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## Health in Negotiation

### Cultural Analytical Perspectives on Health and Inequalities in the Swedish Asylum Context

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PO Box 117  
221 00 Lund  
+46 46-222 00 00



*Talieh Mirsalehi*

# Health in Negotiation

CULTURAL ANALYTICAL PERSPECTIVES  
ON HEALTH AND INEQUALITIES  
IN THE SWEDISH ASYLUM CONTEXT

This dissertation addresses the complex and multifaceted relation between ‘irregular’ migration and the phenomenon of health inequalities. The aim is to provide a cultural analytical account of the ways in which people who undergo the asylum process in Sweden navigate, negotiate, and practice health in uncertain times. Through an ethnographic investigation into a group of asylum seekers’ embodied experiences of evaluating health, assessing risk, and preventing illness before and during the COVID-19 pandemic, this study explores how ambiguities of the asylum process is perceived and responded to by those who hope to gain membership of the new society.

The analysis suggests that the notions of health, care, immunity, and risk are boundary, contextual, situational—and therefore negotiable—concepts, interpreted and enacted in relation to ambivalent conditions of displacement in an asylum context. In a healthcare paradigm where maintaining a healthy lifestyle and preserving one’s body are promoted as a personal responsibility and moral percept, generating good health becomes a matter extending beyond its biological properties to a performance of belonging. As well, disparities in health are seen as reversible through alterations to individuals’ health and care practices. This, in turn, results in the formation of strategies to not only generate health, but to also show one’s attempt at following the socioculturally constructed norms of health and care as an accountable member of the new society. The findings also highlight the importance of methodological considerations when it concerns accessing and assessing the experiences and perceptions of those who are deemed inaccessible, yet silently and statistically present in public health reports.

# Health in Negotiation

## Cultural Analytical Perspectives on Health and Inequalities in The Swedish Asylum Context

Talieh Mirsalehi



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DOCTORAL DISSERTATION

Doctoral dissertation for the degree of Doctor of Philosophy (PhD) at the Faculty of Humanities and Theology at Lund University to be publicly defended on 24 of May at 10.00 in room C121, Department of Arts and Cultural Sciences, Helgonavägen 3, 223 62, Lund.

*Faculty opponent*  
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**Abstract:** Health inequalities are a persistent and growing issue in different countries worldwide. Sweden, despite being one of the Scandinavian countries with internationally recognized welfare system is no exception. The issue of health disparities and its increase among some groups, including those who are categorised as migrant have been acknowledged. Emergence of the COVID-19 pandemic, however, revealed the gravity of the situation when groups of people who had migrated to Sweden from countries mainly within Africa and the Middle East were on the frontline experiencing disproportionate impacts of the Coronavirus. Although the effect of structural factors on health vulnerabilities among these groups have been identified, there is still little knowledge about how individuals who are placed into migrant categories have experienced and responded to health risks caused by the pandemic. This dissertation aims to provide a cultural analytical account of the ways in which people who undergo an asylum process in Sweden relate to, navigate, and negotiate health. By empirically investigating a group of asylum seekers' perceptions of health, body, and risk, this study demonstrates how the participants make meaning of their embodied experiences of generating health and practicing self-care while living in a transitional state. In a health care landscape where taking responsibility for one's health is a sociocultural norm, protecting health and preserving body is seen as a moral percept, expected from all members of society. Disparities in health, from this view, may be perceived as avoidable by leading a healthy way of life and avoiding exposure to health risks. By focusing on a group of asylum seekers' experiences of navigating health and care before and during the COVID-19 pandemic in Sweden, this study reveals how perceptions and practices of health and care are situational, contextual, and negotiable in relation to the conditions within asylum processes. While being expected to actively participate in the society they want to be a part of, those who joined this study revealed how uncertainties about the state of their 'at-risk' bodies clash with performances of membership. While making meaning of notions of health and care in the new society and turning it to projects of familiarization, those who joined this study shared challenges of building a fit and equally immune body that matches new parameters of health and well-being under unequal circumstances. However, it may not be translated as passivity and lack of initiation among 'vulnerable' groups when it comes to generating health. The notions of health, care, risk, and immunity, from this perspective, are boundary concepts and open to interpretation. In order to access the experiences, perceptions and practices of health among 'inaccessible' migrant populations, more emphasis needs to be put on methodological considerations in health research among different groups.

**Key words:** Health, care, migration, health inequalities, asylum seekers, liminality, immunity, boundary concepts, health research, methodology, ethnographic research, ethnology, Sweden

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## HEALTH IN NEGOTIATION



# Health in Negotiation

Cultural Analytical Perspectives on Health and  
Inequalities in The Swedish Asylum Context

TALIEH MIRSALEHI



**LUND**  
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*To my family*



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## Introduction

“I have prepared myself; this disease [COVID-19] is not a joke”, Gholam says during our phone conversation on an April day in 2021. He is on a bus heading toward the outskirts of a small town in southern Sweden, where he lives with his wife, Ghamar, and their children in a temporary accommodation while going through their asylum process. Gholam arrived in Sweden in 2015, the year that is often referred to as the year of ‘European refugee crisis’<sup>1</sup>. After years of living apart, the family reunited in 2019 when he received an impermanent residence permit which allowed him to apply for ‘family reunification’ and bring his family to Sweden<sup>2</sup>.

