Lau, 2019; Essen et al., 2000; Fair et al., 2020; Ganann, Sword, Black, & Carpio, 2012; Origlia Ikhilor et al., 2019; Schmidt et al., 2018; Yelland et al., 2016). Therefore, questions about social complications were included such as housing problems, financial difficulties, lack of support, physical abuse, mental abuse, anxiety, depression and difficulty accessing health care.

Generally, this group of women has reported different birth experiences when compared to the experiences of their native counterparts (Bohren et al., 2019; Chu et al., 2017; Crowther & Lau, 2019; Ebert et al., 2014; Hennegan et al., 2014; Sami et al., 2019; Vedam, Stoll, Taiwo, et al., 2019). Furthermore, diversity is increasing within the population of migrant women in Iceland (Statistics Iceland, 2019). It was also important to be able to differentiate among the many subgroups which can be categorized by country of origin, religious background, language or length of residence in Iceland. Differences in birth experiences and outcomes may exist among these different subgroups (Barkensjö et al., 2018; Bollini, Stotzer, & Wanner, 2007; Sami et al., 2019). For instance, university-educated, English-speaking women who have lived in Iceland for more than five years may have completely different experiences and birth outcomes when compared to non-English speaking women who have completed primary school education and have lived in Iceland for less than a year. For these reasons, it was necessary to include questions about pregnancy complications, birth outcomes and newborn health which may be representative of the care that they received.

Migrant women benefit from continuity of maternity care (Fair et al., 2020; Lyberg et al., 2012; Shakibazadeh et al., 2018); however, in the Capital Area of Reykjavík where over 75% of births occur (Jónasdóttir & Eiríksdóttir, 2019), the maternal health care system is fragmented, and many women receive services from several different healthcare providers throughout pregnancy, childbirth and postpartum. Research shows that negative encounters with care providers can cause emotional distress and fear while positive encounters can promote trust, empowerment and a sense of relief (Barkensjö et al., 2018). Therefore, it was deemed necessary to include questions that required participants to rate the different levels of respect they experienced from their different care providers to gain a more accurate understanding of their encounters. Three questions asking to rate the level of respect that the participants perceived from each care provider during pregnancy, childbirth and the postpartum period were adapted from the Canadian survey and added to this survey (Vedam, Stoll, Martin, et al., 2017; Vedam, Stoll, Rubashkin, et al., 2017; Vedam, Stoll, McRae, et al., 2019). Answer options included rating perceived levels of respect from different health care providers such as midwives, midwifery students, obstetricians, general practitioners, anesthesiologists and neonatologists.

It has been reported that both women of foreign origin and health care professionals experience difficulties accessing and utilizing interpretation services (Ahrne et al., 2019; Almeida et al., 2013; Crowther & Lau, 2019; Higginbottom et al., 2014; Pelaez et al., 2017; Reitmanova & Gustafson, 2008). Lack of adequate interpretation services or the use of unprofessional interpreters (i.e. family members or friends) can lead to miscommunication and difficulties accessing services and/or reliable information

(Essen et al., 2000; Origlia Ikhilor et al., 2019; Sami et al., 2019; Yelland et al., 2016). Therefore, two questions were added about client use of and satisfaction with interpreters.

Thirty-nine questions about sociodemographic characteristics at the time of childbirth, social complications, language proficiency, birth outcomes, neonatal outcomes, perceived respect in maternity care and interpretation services were reviewed by an expert panel consisting of a midwifery Professor (Dr. Helga Gottfreðsdóttir) and a practicing midwife and Assistant Professor (Dr. Emma Marie Swift) who were knowledgeable in the field of migrant women receiving maternity care. The panel of experts' job was to evaluate individual items and consider whether the items taken as a whole adequately cover the construct domain (Polit & Beck, 2017).

2.1.2 International standardized instruments

The survey questions were adapted to the Icelandic maternity care system in collaboration with a researcher (Dr. Kathrin Stoll) from the team that originally developed the MORi and MADM scales in Canada. By including the MORi, MADM and MCPC items, the survey aimed to look at respect, autonomy and mistreatment as experienced by participants. The following three sections discuss each of the three instruments in detail.

Mothers on Respect Index (MORi)

There are currently three instruments that aim to assess women's experiences of respectful maternity care (Ayoubi et al., 2020; Sheferaw et al., 2016; Vedam, Stoll, Rubashkin, et al., 2017). Developed by Vedam and colleagues (2017), the MORi scale was chosen to be used in this survey because it has been tested internationally and focuses on assessing quality, safety and women's rights in maternity care. MORi is "a reliable, client-informed quality and safety indicator that can be applied across jurisdictions to assess the nature of provider-patient relationships, and access to person-centered maternity care" (Vedam, Stoll, Rubashkin, et al., 2017). The 14-item scale was administered with a 6-point Likert response format (strongly disagree, disagree, slightly disagree, slightly agree, agree and strongly agree) as recommended by the researchers who developed the index to capture the complexity of a woman's experience of respectful care (Vedam, Stoll, Rubashkin, et al., 2017). It evaluates respectful maternity care based on client-provider interactions and the impact of these interactions on a person's sense of comfort, behavior and perceptions of discrimination or racism (Vedam, Stoll, Rubashkin, et al., 2017). Because the focus of this study is on immigrant women, the adapted 17-item MORi Scale including Perceptions of Racism items, which was adapted for use in the United States, was used in this survey (Vedam, Stoll, Taiwo, et al., 2019); therefore, questions 11, 12 and 17 were added (See Table 2). For item nr. 17: "How often have you felt treated unfairly because of your race, heritage or ethnic group?" possible responses were: never, rarely, sometimes, often, very often and always.

Table 2. Mothers on Respect Index including Perceptions of Racism items. Vedam, Stoll, Taiwo, et al. (2019)

MORi scale items
Overall while making decisions during my pregnancy, I felt:
1. *Comfortable asking questions.*
2. *Comfortable declining care that was offered.*
3. *Comfortable accepting the options for care that my (midwife, doctor) recommended.*
4. *Pushed into accepting the options my (midwife, doctor) suggested. (reverse scored)*
5. *I chose the care options that I received.*
6. *My personal preferences were respected.*
7. *My cultural preferences were respected.*
During a prenatal visit I held back from asking questions or discussing my concerns because:
8. *My midwife/doctor seemed rushed. (reverse scored)*
9. *Because I wanted maternity care that differed from what my midwife/doctor recommended. (reverse scored)*
10. *I thought my midwife/doctor might think I was being difficult. (reverse scored)*
11. *I felt discriminated against.*
12. *My care provider used language I could not understand.*
When I had my baby, I felt that I was treated poorly by my midwife/doctor:
13. *Because of my race, ethnicity, cultural background or language. (reverse scored)*
14. *Because of my sexual orientation and/or gender identity. (reverse scored)*
15. *Because of my health insurance. (reverse scored)*
16. *Because of a difference in opinion with my caregivers about the right care for myself or my baby. (reverse scored)*
17. *How often have you felt treated unfairly because of your race, heritage or ethnic group?*

Mother's Autonomy in Decision Making Scale (MADM)

The MADM scale has proven to be "a reliable instrument for assessing the experience of decision-making during maternity care" (Vedam, Stoll, Martin, et al., 2017). The 7-item scale (Table 3) was developed and validated by members of the community from various populations of childbearing women in Canada, including women from vulnerable populations. The 7-item scale was administered with a 6-point Likert response format (strongly disagree, disagree, slightly disagree, slightly agree, agree and strongly disagree). The MADM measures a woman's ablility to take the lead when making decisions about her maternity care, whether she was given enough time to consider her options, and whether her choices were respected. In a reliable manner, it assesses interactions and communication with maternity providers and a woman's ability to lead in decision-making throughout her maternity care (Vedam, Stoll, Martin, et al., 2017).

Table 3. Mother's on Autonomy in Decision Making Scale (MADM). Vedam, Stoll, Martin, et al. (2017).

MADM scale items
1. *My provider asked me how involved in decision-making I wanted to be.*
2. *My provider told me that there are different options for my maternity care.*
3. *My provider explained the advantages/disadvantages of the maternity care options.*
4. *My provider helped me understand all the information.*
5. *I was given enough time to thoroughly consider the different care options.*
6. *I was able to choose what I considered to be the best care options.*
7. *My provider respected that choice.*

Mistreatment by Care Providers in Childbirth (MCPC)

In addition to the MORi and MADM scales, the MCPC indicators were included to measure domains that align with the WHO Typology of Mistreatment items such as stigma, failure to meet professional standards of care, lack of informed consent and loss of autonomy (Bohren et al., 2019). The MCPC indicators have been used when conducting research in the United States, and the items have been designed and validated to assess mistreatment in childbirth (Vedam, Stoll, Taiwo, et al., 2019). Because immigrant women are considered a vulnerable population, it was deemed necessary to inquire about mistreatment during childbirth to obtain a more complete picture of their experiences (Table 4).

Table 4. Mistreatment by Care Providers in Childbirth Indicators (MCPC). Vedam, Stoll, Taiwo, et al. (2019).

Physical Abuse	1.	*Did you experience physical abuse (including aggressive physical contact, inappropriate sexual conduct, a refusal to provide anesthesia for an episiotomy, etc.)?*
Verbal Abuse	2.	*Did health care providers scold or shout at you?*
	3.	*Did health care providers threaten you in any other way?*
Failure to meet professional standards of care	4.	*Was your private or personal information shared without your consent?*
	5.	*Was your physical privacy violated (i.e. being uncovered or having people in the delivery room without your consent)?*
	6.	*Did your midwife/doctor explain different options for care during your labor and birth?*
	7.	*Did your midwife/doctor ask you what you wanted to do before the following procedures were done: (episiotomy, continuous fetal monitoring, screening tests, etc).*
	8.	*Did health care providers ignore you, refuse your requests for help or fail to respond to requests for help in a reasonable amount of time?*

2.2 Translation

The background questions and standardized instruments were originally written in English; therefore, the survey needed to be translated to Polish in order to collect information from the largest group of female immigrants in Iceland. Although cross-cultural and international collaborative studies have gained popularity over the past few decades, experts have yet to agree on the best method for translating instruments (Chen & Boore, 2010; Wang, Lee, & Fetzer, 2006). The most common and highly recommended method is forward-backward translation (Brislin & Freimanis, 2001; Chen & Boore, 2010). This method has been improved over the years and applied to several WHO studies. Implementation of this method includes the following steps: 1) Forward translation; 2) Back-translation; 3) Pretesting; and 4) Final version (Chen & Boore, 2010; Shigenobu, 2007; WHO, n.d.). This method is recommended when the researcher has limited knowledge of the target language and must rely on translators, and backward translation is used to ensure the quality of the translations and to be able to create or modify items that will be understandable to respondents (Brislin & Freimanis, 2001). Although forward-

backward translation is a more costly and time-consuming method than simple forward-translation, it achieves a higher level of rigor (Chen & Boore, 2010).

The survey questions were first written in English and later translated into Polish using professional translation services. For the translation of the survey from English to Polish, the forward-backward translation process was used since the focus was on cross-cultural and conceptual equivalence rather than on linguistic or literal similarity. First, the consent form and survey items were translated from the original language (English) to the target language (Polish). Next, the resulting Polish version of the survey was translated back to English. Then, the researcher compared the original survey and back-translated survey to evaluate the quality of translation and cross-cultural and conceptual equivalence. A small group of Polish-speaking women who fulfilled the eligibility requirements pretested the survey and provided feedback. To assess difference in wording in the Polish version, a Polish midwife with good understanding of English and Icelandic, as well as good understanding of the Icelandic setting, was consulted. In collaboration with the Polish-speaking midwife and using feedback from Polish community members who pretested the survey, items were revised resulting in the final version of the survey in Polish.

2.3 Pretesting and written evaluations

The objective of pretesting the survey was to evaluate whether migrant women who speak either English or Polish were able to access, understand and answer an online survey about respect, autonomy in decision-making and mistreatment in Icelandic maternity care. Specifically, the aim of pretesting was to evaluate: 1) the functionality and format of the online survey; 2) comprehension of the survey items and tasks; 3) comprehensive answer options; and 4) the length of time required to complete the survey. The written evaluation included questions that were based on cognitive methods of pretesting survey instruments (Collins, 2003). Derived from social and cognitive psychology, these methods explore the process of how respondents answer survey question items. By pretesting questions in the survey context, it was possible to determine whether respondents understood the questions, concepts and tasks consistently in a way the researcher intended (Polit & Beck, 2017). Using the Task-focused model to classify possible measurement error, ten feedback questions were based on the following components: 1) Comprehension problems resulting from wording or sentence structure; 2) Validity problems resulting from different interpretations of the survey question; 3) Processing difficulties due to inability to retrieve information necessary to answer the survey question; and 4) Communication difficulties (Collins, 2003) (See Table 5). One question about the structure and flow of the survey questions was added along with another question about whether the participant would recommend the survey to a family member or friend. These two questions were added to the written evaluation to assess whether or not the online survey was considered to be user-friendly. In addition, three questions about the length of time to complete the survey were included. In internet-based surveys, shorter questionnaires have a higher response rate (Deutskens, De Ruyter, Wetzels, & Oosterveld, 2004).

Table 5. Task-focused model components of measurement error and corresponding feedback questions

Component of measurement error	Feedback Questions
Comprehension problems	*Were there any words or sentences that you did not understand?*
Validity problems	*Were any of the instructions unclear?*
	Did you understand all of the questions?
Processing difficulties	*Did you think the survey was easy to access?*
	Were there any questions that you thought were inappropriate?
	Were all of the answer options available for your answers?
	Did any of the questions make you feel uncomfortable?
Communication problems	*Were there any spelling or grammatical errors?*
	Were the questions easy to read?
	At any point in the survey, was there too much text?

To evaluate the appropriateness of the survey in terms of grade level of reading required to understand the survey, the Flesh-Kincaid reading level test was used. We aimed to have the reading level of the survey at level 7 or lower because research has shown that a lower reading level is ideal for a population that includes people with limited education (Norman & Streiner, 2008). Participants from the community of foreign women living in Iceland were recruited to pretest both the English and Polish versions of the online survey and sent instructions along with evaluation questions about the length of time, language, comprehension, answer options, structure and design of the survey (Appendix E). Participants were informed about the aims of the survey and the objective of the written evaluations. Upon completion of the online survey and written evaluations, participants sent their feedback to the researcher through email.

2.4 Participants for pretesting

Women of foreign origin who have given birth in Iceland between 2015 and 2020 and who are proficient in either English or Polish could participate in pretesting. This group of participants was chosen because it is representative of members of the community that the survey aims to target. Particpants were asked to answer survey questions according to their most recent pregnancy and childbirth. In order to identify problem areas, minimize respondent burden, reduce measurement error, assess readability and comprehension, a small sample of women representing the target population was invited to participate in pretesting and writing evaluations. Purposive and snowball sampling were used to recruit participants fulfilling the aforementioned requirements to pretest the survey either in English or Polish. To gain valuable input from members of the community, a mininum og 10 English-speaking women and 5 Polish-speaking women was required to pretest the survey. On February 11th, 2020, an announcement for potential participants was advertised through social media in Facebook groups which included members from the target population, e.g. “Women of Multi-ethnic Network in Iceland”, “Iceland’s International

Parents", "Foreigners in Iceland", "Far away from home, living in Iceland", "Americans living in Iceland" and "Polish living in Iceland." Potential candidates were asked to contact the lead investigator via email in order to receive information and possibly take part in the pretesting and written evaluation processes. Polish-speaking participants were required to be able to communicate, read and give feedback in English.

2.5 Data analysis

Data analysis of the participants who pretested the survey was conducted using the Statistical Package for the Social Sciences (SPSS) program. Descriptive statistics were used to describe the sample of participants. Age, a continuous variable, was recoded into higher and lower than the mean age. The following sociodemographic items were included in the analysis: relationship status (single, living together, married, widowed, divorced, other), country of origin, residency status (refugee, asylum seeker, temporary resident, permanent resident, citizen of the European Economic Area, Icelandic citizen, other), place of residence (Capital area of Reykjavík, West Iceland, West Fjörds, North Iceland, East Iceland, South Icelandm Reykjanes), level of education (no formal education, primary education, secondary education, university education) and employment status (employed, student, working at home, disability, unemployed, other).

In addition, the following maternal health characteristic items were also described: parity (primipara, multipara), social complications (housing problems, financial difficulties, lack of support from friends and family, difficulty accessing health care, physical abuse, mental abuse, anxiety, depression), pregnancy complications (bleeding, anemia, high blood pressure, gestational diabetes, placenta problems, infection, Group B Streptococcus positive infection, problems with baby's growth, problems with baby's position, twins or more, premature labor), mode of delivery (vaginal, cesarean section), use of epidural analgesia, induction of labor, infant feeding (breastfeeding only, formula-feeding only, combination of breast- and formula-feeding) and neonatal complications (breathing problems, digestive tract problems, jaundice, birth defects, low weight gain, dehydration, stillbirth, born too early, congenital or genetic problems). Furthermore, social complications, pregnancy complications and neonatal complications were nominal variables which were recoded. Social complications were recoded into three categories (no complications, 1 complication, ≥2 complications). Pregnancy complications were recoded into two categories (no complications, ≥1 pregancy complication). Neonatal complications were also recoded into two categories (no complications, ≥1 neonatal complication).

The MORi and MADM scale scores were calculated using SPSS by adding the sum of the items for each scale. The English and Polish versions the MORi scale that was adapted to the Icelandic setting consisted of 17 items rated on a 6-point Likert scale and thus, had a theoretical range of 17 to 102. As in the Canadian, American and Dutch studies, it was also possible to calculate MORi scores for 14 items (item nr. 1-10 and 13-16) rated on a 6-point Likert scale with a theoretical range of 14 to 84. MORi scale items nr. 4, 8, 9, 10, 11, 12, 13, 14, 15, 16 and 17 were reversed scored. A higher score indicated more experiences of respect in maternity care. The English and Polish versions of the MADM scale that was adapted to the Icelandic setting consisted of seven items rated on a 6-point Likert scale and had a

theoretical range of 7 to 42. Median scores were reported for the MORi and MADM scales because the scores were not normally distributed.

Finally, data from MCPC indicators were analyzed. Since each of the six indicators had its own corresponding variable in the data set, the six variables were grouped into one variable which counted the total number of mistreatment indicators for each respondent. SPSS was used to calculate the number of respondents who experienced at least one occurence of mistreatment and each respondent‘s total number of mistreatment indicators.

2.6 Survey platform

The survey was made accessible online using Research Electronic Data Capture (REDCap), a safe web application used for developing and conducting online surveys and databases. The application was specifically intended to support online and offline data collection for research. Originally, the survey included three eligibility questions and 64 survey questions before pretesting. Data analysis was conducted to test the process of extracting data from REDCap and entering it into SPSS.

2.7 Ethical considerations

The Icelandic Data Protection Authority (Icelandic: Persónuvernd) was contacted, and according to the recently passed law nr. 90/2018, compulsory notification and approval was not necessary for this survey. In order to participate, women were required to self-register and were able to stop participating at any time. A letter of consent including information about the survey preceded the questions for eligibiltiy (Appendices A and B). By clicking on the “Start” button in the online survey, participants indicated informed consent. All answers were anonymous. In the event that the survey brought up difficult emotions or issues, participants were directed towards resources that could provide them with support through “Lend me your ear” (Icelandic: Ljáðu mér eyra) or a psychologist at their local health clinic. If a participant admitted to being a victim of abuse, she received information in either English or Polish about the Women’s Shelter (Icelandic: Kvennaathvarf). The results of the survey were stored anonymously on a password-locked computer only accessible by the research team at the University of Iceland.

3 Findings

In this section, the findings of the study will be reported. First, the results of the translation process of the survey to Polish will be explained. Then, the results from the written evaluations from the pre-testers about the survey questions will be presented. Lastly, sociodemographic, obstetric characteristics and the MORi and MADM median scores will be described along with MCPC indicators for the participants involved in the pretesting stage.

3.1 Polish translation of survey

On comparison, the original version of the English survey and the backward-translation were found to be very similar. Overall, backtranslation of the sentences, language, meaning and wording was equivalent with the exception of the wording of 10 questions. These ten questions were back-translated with different wording from the original text (Table 6).

Table 6. Differences between ten original and back-translated survey questions in English.

Question nr.	Original English text	Back-translated text
3	Which statement about your ethnicity do you agree with?	Which statement about your origin do you agree with?
24	Overall while making decisions during my pregnancy, I felt coerced/pushed into accepting the options my midwife/doctor suggested.	Overall while making decisions at the time of pregnancy, I felt I was forced to accept the care options offered by my midwife/doctor.
25	Overall while making decisions during my pregnancy, I felt I chose the care options that I received.	Overall, while making decisions at the time of pregnancy, I felt I decided to make use of the recommended care options.
28	During a prenatal visit I held back asking questions or discussion my concerns because my midwife/doctor seemed rushed.	I refrained from asking questions or discussing my concerns during prenatal visits because my midwife/doctor seemed to be in a hurry.
30	During a prenatal visit I held back asking questions or discussing my concerns because I thought my midwife/doctor might think I was being difficult.	I refrained from asking questions or discussing my concerns during prenatal visits because it seemed that the midwife/doctor thought I was causing problems.
32	During a prenatal visit I held back asking questions or discussing my concerns because I felt my midwife/doctor did not value my opinion.	I refrained from asking questions or discussing my concerns during prenatal visits because it seemed the midwife/doctor was not interested in my opinion.
40	When I had my baby, I felt that I was treated poorly by my midwife/doctor because of a difference in opinion with my caregivers about the right care for myself or my baby.	I felt that my midwife/doctor treated my badly after giving birth because of a difference in opinion with my caregivers about the right care for myself or my baby.
44	My provider explained the advantages/disadvantages of the maternity care options.	My guardian explained the advantages/disadvantages of the maternity care options.
45	My midwife/doctor helped me understand all the information.	My midwife/doctor helped me understand the whole procedure.

Upon further inspection and consultation with a Polish midwife, three of the questions (Questions 40, 44 and 45) were found to require rewording in Polish to ensure cultural and literal equivalency (Table 7). In Question 40: “When I had my baby, I felt that I was treated poorly by my midwife/doctor because of a difference in opinion with my caregivers about the right care for myself or my baby” and Question 44: “My provider explained the advantages/disadvantages of the maternity care options,” the words ‘caregivers’ and ‘provider’ were both back-translated as ‘guardians’ which lead to a misunderstanding of the questions. To resolve this misunderstanding, the head researcher and Polish midwife decided to replace the word “opiekunów” (English: caregiver) with the words “midwife/doctor” (English: położna/lekarz) in the Polish version of both of the questions.

In Question 45: “My midwife/doctor helped my understand all the information,” the phrase ‘all the information’ was back-translated to ‘the whole procedure’ which have two different meanings. Use of the wording ‘całą procedurę’ (English: the whole procedure) implies that the participant is only answering for understanding one procedure during maternity care as opposed to understanding all of the information provided by healthcare providers about different options for care. In collaboration with the Polish midwife, the wording ‘całą procedurę’ (English: the whole procedure) was replaced with ‘wszystkie informacje’ (English: all the information).

Table 7. Original and improved Polish version of three survey questions requiring rephrasing in Polish after the back-translation process

Question nr.	Original Polish translation	Improved Polish translation
40	Po urodzeniu dziecka, czułam, że moja położna/lekarz źle mnie traktowali z powodu różnicy opinii moich opiekunów na temat opieki mojej lub mojego dziecka.	Po urodzeniu dziecka, czułam, że moja położna/lekarz źle mnie traktowali z powodu różnicy opinii moją położną/ lekarzem na temat opieki mojej lub mojego dziecka.
44	Moja położna/lekarz wyjaśnił mi zalety/wady dostępnych opcji mojej opieki położniczej.	Moja położna/lekarz wyjaśniły zalety/wady opcji opieki położniczej
45	Moja położna/lekarz pomogli mi zrozumieć całą procedurę.	Moja położna/lekarz pomogli mi zrozumieć wszystkie informacje.

3.2 Participants in pretesting

After two days of advertising for English-speaking participants through social media, the minimum requirement of 10 participants for the English pretest was reached. After four days of advertising for Polish participants through social media, the minimum of five participants was reached. In all, a total of 17 women participated. Eleven English-speaking and six Polish-speaking participants pretested the survey. All participants fulfilled the following requirements to participate: 1) woman of foreign origin living in Iceland at time of childbirth; 2) childbirth between 2015 and 2020; and 3) language proficiency in English or Polish.

3.3 General feedback of survey questions

Participants answered 16 feedback questions about the survey (Appendix E), and all seventeen reported that the survey was easily accessible on the internet using computers and mobile devices (Table 8). Participants found the length of the survey to be satisfactory, and none of the participants needed to take a break from answering questions. In general, participants agreed that the amount of text in the survey was appropriate. In the final version, the survey consisted of three eligibility questions, and 64 survey questions. Errors in the survey format were fixed in REDCap. Using the Flesch-Kincaid reading level test in Microsoft Word version 16.35, the survey items in English were evaluated to be at the seventh-grade reading level. Overall, the participants reported that the structure was consistent and the survey was comprehensive and professional. On average, participants completed the survey in 19.7 minutes.

Table 8. Pretest survey participants' answers to close-ended feedback questions about completing the survey (N=17)

Feedback questions	Answer	N (%)
1. Did you think the survey was easy to access?	Yes	17 (100)
2. Did you like the structure and flow of the survey questions?	Yes	17 (100)
3. Were the instructions clear?	Yes	15 (88.2)
4. Were the questions easy to read?	Yes	15 (88.2)
5. Did you understand all of the questions?	Yes	15 (88.2)
6. Were there any questions that you thought were inappropriate?	No	17 (100)
7. Did any of the questions make you feel uncomfortable?	No	17 (100)
8. Were all of the options available for your answers?	Yes	5 (29.4)
9. At any point in the survey, was there too much text?	No	17 (100)
10. Would you recommend this survey to a family member or friend?	Yes	17 (100)
11. Did you think the survey was too long?	No	17 (100)
12. Did you need to take a break from answering the questions?	No	17 (100)
13. How long did it take you to complete the survey?	19.7 min.	