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<sup>1</sup> The year 2015 is often referred to as the year of ‘Refugee crisis’ when many people crossed international borders to seek asylum in different countries, including those within Europe. The term ‘crisis’ refers to a dramatic increase in both the number of asylum seekers and human casualties that occurred mainly among those who attempted to cross the Mediterranean to reach Europe, as well as the challenges that the countries within EU faced. I will elaborate on this matter in the following section. More information about the migrant fatalities in 2015 is available at: <https://www.iom.int/news/iom-counts-3771-migrant-fatalities-mediterranean-2015>

<sup>2</sup> Family reunification (*Familjeåterförening*) refers to the legal right that allows those who have applied for asylum to reunite with their family in Sweden. The right is applicable only after receiving a permanent or temporary residence permit as a refugee, or for those in need of alternative protection while having well-founded prospects of being granted a permanent residence permit. After the events in 2015, there are some stricter requirements for the reunification. Based on the implemented conditions that came to force after 2015, only those who have received a minimum of three-year or a permanent residence permit are allowed to proceed with the process of family reunification. In case of approval, adult applicants can bring their spouse and children under the age of 18, or parents, in case the applicant is an unaccompanied child migrant. In case the applicant qualifies for family reunification on a temporary residence permit, the family members also receive a temporary permit which is valid for as long as the applicant’s own permit is in effect. More information is available at: <https://www.migrationsverket.se/Privatpersoner/Skydd-och-asyl-i-Sverige/Efter-beslut/Om-du-far-stanna/Familjeaterforening.html>

The trip is long, and he is eager to talk. Gholam begins by revealing his concern over the rapid development of the COVID-19 pandemic in Sweden as well as around the world. He also explains how his family has adjusted their daily routines in accordance with the new circumstances to stay safe. They have, for example, altered their diet to ingest more vitamin C, which they have heard can enhance their immune system and help it fight against the coronavirus. They have also started walking in the nearby woods as a newly adopted strategy to strengthen their bodies while keeping away from other people. “We, like the rest of the society, make sure to stay active”, Gholam says with reference to his earlier comment about the importance of following the recommendations provided by The Public Health Authority in Sweden. Referring to the individuals with ethnic Swedish backgrounds and, from his opinion, their full dedication to pursuing the guidelines and advancing their health, he adds “whatever they do, we do it too, every day of the week”. Throughout the conversation, Gholam comments on the role that adapting healthy habits plays in boosting the body’s immunity to disease. He also repeatedly emphasises that this change in lifestyle is one of the main strategies that his family has embarked after moving to Sweden, which, he thinks, has kept them from harm even during the pandemic.

During a video call with Gholam’s wife earlier that week, she, too, revealed her apprehension over the situation and the unpredictability of the disease. Ghamar mentioned how their neighbours, who are also asylum-seeking families from different parts of the world, have been contracting the virus one after another, with some finding recovery from the disease harder than the others. The fear of contagion and the irreversible health consequences that it could entail for, as she wondered, their unfit bodies led to them becoming increasingly isolated, particularly in the beginning of the outbreak. Yet, the risk of infection was not the only issue at hand. “Gholam’s residence permit was valid for three years, and it was four months ago when we applied for the extension”, Ghamar said, and continued “We’re still waiting for a decision”. Like Gholam, she listed the changes that they have made to their daily routines in response to the pandemic. However, she did not hold back from disclosing how following

the guidelines and altering their lifestyle to what is considered healthy in this new society is a delicate task for them and their situation:

My husband and I come from Afghanistan, from conflicts... We've got all kinds of diseases, and now... We haven't had the chance to do anything about it [health]... I mean, since we've moved here with the kids, things have been difficult... Things were better the first year, but it gets harder and harder as time goes by.

Slightly over a year prior to our phone conversations with Ghamar and Gholam, the World Health Organisation (WHO) declared the spread of the Coronavirus disease 2019 (COVID-19) a global pandemic on March 11, 2020 (WHO, 2020). Shortly after this press release, the first wave of the pandemic reached Sweden (Socialstyrelsen, 2021) and left the society, like the rest of the world, in a state of shock and ambivalence. From the initial stages of the outbreak, public health reports and literature from around the world pointed out the unequal impacts of the pandemic on different groups (Khalatbari-Soltani et al., 2020). Not long after the emergence of the coronavirus in Sweden, it became evident that the disease had a severe impact on senior members of society as well as those who were categorised as foreign-born and migrants<sup>3</sup> (Hansson et al., 2020; Rostila et al., 2021). Besides age, which was considered one of the main risk factors behind