*Average time calculated from participants' responses.

3.4 Pretesting of the survey questions

Written evaluations from participants who pretested the survey were grouped into the following four categories: 1) Comments on language and wording; 2) Comments on comprehensibility; 3) Comments on answer options; and 4) Comments on structure and design (Table 9). In total, the participants had 2 comments on language and wording, two comments on comprehensibility, five comments regarding answer options and two comments about structure and design.

Because the survey platform is provided by the University of Iceland, five action buttons on the survey were in Icelandic. Participants indicated that it would be useful to include the translation of the commands „Næsta síða" (English: Next page), „Fyrri síða" (English: Previous page), „Vista og halda áfram síðar" (English: Save and complete later), „Hreinsa" (English: Clear), and „Staðfesta" (English:

Confirm). Correspondingly, translations of these commands in English and Polish were added to the survey (Appendices A and B). There was one issue with the survey format on mobile devices (e.g. smartphones) when answering Questions 17-19. Using a matrix, pre-testers were asked to rate the level of respect from 0 to 100 for each of the healthcare professionals who provided maternity care. To resolve this problem, a sliding scale was used in the survey instead of a matrix format (Appendices C and D. Participants also expressed that more answer options were needed in Questions 17-19, as in the case of a woman who received care from multiple midwives in labor and childbirth. One participant indicated that "it was not clear how to answer questions that seemed to presume that one interacted with a single midwife or nurse. I provided an 'average' opinion but I am not sure this really reflects my experience." To address this concern, answer options were changed to have the possibility to report level of respect scores for up to three midwives in antenatal care, three midwives in intrapartum care and three midwives in postpartum care (Appendices C and D).

One of the eligibility questions (Eligibility Question 1) and three of the survey questions (Questions 13, 35 and 41) required changes in wording and more clarification. In Eligibility Question 1: "Are you an immigrant woman living in Iceland?", one participant suggested using the description 'woman of foreign origin' instead of 'immigrant woman' which has a negative connotation. Thus, Eligibility Question 1 was changed to: "Are you a woman of foreign origin living in Iceland?" which has a more positive connotation. Five participants also indicated that wording needed to be changed in Question 13: "What was your annual household income?" because answer options reflected income ranges for monthly household income. In Iceland, monthly income is more commonly reported in surveys as opposed to annual income which is more commonly reported in other countries such as Canada and the United States. Therefore, Question 13 was changed to: "What was your average monthly household income?" and included the same income ranges for monthly household income. Four participants also pointed out that Question 35: "Did a family member or friend who was not a certified interpreter interpret for you at any time during maternity care?" was confusing and needed to be worded more clearly and concisely. Upon reflection, Question 35 was reworded as follows: "Did a family member or friend interpret for you at any time during maternity care?" to reflect this concern. Lastly, when answering Question 41: "How often have you felt treated unfairly because of your race, heritage or ethnic group?" four participants expressed that it was unclear whether the question referred to feeling treated unfairly in maternity care settings or in general. Because the aim of the self-administered questionnaire is to assess respect, autonomy and mistreatment in maternity care in Iceland, Question 41 was changed to: "How often have you felt treated unfairly because of your race, heritage or ethnic group during maternity care?" for clarification.

Participants also commented on the response options of a few of the survey items. One participant pointed out that changes needed to be made to Question 4 regarding the categorization of religious groups. In particular, the participant pointed out that the option of choosing Catholic or Christian was confusing since the largest branches of the Christian religion are Catholicism, Protestantism and Orthodox. Originally, the survey offered 13 answer options based on the religious groupings according to the *Saga* electronic patient record-keeping system: National Church of Iceland, Protestant, Christian, Catholic, Heathenism, Humanism, Zuism, Buddhism, Islam, Bahá´í Faith, Unaffiliated, Other and

Choose not to answer. Changes were made to address this issue. The survey was changed to include the following 13 answer options instead: National Church of Iceland, Protestant, Catholic, Orthodox, Heathenism, Humanism, Zuism, Buddhism, Islam, Bahá´í Faith, Unaffiliated, Other and Choose not to answer.

For the MORi and MADM scales in Questions 21-33, 37-40 and 42-48, a 6-point Likert scale was used with the following answering options of: strongly disagree, disagree, slightly disagree, slightly agree, agree and strongly agree. Two participants expressed that Question 27: “My cultural preferences were respected” and Question 48 “My midwife/doctor respected that choice” lacked the option for “Does not apply.” Because the MORi and MADM scales are international standardized instruments, no changes were made to Questions 27 and 48. In Question 34: “Did you need interpreter services during your maternity care?”, one participant suggested adding an option for women who required interpreter services but did not necessarily want to accept or use the services. Originally, the answer options were: yes, no and not sure. In order to ensure accuracy in obtaining information about interpreter services, answer options were changed to the following: I needed and wanted interpreter services; I needed but did not want interpreter services; I did not need interpreter services; and I am not sure.

Several participants commented on the possibility of adding open-ended questions in free form sections to capture qualitative date that can lead to more insights and capture the complexity of the situation for foreign women. At this point, the head researcher decided not to add open-ended questions to the survey due to the extra cost and time required for interpreting comments written in languages other than English, e.g. Polish.

Table 9. Categorized comments from participants in pre-testing of the survey.

Comment Category	No. of Comments	Written Comments
Language and wording	2	Button commands were in Icelandic but needed to be translated in English and Polish in the instructions.
		Error in wording in Question 13 asking about annual income rather than monthly income.
Comprehensibility	2	Question 35 about family member/friend interpreting during maternity services was unclear and confusing.
		Question 41 about unfair treatment because of race, heritage or ethnic group was unclear – in general or during maternity care?
Answer options	5	In Questions 17-19 about rating midwives during pregnancy and labor, is it possible to rate multiple midwives?
		Add a question about satisfaction/experience with IBLC.
		Option of 'does not apply' for the questions being rated 'strongly disagree' to 'strongly agree'. In particular, I would have answered 'does not apply' for questions asking "Because of my health insurance", "My cultural preferences were respected" and "My midwife/doctor respected that choice."
		In Question 34 about needing services of a professional interpreter, the answer option 'I did not want one' was missing.
		An open comment section at the end of the survey might lead to more insights.
Structure and design	2	Questions 17-19 about rating different healthcare providers on a scale of 0-100 were difficult to answer on a mobile phone.
		Emphasize in bold letters the words 'during pregnancy', 'in labor' and 'after birth' in the questions.

3.5 Sociodemographic characteristics and MORi and MADM median scores of participants in pretesting

Participants who pretested the English version of the survey were originally from the following countries: Canada (1), Germany (2), Pakistan (1), Serbia and Montenegro (1), Ukraine (1), United Kingdom (1) and the United States (4). Religious backgrounds of the participants were as follows: Catholic (1), Christian (5), Humanism (1) and Islam (1). Six participants were not affiliated with any religion, two chose "Other" and one chose not to answer. Only one participant identified herself as a woman of color.

The age of participants at the time of childbirth ranged from 25 to 45 years with an average of 31 years (Table 10). The majority *(n=14, 82%)* lived in the Capital Area of Reykjavík at the time of childbirth and 70% *(n=12)* had given birth within 5 years of moving to Iceland. Forty percent *(n=7)* of the participants were permanent residents in Iceland at the time of childbirth and 76% *(n=13)* had completed university-level education at the time of pregnancy and childbirth. Seven participants reported speaking Icelandic at the beginner level at the time of pregnancy, and all participants reported speaking English at either an advanced level or fluently. All participants were either living with or married to their partners

at the time of childbirth. The majority of participants were employed at the time of pregnancy. For all 17 participants, the median MORi score for the 14-item scale was 61 and for the 17-item scale was 69. The median MADM score was 21.

Table 10. Sociodemographic information for participants in the pretest survey at the time of childbirth (N=17)

	N	%
Total	**17**	**100**
Age		
25-30	8	47.1
>31	9	53.0
Relationship Status		
Living together	7	41.2
Married	10	58.8
Residency Status		
Temporary Resident	4	23.5
Permanent Resident	7	41.2
Citizen of the EEA	4	23.5
Icelandic Citizen	2	11.8
Place of Residence		
Capital Area of Reykjavík	14	82.4
Countryside	3	17.6
Highest Level of Education		
Secondary	4	23.5
University	13	76.5
Employment Status		
Employed	11	64.7
Other	6	35.3

3.6 Obstetric characteristics of participants in pretesting

Eight participants were primiparas and nine were multiparas (Table 11). The majority of participants (*n=11, 70.6%)* gave birth at Landspítali University Hospital. Ten participants reported at least one social complication (housing, financial, lack of social support, difficulty accessing services, anxiety, depression) with anxiety being the most frequently reported *(n=6)*. All participants reported giving birth vaginally. Approximately 30% *(n=5)* were induced and 41% *(n=7)* had an epidural during labor. Nine participants reported at least one neonatal complication with neonatal jaundice being the most common. None of the participants needed or received interpretation services; however, eight participants reported that a family member or friend interpreted for them at some point when receiving in maternity care.

Table 11. Obstetric characteristics of participants in the pretest survey (N=17)

	N	%
Parity		
Primipara	8	47.1
Multipara	9	52.9
Place of Birth		
Landspítali Hospital	12	70.6
Other	5	29.4
Social Complications*		
None	8	47.1
1	5	29.4
≥2	4	23.5
Pregnancy Complication		
Yes	8	47.1
No	9	52.9
Mode of Delivery		
Vaginal	17	100
Cesarean Section	0	0
Epidural Anesthesia		
Yes	7	41.2
No	10	58.8
Induction		
Yes	5	29.4
No	12	70.6
Infant Feeding		
Exclusively breastfeeding	13	76.4
Exclusively formula-feeding	3	17.6
Neonatal Complication		
Yes	9	52.9
No	8	47.1

*During pregnancy, childbirth and/or postpartum.

3.7 MCPC Indicators for participants in pretesting

Three participants (*17.6%*) experienced at least one incident of mistreatment by a care provider, including one participant who reported three different incidents. Two participants indicated that a midwife/doctor had shouted or scolded at them during childbirth. Two participants reported that midwives/doctors ignored them, refused their requests for help or failed to respond to their requests for help in a reasonable amount of time. One participant experienced physical abuse (including aggressive physical contact, inappropriate sexual conduct, a refusal to provide anesthesia, etc.).

4 Discussion

In this chapter, results of this study will be summarized and reflected upon. Then, the strengths and limitations of this study will be considered along with possibilities for future research. Finally, implications for midwifery will be presented.

4.1 Summary

The aim of this study was to develop, translate and pre-test a survey that assess the experiences of foreign women who have received maternity care services in Iceland with regard to respect, autonomy in decision-making and mistreatment. Specifically, this study explored whether migrant women who speak either English or Polish are able to answer an online survey about respect, autonomy in decision-making and mistreatment in Icelandic maternity care. The results show that respondents are able to easily access, understand and respond to the online survey in both English and Polish. The revised and adapted survey includes 64 items that collect data on background, sociodemographic characteristics, migration history, language proficiency and obstetric history as well as standardized instruments that assess the domains of respectful maternity care, autonomy in decision-making and mistreatment during childbirth.

4.2 Reflection on the results

This is the first survey in Iceland to measure respectful care, autonomy in decision-making and mistreatment in maternity care in the country. Studies have been conducted in Canada, the United States and the Netherlands using the same standardized instruments that were used in this survey (Feijen-de Jong et al., 2019; Vedam, Stoll, Martin, et al., 2017; Vedam, Stoll, Rubashkin, et al., 2017; Vedam, Stoll, Taiwo, et al., 2019; Vedam, Stoll, McRae, et al., 2019). Overall, pre-testers reported that the online survey was easily accessible with a short response time of approximately 20 minutes and had clear instructions and comprehensible questions. All participants expressed that they would recommend the survey to family and friends. These factors could contribute to attaining a high response rate from the target population in future studies.

The survey was originally written and developed in English and then translated to Polish before pretesting. In this study, backward-translation of the survey from Polish to English showed inadequate translation of three MADM scale items which could have potentially led to misinterpretation of the questions. If scale items in Polish are ambiguous, the responses from survey participants will be unreliable and therefore, calculated MADM scores would be inaccurate. This demonstrates the value of using forward- and backward-translation when translating surveys. This finding is similar to the results of other studies using the forward- and backward-translation method (Brislin & Freimanis, 2001; Chen & Boore, 2010; Maneesriwongul & Dixon, 2004; Shigenobu, 2007; Wang et al., 2006; WHO, n.d.).

It is interesting to note that there was an overwhelming response of willingness to participate in the pretesting of the survey from the target population. Within only two days, eleven English-speaking women who fulfilled the requirements volunteered to participate and many more were interested, and within four days, six Polish-speaking women volunteered. The sample of participants consisted mostly

of women who were university-educated and gave birth at an average age of 31 years. Eight of the participants were primiparas and nine multiparas. Only one participant identified herself as a “woman of color.” These characteristics are not entirely reflective of the population of migrant women receiving maternity care in Iceland; however, participants were required to not only be able to understand and read English or Polish but were also required to give written feedback about the survey in English. The community of migrant women in Iceland has expressed a strong interest in answering questions about their pregnancy and birth experiences within the Icelandic maternity care system. This shows that there is a high demand for valid and reliable tools to evaluate these women’s experiences. By including participants that were members of the community, it was possible to receive feedback on survey questions to prevent misunderstandings or misinterpretations as well as to ensure a culturally sensitive approach. For example, one participant suggested using the phrase “woman of foreign origin” which has a more positive connotation than the phrase “migrant woman”.

The pretesting was also necessary in identifying several issues that needed to be addressed in the areas of wording, question ambiguity, lack of answer options and flaws in survey design. One example that highlights the importance of survey pretesting is the wording in Question 13 about household income. Originally, the survey question asked about annual household income but included options for monthly household income. If this error had not been detected in the pretesting stage, the research team would not have been able to collect reliable data about how social status or income affects a woman’s experience of respectful care, autonomy and mistreatment. It is especially important to be able to research levels of income among vulnerable populations such as migrant women in Iceland because the average income of immigrants is 8% lower than the average income of native Icelanders after correcting for gender, age, education, family status, residency and employment-related factors (Statistics Iceland, 2019). There is also a pay gap among immigrants in Iceland. Those that come from Nordic countries have a higher income than those born in other countries, such as Asian immigrants who are reported as having the lowest pay, approximately 7% lower on average (Statistics Iceland, 2019).

Through written evaluations from members of the community we found that 70% of the pre-testers reported that not all answer options were available. Changes were made to accommodate the need for more answer options in six of the survey questions. For example, in Question 34: “Did you need interpreter services during your maternity care?”, one participant suggested adding an option for women who required interpreter services but did not necessarily want to accept or use the services. Originally, the answer options were: yes, no and not sure. Interestingly, in a survey of 800 immigrants in Iceland about their attitudes towards living in Iceland, 19% of respondents indicated that they did not trust interpreters to adhere to the confidentiality agreement (Jónsdóttir, Harðardóttir & Garðarsdóttir, 2009). Reliable and trustworthy interpretation services are essential when providing care for women who do not speak Icelandic or English in order to ensure high-quality care. Therefore, it was important to address this issue by changing the answer options to the following: I needed and wanted interpreter services; I needed but did not want interpreter services; I did not need interpreter services; and I am not sure.

Also, participants commented on the lack of open-ended questions about women's experiences in the survey. It was decided that open-ended questions would not be included in the survey since the purpose of this study was not to collect data on outcomes but rather to assess whether REDCap was a feasible tool in terms of collecting data and then exporting and analyzing data. This study demonstrates the ease, reliability and advantages of using REDCap and SPSS.

Although the aim of this study was not to draw conclusions about the population of migrant women from the data, it is nevertheless interesting to compare the experiences of this group of migrant women to studies that have been conducted abroad using the MORi, MADM and MCPC scales. Due to the small sample size, it is not possible to make generalizations about the target population; however, the responses from the pre-testing stage can shed light on the experiences of this particular group of 17 migrant women who have received maternity care in Iceland. In the survey pretest, the median MORi score for the 14-item scale was 61 and the median MADM score was 21 for all 17 participants. These median scores are lower than the median scores in the Dutch and Canadian studies. In the Netherlands, the median MORi score for the 14-item scale was 75 and the median MADM score was 35 in a sample of 557 women, and those with a healthy pregnancy reported statistically higher MORi scores compared to women with pregnancy complications (Feijen-de Jong et al., 2019). In Canada, the median MADM score was 39 in a sample of 1,705 women reporting 2,806 pregnancies, and those belonging to vulnerable populations, such as recent immigrants and refugees, were more likely to report lower MORi scores (Vedam, Stoll, Taiwo, et al., 2019). Since a 6-point Likert scale was not used for the MORi scoring in the Canadian study, a comparable median score was unable to be calculated.

Three of the participants, approximately 17%, experienced at least one form of mistreatment by a care provider during childbirth. In the pretest of this survey, women reported mistreatment by care providers during childbirth in Iceland which included scolding or shouting at the women, ignoring their requests for help and physically abusing them. Other studies show that scolding or shouting at women during childbirth is the most commonly reported form of mistreatment (Abuya, Sripad, Ritter, Ndwiga, & Warren, 2018; Bohren et al., 2019; Kassa & Husen, 2019; Sharma et al., 2019; Vedam, Stoll, Taiwo, et al., 2019). In a study by Vedam and colleagues (2019) in the United States about mistreatment in childbirth using the MCPC indicators, 17.3% of women experienced at least one form of mistreatment, with Indigenous, Hispanic and Black women being more likely to report mistreatment compared to women who identified as white. It is important that healthcare professionals understand the effects of disparities when providing care for vulnerable populations and recognize the presence of mistreatment in childbirth in order to find and eliminate the underlying causes.

4.3 Strengths and limitations

Strengths of this study include survey item generation which was based on existing databases, a survey model and previous research as well as collaboration with an expert panel. Survey items were based on information from the National Statistical Institue of Iceland (Icelandic: Hagstofa Íslands), the Icelandic Birth Register (Icelandic: Fæðingaskrá), the Icelandic electronic patient record system *Saga*, and items from the original Canadian survey assessing women's experiences of respect and autonomy in

decision-making in maternity care. By using this approach when developing the survey questions, it will be possible to compare information with prior research and population-based data in future studies. Also, collaboration with an expert panel of two midwife researchers was used to assess the scale's content validity. From their input, it was possible to refine and remove any faulty items or add new items to cover the domain adequately.

In addition, forward and backward-translation by professional translators and written feedback evaluations from members of the community strengthened the study. Forward and backward-translation of this survey showed mistranslation of three questions that were part of the MADM scale that were translated to Polish. Because of this finding, appropriate changes were made and the reliability and content validity of the MADM scale in Polish were ensured.

Limitations of this study were the purposive and snowball sampling and the potential bias from self-reporting of the participants. Purposive and snowball sampling along with the participation requirement of speaking fluent English resulted in a sample of women who were older and highly educated. Also, self-reporting has limitations such as potential bias. Participants may have had a tendency to want to present themselves more positively although this may conflict with the truth.

4.4 Future research possibilities

In the future, the survey can be used to collect data on the experiences of migrant women receiving maternity care in Iceland in regard to respectful care, autonomy in decision-making and mistreatment. Because the online survey consists of background questions, socioeconomic characteristics, migration history, obstetric history and standardized instruments, it will be possible to research inequities in Icelandic maternity care using an intersectional approach. The more diverse the group of migrant women in Iceland becomes, the more challenging and complicated it is for healthcare professionals to meet the unique needs of each and every woman; however, this survey can possibly evaluate the complexity of the needs and experiences of this vulnerable group. For example, the survey can be used to look at how income or social complications affect the experience of maternity care. Researchers will be able to study whether the way people are treated during pregnancy and birth mediates the relationship between immigrant status and birth outcomes. Also, it will be possible to explore the differences between the experiences of immigrant women of color versus white immigrant women. To gain a deeper understanding of the diverse and complex experiences of migrant women receiving maternity care in Iceland, the survey could be incorporated into a mixed-methods study in which qualitative data could be collected through interviews or focus groups alongside quantitative data from the survey.

In addition, Icelandic women's experiences of respectful maternity, autonomy in decision-making and mistreatment have not been researched. I would be possible to translate the survey from English to Icelandic to collect comparative data for Icelandic women. The data could be used to compare experiences of Icelandic women versus migrant women who have received maternity care in Iceland. Also, it would be possible to research the experiences of other vulnerable groups of women

with complex social factors such as women who suffer from mental health disorders, women who misuse alcohol or drugs, pregnant women under 20 years of age and women who experience abuse.

4.5 Implications for midwifery

In Iceland, maternity care is primarily provided by midwives using a woman-centered approach. The development, translation and pretesting of this online survey will give midwives, obstetricians and other healthcare providers a unique opportunity to address key maternity care issues such as limited access to services, disrespectful care, informed consent and mistreatment in childbirth. When providing care for migrant women, it is essential that midwives are aware of the effects of factors such as race, skin color, social complications, language barriers and obstetric complications.

If translated into Icelandic, this online survey can be routinely used to measure safety and quality of maternity care in local healthcare centers as well as in hospitals. The survey can also be used to assess maternity care on a population level where MORi, MADM and MCPC scale scores can potentially serve as standards for care. In the future, data collected from this survey can improve maternity care services by informing client-driven policy changes regarding respectful care, informed consent, access to reliable information and access to different options for care.

5 Conclusion

The revised and adapted survey includes 64 items that collect data on background, sociodemographic characteristics, migration history, language proficiency and obstetric history as well as standardized instruments that assess the domains of respectful maternity care, autonomy in decision-making and mistreatment during childbirth. The aim of this study was to develop, translate and pre-test a survey that assesses the experiences of foreign women who have received maternity care services in Iceland. Results showed that this survey can be used to assess migrant women's experiences of Icelandic maternity care and is accessible, understandable and easy to answer in both English and Polish. Information collected from the survey may improve access to a maternity care model that prioritizes relationship-based and woman-centered care. This information is also essential in making an impact on important issues such as equity in maternity care and human rights in childbirth.

With the increasing diversity of the Icelandic population, it is necessary for healthcare professionals to understand the special needs of foreigners receiving services. This is especially important when providing maternity care because social factors, communication difficulties and systematic and cultural differences can significantly affect the experiences of expectant mothers during pregnancy, in childbirth and postpartum. Midwives have the opportunity to provide woman-centered care for migrant women in Iceland. They are advocates for this vulnerable group and play a key role in providing care for these women and their families. With information obtained from this survey, midwives and other healthcare professionals could gain insight and a deeper understanding of the experiences of migrant women receiving Icelandic maternity care and therefore, increase the possibility of meeting the special needs of this vulnerable group and providing higher quality care.

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Appendix A: Consent Form (English)

Giving Mothers a Voice Survey

We are conducting a national survey in order to assess immigrant women's experiences of respect and autonomy in Icelandic maternity health care services. We invite you to participate because you fit the demographic profile of our target population (i.e. immigrant woman who has given birth in Iceland within the last 5 years and can read and understand English, Icelandic or Polish). The survey is web-based and should take no more than 30 to 40 minutes to complete.

Participating in this survey is voluntary and anonymous since the surveys can only be identified by code number. The results from the survey will be stored anonymously at the University of Iceland. When results from the survey are published in journals, no identifying information will be presented. If you have any questions or need more information about this study, please contact Edythe L. Mangindin (elm9@hi.is , Tel. 771 4337). You may withdraw from participating in the survey at any time. The data protection law of Lower Saxony will be respected and the data will not be shared with unaffiliated institutions.

The survey link will be open from January 1st, 2020 until February 29th, 2020.

The survey is mobile-ready and can be opened on any device (iPad, iPhone, Android etc.). You have the option of starting the survey and completing it at a later time. Starting the survey equals your signature on an informed consent form and confirms that you have received enough information about the survey and that all of your questions have been answered.

If you experience technical difficulties with the survey, please contact elm9@hi.is.

Translation of Icelandic instructions:

Verður að svara = Required to answer

Næsta síða = Next page

Fyrri síða = Previous page

Vista og halda áfram síðar = Save and continue later

Contact Details

Edythe L. Mangindin, RN, RM

E-mail: elm9@hi.is

Telephone: 771 4337

Appendix B: Consent Form (Polish)

Oddajemy głos matkom: Ankieta

Przeprowadzamy ogólnokrajową ankietę w związku z oceną doświadczeń imigrantek w związku z szacunkiem i niezależnością pod kątem opieki położniczej w Islandii. Zapraszamy Cię do udziału, ponieważ możesz pasować do profilu demograficznego naszej wybranej grupy populacji docelowej (tj. Imigrantki, które urodziły dziecko w Islandii w ciągu ostatnich 5 lat i potrafią czytać i rozumieć język islandzki, angielski lub polski). Ankieta jest w formie internetowej i nie powinna zająć więcej niż 30-40 minut. Udział w tej ankiecie jest dobrowolny i anonimowy, ponieważ ankiety można rozpoznać tylko po kodzie numerycznym. Wyniki ankiety będą przechowywane anonimowo na uniwersytecie Háskóli Íslands. Podczas publikacji wyników ankiety, nie zostaną przedstawione żadne dane identyfikujące. Jeśli masz pytania lub potrzebujesz więcej informacji na temat tego badania, skontaktuj się z Edythe L. Mangindin (elm9@hi.is, tel. 771 4337). Możesz zrezygnować z udziału w ankiecie w dowolnym momencie. Przestrzegane będą przepisy o Ochronie Danych Osobowych dla Dolnej Saksonii, a dane nie będą udostępniane niepowiązanym instytucjom.

Link do ankiety będzie dostępny od 1 stycznia do 29 lutego.

Ankieta jest dostępna na urządzenia mobilne i można ją otworzyć na dowolnym urządzeniu (iPad, iPhone, Android itp.). Masz możliwość rozpoczęcia ankiety i dokończenia jej w późniejszym terminie. Rozpoczęcie ankiety jest równoznaczne z podpisem na formularzu zgody i potwierdza, że otrzymałaś wystarczającą ilość informacji o ankiecie, oraz że na wszystkie Twoje pytania udzielono odpowiedzi.

W przypadku problemów technicznych z ankietą prosimy o kontakt z elm9@hi.is.

Tłumaczenie instrukcji islandzkich:

Verður að svara = Wymagane odpowiedź

Næsta síða = Następna strona

Fyrri síða = Poprzednia strona

Vista og halda áfram síðar = Zapisz i kontynuuj później

Osoba Kontaktowa

Edythe L. Mangindin

E-mail: elm9@hi.is

Tel: 771 4337

Appendix C: Survey Questions (English)

Eligibility questions:

Are you a woman of foreign origin living in Iceland?

- ☐ Yes
- ☐ No

Was your most recent pregnancy and birth between the years 2015 and 2020?

- ☐ Yes
- ☐ No

Was your most recent pregnancy and birth in Iceland?

- ☐ Yes
- ☐ No

***If you have answered "yes" to all of the above questions, you are eligible to participate in the survey. Click on "Start" to begin.**

INFORMATION ABOUT YOU

This first section asks some questions that might seem very personal. Remember that the survey does not collect names or any information that could identify you or your family. You can share whatever you are comfortable sharing and the information might help to improve maternity care for others.

1. What is your continent of origin?
   a. Africa
   b. Asia
   c. Europe
   d. North America
   e. South America
   f. Oceania
2. Please specify your country of origin below: _____
3. Which statement about your ethnicity do you agree with?
   a. I self-identify as a woman of color
   b. I self-identify as a white woman
   c. I choose not to answer
4. What religious group do you belong to?
   a. National Church of Iceland
   b. Protestant
   c. Catholic
   d. Orthodox
   e. Heathenism
   f. Humanism
   g. Zuism
   h. Buddhism
   i. Islam
   j. Bahá´í Faith
   k. Unaffiliated
   l. Other
   m. Choose not to answer

Please think about your most recent pregnancy within the past 5 years. Answer all of the following questions as you remember your experiences during that pregnancy and childbirth.

5. In total, I have given birth to ___ child/children.
6. What was your age at the time of your most recent childbirth? _____

7. What area did you live in at time you gave birth?
    a. The Capital Area of Reykjavík
    b. West Iceland
    c. West Fjords
    d. North Iceland
    e. East Iceland
    f. South Iceland
    g. Reykjanes

8. In what region of Iceland was your baby born?
    a. The Capital Area of Reykjavík
    b. West Iceland
    c. West Fjords
    d. North Iceland
    e. East Iceland
    f. South Iceland
    g. Reykjanes

9. How many years had you lived in Iceland at the time you gave birth?
    a. <1 year
    b. 1-5 years
    c. 6-10 years
    d. >10 years

10. What was your residency status at the time of childbirth?
    a. Refugee
    b. Asylum seeker
    c. Temporary resident (work, education, etc)
    d. Permanent resident
    e. Citizen of the European Economic Area (EEA)
    f. Icelandic citizen
    g. Other (Please specify) _____

11. What was your relationship status at the time of childbirth?
    a. Single
    b. Living together
    c. Married
    d. Widowed
    e. Divorced
    f. Other

12. What was the highest level of education that you completed at the beginning of the pregnancy?
    a. No formal education
    b. Primary education
    c. Secondary education
    d. University education

13. What was your average monthly household income? (This amount includes money made by anyone living in your home and who helps with you and your family's costs).
    a. <300.000 ISK
    b. 300.000-500.000 ISK
    c. 500.000-700.000 ISK
    d. 700.000-900.000 ISK
    e. >900.000 ISK

14. What was your position or work situation during pregnancy?
    a. Employed
    b. Student
    c. Working at home
    d. Disability
    e. Unemployed
    f. Other

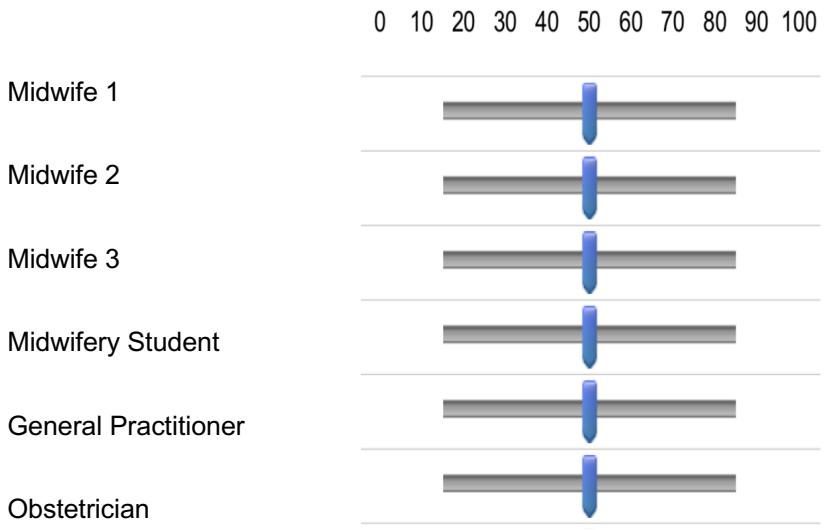
15. How well could you speak **Icelandic** when you were pregnant?
    a. Unable to understand, read or speak Icelandic
    b. Beginner
    c. Intermediate
    d. Advanced
    e. Fluent

16. How well could you speak **English** when you were pregnant?
    a. Unable to understand, read or speak English
    b. Beginner
    c. Intermediate
    d. Advanced
    e. Fluent

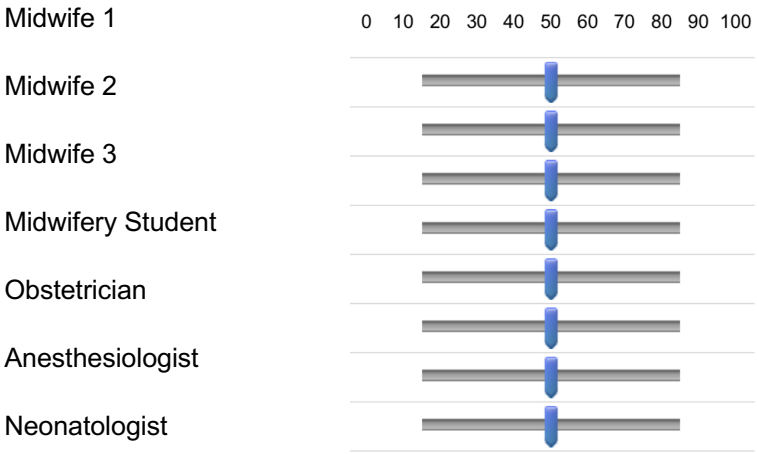
RESPECTFUL MATERNITY CARE

In this section of the survey, you will be asked about your experience of respect in Icelandic maternity care services.

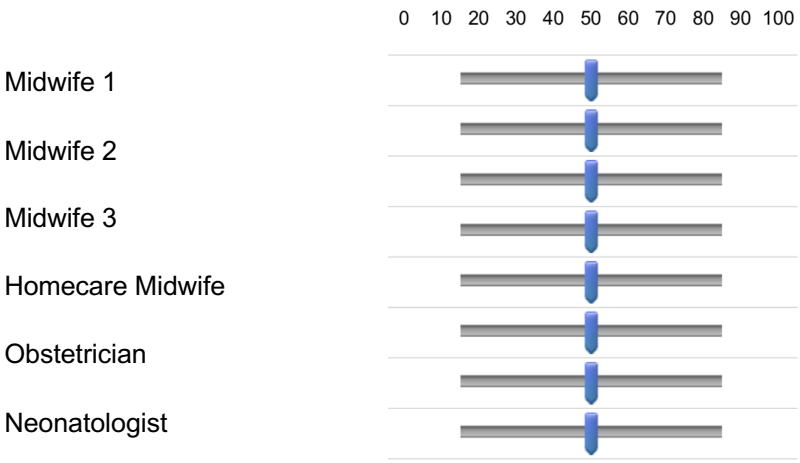
17. Please let us know who was involved in your care **during pregnancy** (options might be: obstetrician, family doctor, midwife, nurse, receptionist, etc). Please tell us how you were treated by each person, on a scale from 1 to 100, with 1 being the most disrespectful and 100 being the most respectful.



18. Please let us know who was involved in your care **during labour/birth** (options might be: obstetrician, midwife, student midwife, medical student, anesthesiologist, neonatologist, pediatrician, etc). Please tell us how you were treated by each person, on a scale from 1 to 100, with 1 being the most disrespectful and 100 being the most respectful.



19. Please let us know who was involved **in your care after birth** (options might be: obstetrician, family doctor, midwife, student midwife, medical student, nurse, anesthesiologist, neonatologist, pediatrician etc). Please tell us how you were treated by each person, on a scale from 1 to 100, with 1 being the most disrespectful and 100 being the most respectful.



20. Did you experience any of the following issues or behaviors once or more often during your pregnancy or childbirth care? (Please select all that apply)
    - ☐ My private or personal information was shared without my consent
    - ☐ My physical privacy was violated (i.e. being uncovered or having people in the delivery room without my consent)
    - ☐ A doctor/midwife shouted or scolded me
    - ☐ Health care provider(s) threated to withhold treatment or to force me to accept treatment that I did not want
    - ☐ The doctors/midwives ignored me, refused my request for help or failed to respond to my requests for help in a reasonable amount of time
    - ☐ I experienced physical abuse (including aggressive physical contact, inappropriate sexual conduct, a refusal to provide anesthesia for an episiotomy, etc.)
    - ☐ None of the above

Overall while making decisions <u>during my pregnancy</u>, I felt:

	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Slightly Agree
21. Comfortable asking questions	○	○	○	○	○	○ hreinsa
22. Comfortable declining care that was offered	○	○	○	○	○	○ hreinsa
23. Comfortable accepting the options for care that my midwife/doctor recommended	○	○	○	○	○	○ hreinsa
24. Coerced/pushed into accepting the options my midwife/doctor suggested	○	○	○	○	○	○ hreinsa
25. I chose the care options that I received	○	○	○	○	○	○ hreinsa
26. My personal preferences were respected	○	○	○	○	○	○ hreinsa
27. My cultural preferences were respected						

<u>During a prenatal visit</u> I held back from asking questions or discussing my concerns because:

	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Slightly Agree
28. My midwife/doctor seemed rushed	○	○	○	○	○	○ hreinsa
29. I wanted maternity care that differed from what my midwife/doctor recommended	○	○	○	○	○	○ hreinsa
30. I thought my midwife/doctor might think I was being difficult	○	○	○	○	○	○ hreinsa
31. I felt discriminated against	○	○	○	○	○	○ hreinsa
32. I felt my doctor/midwife did not value my opinion	○	○	○	○	○	○ hreinsa
33. My care provider used language I could not understand	○	○	○	○	○	○ hreinsa

34. Did you need interpreter services during your maternity care?
    a. Yes
    b. No
    c. Not sure

35. Did a family member or friend who was is not a certified interpreter interpret for you at any time during maternity care?
    a. Yes
    b. No
    c. Choose not to answer

36. Did you receive professional interpreter services?
    a. Yes
    b. No
    c. Choose not to answer

    → If "Yes" ask:

    36a. What type of interpreter service did you receive?

        a. In-person interpreter
        b. Interpreter by phone
        c. Other (Please specify) _____

    36b. How satisfied were you with the interpreter service you received?

        a. Very unsatisfied
        b. Somewhat unsatisfied
        c. Somewhat satisfied
        d. Very satisfied

    36c. When did you receive interpreter services? (Please check all that apply)

    ☐ During pregnancy check ups
    ☐ During labor and childbirth
    ☐ During care after giving birth

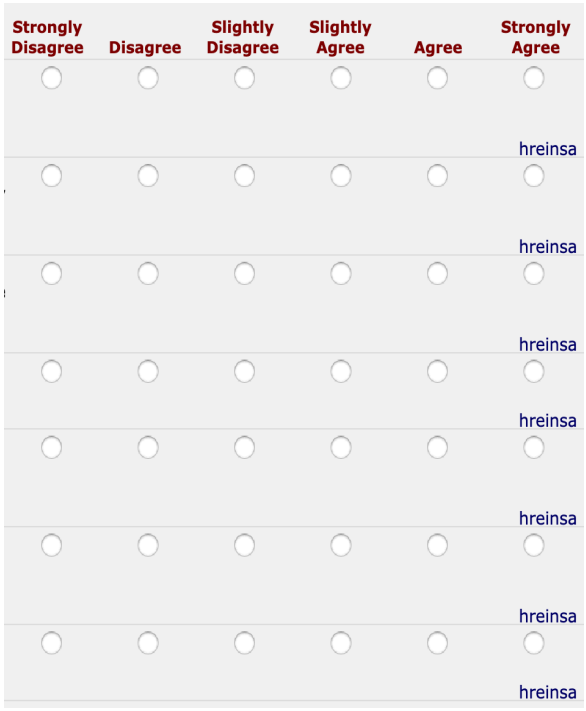
When I had my baby, I felt that I was treated poorly by my midwife/doctor:

	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Slightly Agree
37. Because of my race, ethnicity, cultural background or language	○	○	○	○	○	○ hreinsa
38. Because of my sexual orientation and/or gender identity	○	○	○	○	○	○ hreinsa
39. Because of my health insurance	○	○	○	○	○	○ hreinsa
40. Because of a difference in opinion with my caregivers about the right care for myself or my baby	○	○	○	○	○	○ hreinsa

41. How often have you felt treated unfairly because of your race, heritage or ethnic group during maternity care?
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Very often
    f. Always

DECISION MAKING

Please use the following questions to tell us about your discussions with your doctor or midwife about your options for care (for example: prenatal testing, starting your labor, medications, cesarean, place of birth, newborn care, etc.).



42. My midwife/doctor asked me how involved in decision-making I wanted to be
43. My midwife/doctor told me that there are different options for my maternity care
44. My provider explained the advantages/disadvantages of the maternity care options
45. My midwife/doctor helped me understand all the information
46. I was given enough time to thoroughly consider the different care options
47. I was able to choose what I considered to be the best care options
48. My midwife/doctor respected that choice

In this section, you will be asked about your health during pregnancy and childbirth.

49. Were you told by your midwife/doctor that you were high risk at any point during your pregnancy?
    a. Yes
    b. No
    c. I am not sure

    →If yes, ask: 49a. Why were you told by your midwife/doctor that you were high risk? (Please check all that apply)
    - ☐ Because I have a chronic disease or health problem (e.g. diabetes, heart disease, obesity)
    - ☐ Because of something that happened in this pregnancy (Placenta problems, Cervical problems, Twins or more, IVF, Bleeding, Gestational diabetes, Pre-eclampsia/high blood pressure)
    - ☐ Because of something that happened in previous pregnancies/birth (Previous Cesarean section, Previous pre-eclampsia, Previous premature birth, previous gestational diabetes, Previous cervical or placental problems)
    - ☐ Because of my age
    - ☐ Because of my ethnicity
    - ☐ Because of lifestyle factors/income
    - ☐ Because of challenges I have experienced in my past (drugs alcohol, incarceration, homelessness, violence)
    - ☐ For reasons I did not understand

    49b. Did you agree that you were “high risk”?
    i. Yes
    ii. No
    iii. Not sure

50. During this pregnancy I experienced: (Please check all that apply)
    - ☐ Spotting or bleeding for more than a few days
    - ☐ Anemia
    - ☐ High blood pressure (pre-eclampsia, pregnancy induced hypertension or HELLP)
    - ☐ Gestational Diabetes
    - ☐ Placenta problems (previa, marginal, detachment)
    - ☐ Any infection (influenza, urinary or kidney infection, Zika, pneumonia)
    - ☐ Group B Strep or GBS positive
    - ☐ Problems with the baby’s growth or with amniotic fluid (too much/too little liquid)
    - ☐ Problems with the baby’s position (breech, transverse)
    - ☐ Twins or more
    - ☐ Premature labor
    - ☐ None of the above
    - ☐ Other (Please specify) _____

51. During pregnancy, childbirth and/or postpartum, did you experience any of the following? (Please check all that apply)
    - ☐ Housing problems
    - ☐ Financial difficulties
    - ☐ Lack of support from friends and family
    - ☐ Difficulty accessing health care
    - ☐ Physical abuse → If respondent chooses “e”: Provide information about Kvennaathvarf.
    - ☐ Mental abuse → If respondent chooses “d”: Provide information about Kvennaathvarf.
    - ☐ Anxiety
    - ☐ Depression
    - ☐ None of the above
    - ☐ I choose not to answer

52. Where did you plan on giving birth?
    a. Akureyri Hospital
    b. Akureyri Hospital
    c. Björkin
    d. Health Care Institution Akranes
    e. Health Care Institution Ísafjörður
    f. Health Care Institution of Southern Peninsula (Keflavík)
    g. Health Care Institution of Eastern Iceland (Neskaupstaður)
    h. Health Care Institution of South Iceland (Selfoss, Vestmannaeyjar)
    i. Home
    j. Landspítali Hospital
    k. Other (Please specify) _____

53. Where did you give birth?
    a. Akureyri Hospital
    b. Björkin
    c. Health Care Institution Akranes
    d. Health Care Institution Ísafjörður
    e. Health Care Institution of Southern Peninsula (Keflavík)
    f. Health Care Institution of Eastern Iceland (Neskaupstaður)
    g. Health Care Institution of South Iceland (Selfoss, Vestmannaeyjar)
    h. Home
    i. Landspítali Hospital
    j. Other (Please specify) _____

54. Was your labor induced?
    a. Yes
    b. No

    → If “Yes”:

        54a. Did you feel pressured to be induced?

            a. Yes
            b. No

55. Did you have an epidural?
    a. Yes
    b. No

    → If “Yes: 55a. Did you feel pressured to have an epidural?

        a. Yes

        b. No

56. Did you give birth by cesarean section?
    a. Yes
    b. No

    → If “Yes: 56a. Were you pressured/forced to have a cesarean section?

        a. Yes
        b. No

This final section is about the postpartum period and newborn care.

57. How much did your baby weigh at birth. If you don't remember, you can estimate. (Please enter only numbers. Do not include commas or decimal points. Example: 3500 grams).
    _____ grams

58. Was your baby healthy and doing well after birth?
    a. Yes
    b. No
    c. Choose not to answer

59. Did your baby have any problems? (Please check all that apply)
    - ☐ Breathing problems
    - ☐ Digestive tract problems
    - ☐ Jaundice
    - ☐ Birth defect
    - ☐ Low weight gain
    - ☐ Dehydration
    - ☐ Stillbirth or newborn loss → If checked, ask: 59a. We are very sorry for your loss. Did you receive any support or services after your loss? a. Yes b. No c. Choose not to answer. → If yes, ask: 59b. What services did you receive? (Please specify) _____→ Skip questions 60-64 and go to end of survey
    - ☐ Born too early
    - ☐ Congenital or genetic problem
    - ☐ No, my baby did not have any problems
    - ☐ Decline not to answer
    - ☐ Other (Please specify) _____

60. At any time after your baby was born, was he or she put in the intensive care unit?
    a. Yes
    b. No
    c. Not sure

61. As you came to the end of your pregnancy, how did you hope to feed your baby? (Select one option)
    a. Breastfeeding only
    b. Formula only
    c. Combination of breastfeeding and formula

62. As of today, has it been at least one month since you have given birth?
    a. Yes
    b. No

    If "Yes": 62a. One month after you gave birth, how were you feeding your baby?

        a. Breastfeeding only
        b. Formula only
        c. Combination of breastfeeding and formula

    If "No": 62b. How are you currently feeding your baby?

        a. Breastfeeding only

        b. Formula only

        c. Combination of breastfeeding and formula

63. Did a board-certified lactation consultant visit you at home after you gave birth?
    a. Yes
    b. No

→If "Yes": 63b. How satisfied were you with the services provided by your lactation consultant?

    a. Very unsatisfied
    b. Somewhat unsatisfied
    c. Somewhat satisfied
    d. Very satisfied

64. Did a homecare midwife visit you at home after you gave birth?
    a. Yes
    b. No

→ If "Yes"

64a. How satisfied were you with the services provided by your homecare midwife?

    e. Very unsatisfied
    f. Somewhat unsatisfied
    g. Somewhat satisfied
    h. Very satisfied

You have completed the survey. Your participation will help contribute to the improvement of maternity care serviced in Iceland. Thank you very much for your input and valuable time!

If you experienced any distress during this survey, you can contact "Lend me your ear" Landspítali Hospital at 543 3253 to make an appointment with a specialist midwife to find some support. In some instances, it is also be possible to speak to an obstetrician or psychologist. Interpreter services are available if required.

If you are a victim of mental or physical abuse and need assistance, please contact the Women's Shelter (Kvennaathvarf). **Victims of violence and their relatives are welcome to call the shelter at 561 1205 to get support and/or advice. The phone is open 24 hours a day, every day of the year. In a case of an emergency dial 112.** You can find further information on the website in many languages: https://www.kvennaathvarf.is/?lang=en.

Appendix D: Survey Questions (Polish)

Oddajemy głos matkom: Ankieta

Pytania kwalifikujące:

Czy jesteś obcy kobieta mieszka w Islandii?

- Tak
- Nie

Czy Twoja ostatnia ciąża i poród miały miejsce w latach 2015 - 2020?

- Tak
- Nie

Czy Twoja ostatnia ciąża i poród miały miejsce na Islandii?

- Tak
- Nie

*Jeśli odpowiedziałaś „tak" na wszystkie powyższe pytania, kwalifikujesz się do udziału w ankiecie. Kliknij „Start", aby rozpocząć.

INFORMACJE O TOBIE

Pierwsza część zawiera pytania, które mogą wydawać się bardzo osobiste. Pamiętaj, że ankieta nie gromadzi nazwisk ani żadnych informacji, które mogłyby zidentyfikować Ciebie lub Twoją rodzinę. Możesz wpisać wszystko, co uważasz za stosowne, a informacje te mogą pomóc poprawić opiekę położniczą innych kobiet.

1. Z jakiego kontynentu pochodzisz?
   a. Afryka
   b. Azja
   c. Europa
   d. Północna Ameryka
   e. Południowa Ameryka
   f. Oceania

2. Napisz kraj Twojego pochodzenia: _____

3. Z jakim oświadczeniem o Twoim pochodzeniu etnicznym zgadzasz się?
   a. Uważam się za kobietę rasy innej niż biała
   b. Uważam się za kobietę rasy białej
   c. Wolę nie odpowiadać

4. Jakiej jesteś wiary?
   a. Kościół Narodowy Islandii
   b. Protestanckiej
   c. Prawosławny
   d. Katolickiej
   e. Pogańskiej
   f. Humanistycznej
   g. Zuistycznej
   h. Buddyjskiej
   i. Islamskiej
   j. Bahá´í Faith
   k. Niezrzeszonej
   l. Inne
   m. Wolę nie odpowiadać

Przypomnij sobie swoja ostatnią ciąże z poprzednich 5 lat. Odpowiedz na wszystkie poniższe pytania, pamiętając o swoich doświadczeniach podczas ciąży i porodu.

5. W sumie urodziłam ___ dziecko/dzieci.

6. Ile miałaś lat podczas ostatniego porodu? _____

7. W jakim regionie Islandii mieszkałaś w momencie porodu?
    a. Reykjavík i okolice
    b. Zachodnia Islandia
    c. Fiordy Zachodnie
    d. Północna Islandia
    e. Wschodnia Islandia
    f. Południowa Islandia
    g. Reykjanes

8. W jakim regionie Islandii urodziło się Twoje dziecko?
    a. Reykjavík i okolice
    b. Zachodnia Islandia
    c. Fiordy Zachodnie
    d. Północna Islandia
    e. Wschodnia Islandia
    f. Południowa Islandia
    g. Reykjanes

9. Ile lat mieszkałaś na Islandii w momencie kiedy urodziłaś dziecko?
    a. <1 rok
    b. 1-5 lat
    c. 6-10 lat
    d. >10 lat

10. Jaki był Twój status imigracyjny w momencie urodzenia dziecka?
    a. Uchodźca
    b. Azylant
    c. Pobyt tymczasowy (praca, edukacja itp.)
    d. Pobyt stały
    e. Obywatel Europejskiego Obszaru Gospodarczego (EOG)
    f. Obywatelka Islandzka
    g. Inne (Prosze podać) _____

11. Jaki był Twój status cywilny w momencie urodzenia dziecka?
    a. Samotna
    b. Żyjąca w konkubinacie
    c. Mężatka
    d. Wdowa
    e. Rozwódka
    f. Inne

12. Jaki był Twój najwyższy poziom edukacji, w momencie zajścia w ciążę?
    a. Brak wykształcenia
    b. Wykształcenie podstawowe
    c. Wykształcenie średnie
    d. Wykształcenie wyższe

13. Jaki był Twój średni miesięczny dochód? (Kwota ta obejmuje pieniądze zarobione przez każdego, kto mieszka w Twoim domu i kto pomaga Ci w pokryciu kosztów Twojej rodziny.)
    a. <300.000 ISK
    b. 300.000-500.000 ISK
    c. 500.000-700.000 ISK
    d. 700.000-900.000 ISK
    e. >900.000 ISK

14. Jaka była Twoja sytuacja zawodowa podczas ciąży?
    a. Zatrudniona
    b. Studentka
    c. Pracująca w domu
    d. Niepełnosprawna
    e. Bezrobotna
    f. Inne

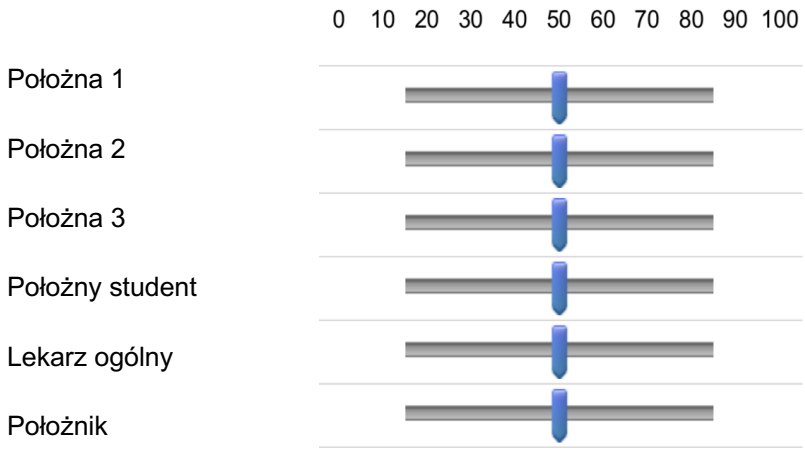
15. Jak dobrze mówiłaś po islandzku, kiedy byłaś w ciąży?
    a. Nie rozumiałam, nie czytałam, ani nie mówiłam po islandzku
    b. Początkująco
    c. Średnio
    d. Zaawansowanie
    e. Płynnie

16. Jak dobrze mówiłaś po angielsku, kiedy byłaś w ciąży?
    a. Nie rozumiałam, nie czytałam, ani nie mówiłam po angielsku
    b. Początkująco
    c. Średnio
    d. Zaawansowanie
    e. Płynnie

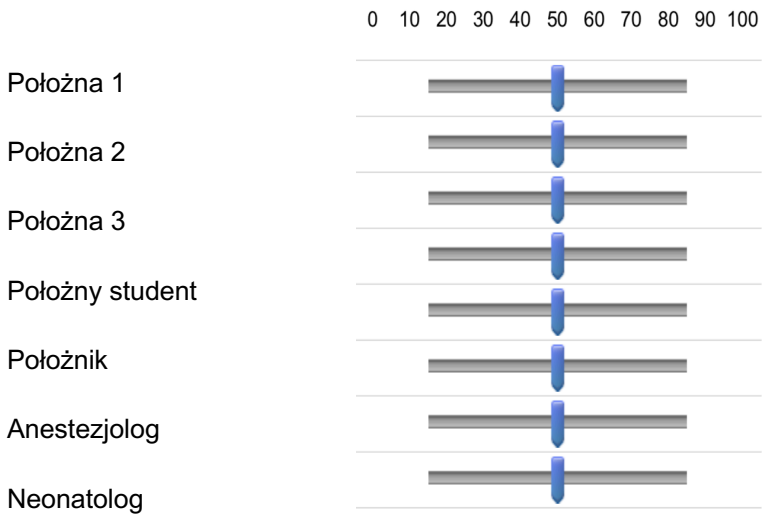
POSZANOWANIE PODCZAS OPIEKI CIĄŻOWEJ

W tej części ankiety zostaniesz zapytana o Twoje doświadczenia związane z szacunkiem pod kątem islandzkiej opieki położniczej.

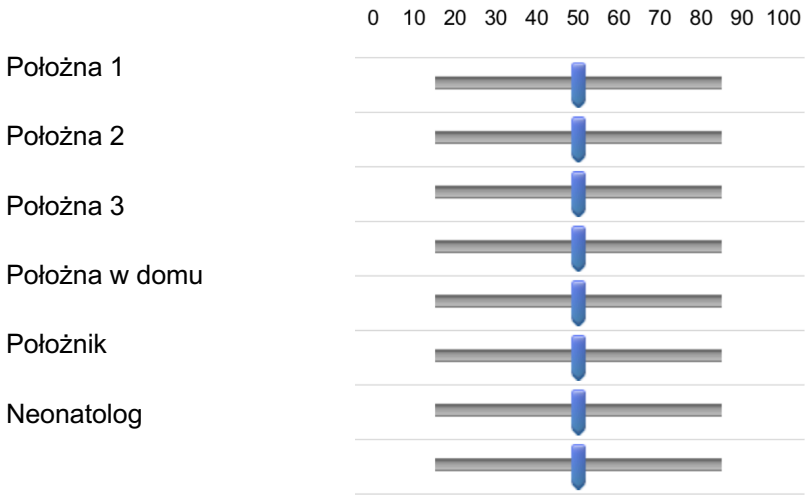
17. Kto był zaangażowany w Twoją opiekę podczas ciąży (dostępne opcje to: lekarz położnik, lekarz rodzinny, położna, pielęgniarka, recepcjonistka, itp.). Poinformuj nas o tym, jak traktowała Cię każda z tych osób, w skali od 1 do 100, przy czym 1 oznacza kompletny brak szacunku, a 100 pełny szacunek.



18. Kto był zaangażowany w Twoją opiekę podczas porodu/urodzin dziecka (dostępne opcje to: lekarz położnik, położna, student położnictwa, student medycyny, anestezjolog, neonatolog, pediatra, itp.). Poinformuj nas o tym, jak traktowała Cię każda z tych osób, w skali od 1 do 100, przy czym 1 oznacza kompletny brak szacunku, a 100 pełny szacunek.



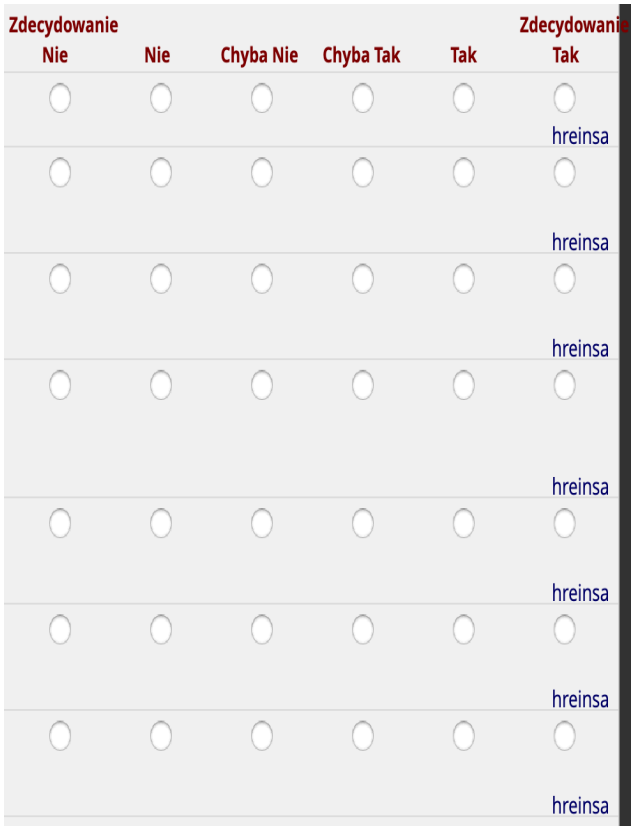
19. Kto był zaangażowany w Twoją opiekę po porodzie (mogą to być: lekarz położnik, lekarz rodzinny, położna, student położnictwa, student medycyny, pielęgniarka, anestezjolog, neonatolog, pediatra, itp.). Poinformuj nas o tym, jak traktowała Cię każda z tych osób, w skali od 1 do 100, przy czym 1 oznacza kompletny brak szacunku, a 100 pełny szacunek.



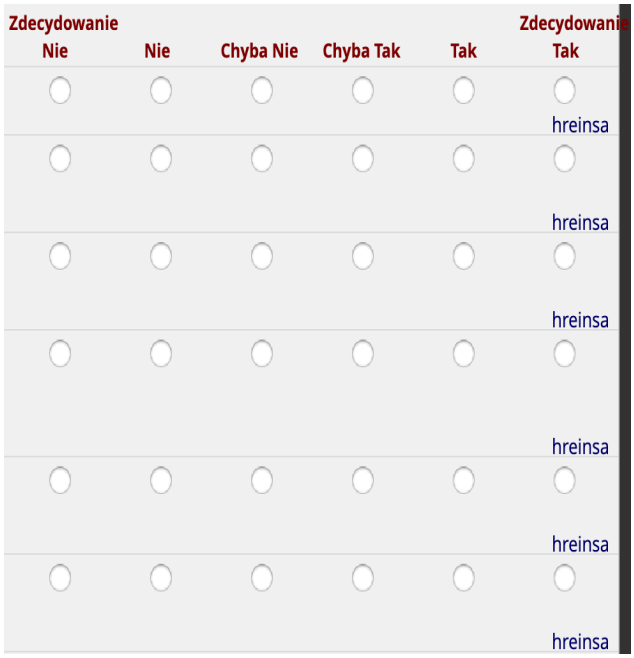
20. Czy doświadczyłeś któregokolwiek z poniższych problemów lub zachowań raz, lub więcej razy podczas ciąży, lub porodu? (Proszę zaznaczyć wszystkie, które pasują).

- ☐ Moje prywatne lub osobowe dane zostały udostępnione bez mojej zgody
- ☐ Moja fizyczna prywatność została naruszona (tj. byłam nieprzykryta, lub ktoś przebywał w pokoju porodowym bez mojej zgody)
- ☐ Lekarz/położna krzyczeli lub karcili mnie
- ☐ Instytucje świadczące opiekę zdrowotną zagroziły wstrzymaniem leczenia, lub zmuszały mnie do zaakceptowania leczenia na które się nie godziłam
- ☐ Lekarze/położne ignorowali mnie, odmawiali pomocy lub nie odpowiedzieli na moją prośbę o pomoc w odpowiednim czasie
- ☐ Doświadczyłam przemocy fizycznej (w tym agresywnego kontaktu fizycznego, niewłaściwych zachowań na tle seksualnym, odmowy podania znieczulenia w przypadku nacięcia krocza podczas porodu, itp.)
- ☐ Żadne z powyższych

W sumie, podejmując decyzje w czasie ciąży, czułam się:



Podczas wizyty prenatalnej powtrzymałam się od zadawania pytań lub omawiania moich obaw, ponieważ:



34. Czy potrzebowałaś usług tłumacza podczas swojej opieki położniczej?
    a. Tak, potrzebowałem tłumacza i chciałem go
    b. Tak, potrzebowałem tłumacza, ale go nie chciałem
    c. Nie
    c. Nie jestem pewna

35. Czy członek rodziny lub bliska osoba, która nie była certyfikowanym tłumaczem, tłumaczyli dla Ciebie w dowolnym momencie opieki macierzyńskiej?
    a. Tak
    b. Nie
    c. Wolę nie odpowiadać

36. Czy otrzymałaś usługi tłumacza profesjonalnego?
    a. Tak
    b. Nie
    c. Wolę nie odpowiadac
    → Jesli "Tak" zapytaj:
    36a. Jaki rodzaj tłumaczenia otrzymałaś?
        a. Tłumaczenie osobiste
        b. Tłumaczenie przez telefon
        c. Inne (Prosze napisać) _____
    36b. Jak bardzo byłaś zadowolona z usługi tłumaczenia?
        a. Bardzo niezadowolona
        b. Nie do końca zadowolona
        c. Zadowolona
        d. Bardzo zadowolona
    36c. Kiedy otrzymałaś usługi tłumaczenia? (Zaznacz wszystkie, które Ciebie dotyczą)
        ☐ Podczas wizyt kontrolnych swojej ciąży
        ☐ Podczas porodu i poczęcia dziecka
        ☐ Podczas opieki poporodowej

Po urodzeniu dziecka, czułam, że moja położna/lekarz źle mnie traktowali:

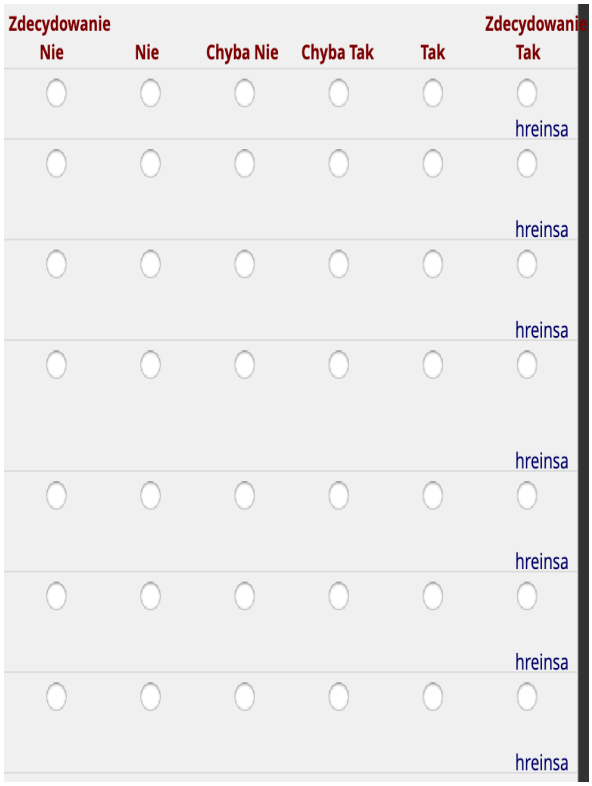
	Zdecydowanie Nie	Nie	Chyba Nie	Chyba Tak	Tak	Zdecydowanie Tak
37. Z powodu rasy, pochodzenia etnicznego/kulturowego lub języka	○	○	○	○	○	○ hreinsa
38. Z powodu mojej orientacji seksualnej i/lub płci	○	○	○	○	○	○ hreinsa
39. Z powodu mojego ubezpieczenia zdrowotnego	○	○	○	○	○	○ hreinsa
40. Z powodu różnicy opinii moją położną/ lekarzem na temat opieki mojej lub mojego dziecka	○	○	○	○	○	○ hreinsa

41. Jak często czułaś się niesprawiedliwie traktowana ze względu na rasę, dziedzictwo kulturowe, lub grupę etniczną

a. Nigdy
b. Rzadko
c. Czasami
d. Często
e. Bardzo często
f. Zawsze

PODEJMOWANIE DECYZJI

Skorzystaj z poniższych pytań, aby opowiedzieć nam o rozmowach z lekarzem lub położną na temat opcji opieki (na przykład: badania prenatalne, rozpoczęcie porodu, leki, cesarskie cięcie, miejsce urodzenia, opieka nad noworodkiem itp.).



42. Położna/doktor pytali mnie jak bardzo chciałam brać udział w podejmowaniu decyzji

43. Moja położna/doktor powiedzieli mi, że są dostępne różne opcje mojej opieki położniczej

44. Moja położna/lekarz wyjaśniły zalety/wady opcji opieki położniczej

45. Moja położna/lekarz pomogli mi zrozumieć wszystkie informacje

46. Dano mi wystarczająco dużo czasu, aby dokładnie rozważyć różne dostępne opcje opieki

47. Byłam w stanie wybrać opcje opieki, którą uważałam za najlepszą

48. Moja położna/doktor respektowali mój wybór

W tej części zostaniesz zapytana o swoje zdrowie podczas ciąży i porodu.

49. Czy w którymś momencie ciąży położna/lekarz poinformowali Cię, że jesteś w grupie wysokiego ryzyka?

a. Tak
b. Nie
c. Nie jestem pewna

→ Jeśli tak, zapytaj: 49a. Dlaczego położna/lekarz poinformowali Cię, że jesteś w grupie wysokiego ryzyka? (Zaznacz wszystkie, które Ciebie dotyczą)

- Ponieważ mam przewlekłą chorobę lub problemy zdrowotne (np. cukrzyca, choroba serca, otyłość)
- Z powodu czegoś, co wydarzyło się podczas tej ciąży (problemy z łożyskiem, problemy z szyjką macicy, ciąża mnoga, in vitro, krwawienie, cukrzyca ciążowa, stan przed rzucawkowy/wysokie ciśnienie krwi)
- Z powodu czegoś, co wydarzyło się w poprzednich ciążach/porodach (cesarskie cięcie, stan przed rzucawkowy, przedwczesne porody, cukrzyca ciążowa, problemy z szyjką macicy lub łożyskiem)
- Z powodu mojego wieku
- Z powodu mojego pochodzenia etnicznego
- Ze względu na styl życia/dochód
- Z powodu problemów, które miałam w przeszłości (narkotyki, alkohol, więzienie, bezdomność, przemoc)
- Z powodów których nie rozumiałam

49b. Czy zgodzisz się, że byłaś w grupie “wysokiego ryzyka”?

a. Tak
b. Nie
c. Nie jestem pewna

50. Podczas tej ciąży doświadczyłam: (Zaznacz wszystkie, które Ciebie dotyczą)

- Plamienia lub krwawienia przez więcej niż kilka dni
- Anemii
- Wysokiego ciśnienia krwi (stan przed rzucawkowy, nadciśnienie wywołane ciążą lub zespół HELLP)
- Cukrzycy ciążowej
- Problemów z łożyskiem (przodujące, marginalne, oderwanie)
- Infekcji (grypa, zakażenie dróg moczowych lub nerek, wirus Zika, zapalenie płuc)
- Paciorkowce z grupy B, albo pozytywne GBS
- Problemu ze wzrostem płodu, lub płynem owodniowym (za dużo/za mało płynu)
- Problemu z pozycja płodu (pośladkowe, poprzeczne)
- Ciąża mnoga
- Przedwczesny poród
- Żadne z powyższych
- Inne (Prosze podać) _____

51. Czy podczas ciąży, porodu i/lub po porodzie, doświadczyłaś któregokolwiek z poniższych? (Proszę zaznaczyć wszystkie, które pasują)

- ☐ Problemy mieszkaniowe
- ☐ Problemy finansowe
- ☐ Brak pomocy od strony rodziny, czy przyjaciół
- ☐ Problemy z dostępem do opieki medycznej
- ☐ Przemoc fizyczna →Jeśli odpowiedź jest "e": proszę podać informacje o Kvennaathvarf (schronisko dla kobiet).
- ☐ Przemoc psychiczna → Jeśli odpowiedź jest "d": proszę podać informacje o Kvennaathvarf (schronisko dla kobiet).
- ☐ Lęki
- ☐ Depresja
- ☐ Żadne z powyższych
- ☐ Wolę nie odpowiadać

52. Gdzie planowałaś urodzić dziecko?

a. Szpital w Akureyri
b. Szpital w Akureyri
c. Björkin
d. Zakład opieki zdrowotnej w Akranes
e. Zakład opieki zdrowotnej w Ísafjörður
f. Zakład opieki zdrowotnej Półwyspu Południowego (Keflavík)
g. Zakład opieki zdrowotnej Wschodniej Islandii (Neskaupstaður)
h. Zakład opieki zdrowotnej Południowej Islandii (Selfoss, Vestmannaeyjar)
i. W domu
j. W szpitalu Landspítali
k. Inne (Proszę podać) _____

53. Gdzie urodziłaś dziecko?

a. Szpital w Akureyri
b. Björkin
c. Zakład opieki zdrowotnej w Akranes
d. Zakład opieki zdrowotnej w Ísafjörður
e. Zakład opieki zdrowotnej Półwyspu Południowego (Keflavík)
f. Zakład opieki zdrowotnej Wschodniej Islandii (Neskaupstaður
g. Zakład opieki zdrowotnej Południowej Islandii (Selfoss, Vestmannaeyjar)
h. W domu
i. W szpitalu Landspítali
j. Inne (Proszę podać) _____

54. Czy Twój poród został wywołany?

a. Tak
b. Nie

→Jeśli "Tak":

54a. Czy czułaś presje, aby wywołać poród?

a. Tak
b. Nie

55. Czy miałaś znieczulenie zewnątrzoponowe?
    a. Tak
    b. Nie
    → Jeśli “Tak”: 55a. Czy czułaś presje, żeby podać Ci znieczulenie zewnątrzoponowe?
        a. Tak
        b. Nie
56. Czy przy porodzie miałaś cesarskie cięcie?
    a. Tak
    b. Nie
    → Jeśli “Tak”: 56a. Czy czułaś presje/byłaś zmuszona do cesarskiego cięcia?
        a. Tak
        b. Nie

Ostatnia część ankiety dotyczy okresu poporodowego i opieki nad noworodkiem.

57. Ile ważył Twój noworodek po urodzeniu? Jeśli nie pamiętasz podaj przybliżoną wartość. (Wpisz pełne liczby, bez przecinków i bez dziesiątek, np. 3500 gramów).
_____ gramów

58. Czy noworodek był zdrowy i miał się dobrze po urodzeniu?
    a. Tak
    b. Nie
    c. Wolę nie odpowiadać

59. Czy Twój noworodek miał problemy zdrowotne? (Zaznacz wszystkie, które pasują)
    - Problemy z oddychaniem
    - Problemy z przewodem pokarmowym
    - Żółtaczka
    - Wada wrodzona
    - Mały przyrost wagi
    - Odwodnienie
    - Urodzony martwy, bądź zmarł podczas porodu
        → Jeśli "Tak", zapytaj: 59a. Bardzo nam przykro z powodu Twojej straty.
        Czy otrzymałaś wsparcie, bądź pomoc po Twojej stracie?
        a. Tak
        b. Nie
        c. Wolę nie odpowiadać.
        → Jeśli "Tak", zapytaj: 59b. Jakie wsparcie otrzymałaś? (Proszę podać) _____
        → Opuść pytania 60-64 i przejdź do końca ankiety
    - Wcześniak
    - Wrodzony, bądź genetyczny problem
    - Nie, moje dziecko nie miało żadnych problemów
    - Odmawiam odpowiedzi
    - Inne (Proszę podać) _____

60. Czy kiedykolwiek po urodzeniu Twoje dziecko przebywało na oddziale intensywnej terapii?
    a. Tak
    b. Nie
    c. Nie jestem pewna

61. Pod koniec ciąży, jak zamierzałaś karmić dziecko? (Wybierz jedną opcję)
    a. Tylko piersią
    b. Tylko butelką
    c. Połaczenie karmienia piersią i butelką

62. Czy do dzisiaj upłynął przynajmniej jeden miesiąc od Twojego porodu?
    a. Tak
    b. Nie

    Jeśli “Tak”: 62a. Jeden miesiąc po urodzeniu, jak karmiłaś Twoje dziecko?
        a. Tylko piersią
        b. Tylko butelką
        c. Połaczenie karmienia piersią z butelką

    Jeśli “Nie”: 62b. Jak obecnie karmisz swoje dziecko?
        a. Tylko piersią
        b. Tylko butelką
        c. Połączenie karmienia piersią z butelką

63. Czy po urodzeniu dziecka był u Ciebie w domu Certyfikowany Doradca Laktacyjny?
        a. Tak
        b. Nie
        →Jeśli “Tak”
            63a. Czy jesteś zadowolony z usług?
            a. Bardzo niezadowlona
            b. Nie do końca zadowolona
            c. Zadowolona
            d. Bardzo zadowolona

64. Czy po urodzeniu dziecka była u Ciebie w domu położna?
        a. Tak
        b. Nie

        →Jeśli “Tak”
            64a. Czy byłaś zadowolona z usług domowej położnej?
            a. Bardzo niezadowlona
            b. Nie do końca zadowolona
            c. Zadowolona
            d. Bardzo zadowolona

Ukończyłaś ankietę. Twój udział przyczyni się do poprawy opieki położniczej świadczonej w Islandii. Dziękujemy bardzo za Twoją pomoc i Twój poświęcony czas!

Jeśli podczas tej ankiety poczułaś się zdenerwowana, możesz aby umówić się na wizytę u specjalistycznej położnej i uzyskać pomoc: skontaktować się z "Gotowi cię wysłuchać" w szpitalu Landspítali pod numerem tel. 543 3253. W niektórych przypadkach można również porozmawiać z lekarzem położnikiem lub psychologiem. W razie potrzeby dostępne są usługi tłumacza.

Jeśli jesteś ofiarą przemocy fizycznej lub psychicznej i potrzebujesz pomocy: skontaktuj się ze schroniskiem dla kobiet (Kvennaathvarf). Aby uzyskać wsparcie i/lub poradę, ofiary przemocy oraz ich krewni mogą zadzwonić do schroniska pod numer tel. 561 1205. Telefon jest czynny 24 godziny na dobę, każdego dnia w roku. W przypadkach alarmowych dzwoń pod numer 112. Więcej informacji dostępnych jest w różnych językach na stronie https://www.kvennaathvarf.is/?lang=pl

Appendix E: Written Evaluation Questions

Giving Mothers a Voice Survey
Pretest: Feedback

Purpose of the survey and pretest:

The aim of this survey is to look at the experiences of childbearing migrant women in the areas of respect and autonomy in decision-making in maternity care in Iceland. By participating in the pretest of this survey, your main objective is to assist in developing the questionnaire. I will review your answers to the survey as well as your understanding and impressions of the questions in it. Your answers to the survey will not be used in the data collection and data processing of the study since it is not anonymous. Through pretesting, we will be able to find potential problems with the survey, thus reducing errors in gathering and reporting data.

Before you begin:

- Choose a comfortable environment with internet access, away from distractions before you begin the survey.
- Find the right time during the day or evening when you can give yourself at least an hour to answer the questions and give feedback. You are able to stop the survey at any time and continue at a later time.
- Use a clock or timer to see how long it takes you to complete the survey.
- In order to give helpful feedback, we recommend having a pen/pencil and paper ready if you want to write down notes, comments or questions that might arise while you are taking the survey.
- Read the feedback questions below before you begin the survey. This will give you an idea of the type of feedback we are looking for. You do not have to answer all of the feedback questions, but please provide as much feedback as possible so that we can further develop our survey.
- You can type your feedback directly on this Word document or send in a picture of written comments. Please send your feedback to Edythe L. Mangindin at: ELM9@hi.is
- Please call Edythe at: 771 4337 if you have any questions or difficulties.

Time:

1. How long did it take you to complete the survey?
2. Did you think the survey was too long?
3. Did you need to take a break from answering the questions?

Language and understanding:

4. Were there any spelling or grammatical errors?
5. Were any of the instructions unclear?
6. Were the questions easy to read?
7. Did you understand all of the questions?
8. Were there any words or sentences that you did not understand?
9. At any point in the survey, was there too much text?

Structure and design:

10. Did you think the survey was easy to access?
11. Were there any questions that you thought were inappropriate?
12. Were all of the options available for your answers?
13. Did any of the questions make you feel uncomfortable?
14. Did you like the structure or flow of the survey questions?
15. Would you recommend this survey to a family member or friend?
16. Other comments?