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<sup>3</sup> The term 'foreign-born' (*Utlandsfödda* or *Utrikesfödda*) refers to those who are born in a country outside Sweden. It also applies to those whose parent(s) were born in a country other than Sweden. Although the term refers to a heterogeneous group of people who have migrated to Sweden for variety of reasons and for different lengths of time, it is still widely used in different reports alongside the term 'migrant'. The terms 'migrant' or 'immigrant' (*Invandrare*) also refer to the heterogeneous group of people who have moved to and resettled in Sweden from different parts of the world. The terminologies around migration that are used in different official reports have been critiqued due to their broad and often negative connotations, contributing to the idea of migration and migrants as problems. Although the term 'migrant' statistically refers to those who were born abroad and have moved to another country for a variety of reasons, the term mainly refers to those who have moved to Sweden from countries outside the territories of the western world. More about this discussion can be found at: <https://mau.se/en/news/common-talk-about-migration-maintains-harmful-assumptions/>

susceptibility to contagion, country of birth was another determinant of particular vulnerability to the virus. According to the assessment reports, the majority of those who were hospitalised in intensive care units or were deceased primarily in the absence of the vaccine were mainly born in countries in The Middle East and Africa (Folkhälsomyndigheten, 2021a; Rostila et al., 2023). The overrepresentation of those categorised as migrants in COVID-19–related morbidity and mortality cases in Sweden called for urgent investigation into the reasons behind the outcomes.

From the onset of the pandemic, it was suggested that health inequalities stemming from social disparities were among the main contributing factors behind the disproportionate effect of the disease on some migrant populations (Hansson et al., 2020; Folkhälsomyndigheten, 2021b). The outbreak of the pandemic in Sweden, as in other countries, has also shown that appearance of such phenomenon can exacerbate already-existing and increasing inequalities in health among different groups, including the displaced populations of asylum seekers and refugees. What is less attended to, however, are empirical investigations into how social disparities and health inequalities are experienced and responded to by those who are most affected by them including asylum seekers and refugees, within or without a pandemic. The emergence of the COVID-19 disease has, in other words, illuminated a paucity of knowledge about social and cultural experiences of health, unhealth, and dealing with societal hazards among these groups who are considered more vulnerable to the effects of a time of health crisis (Folkhälsomyndigheten, 2021b). Approaching the impact of inequalities on displaced populations from their own perspective requires an analytical view on the notions of health and body from a social and cultural perspective. The meaning of health is situated in one's subjective, lived experiences of the body and its bodily responses to the surrounding world (Frykman, 1992). From this point of view, health is a spatial and temporal concept, and its meaning is open to negotiation and reconstruction in relation to one's former, present, and anticipated future experiences.

Ghamar and Gholam, as well as the rest of the participants who joined in the research from which this dissertation has evolved, shared their experiences of health and their views on the body while undergoing the

asylum process in Sweden. Their comments reveal an attempt to make sense of, relate to, and to adapt their physical state to the social norms and expectations around wellness in the new society, especially during the pandemic. Their experiences also unfold the complex and shifting interplay between the body and society, where perceptions of health and practices of care are placed, reconstructed, and contested at the intersections of biology, context, and culture (Lundin & Åkesson, 1996). Health, from this perspective, refers to the body's biological response to the surrounding infectious agents, while also indicating a desire to reconstruct one's social body (Lundin & Åkesson, 1996). From a cultural analytical perspective, the aforementioned remarks, as well as the rest of the presented ethnography in this dissertation reveal the ways in which health practices are culturally created and socially co-constructed. The presented insights, in other words, demonstrate how the notion of health is interpreted, negotiated, resisted, and reproduced during a transitional asylum procedure. An asylum journey—or, as the anthropologist Sharam Khosravi (2010a) puts it—an *irregular* course of migration, influences one's body in various ways. Living a precarious asylum life can lead to the exacerbation of physical, psychological, and emotional discomfort. At the same time, the irregularity of the process can illuminate performances that are initiated from uncertainties of the procedure; performances which are aimed at assessing the impossibilities and discovering the “possibilities of the body” for creating a desired self and actualising perceptions of an ideal life (Lundin & Åkesson, 1996, p. 6). My approach to inequalities in health is through an ethnographic exploration of health as a state and strategy among those who navigate and respond to the transitional stages of an asylum life.

## Displaced bodies and transitional health

Intentions behind migration may differ, and so do the type and means of the mobility. Migration, regardless of its divergent forms and conditions, involves movement of bodies and processes of “configurations of placement” by crossing and creating boundaries while changing dwelling places (Ahmed, 2003, p. 1). By stepping into an asylum terrain, one enrolls in the process of repositioning which takes place throughout the journey

and at the end, in the new place. An asylum journey can be seen as an act of embodied displacement when one's body is put through experiences of preparation, separation, relocation, re-placement, and reformation. This dissertation takes its starting point in examining the interplay between displacement and health. It takes a cultural analytical approach to understanding how people manage health and experience illness as asylum seekers before and during what has been referred to as 'forced migration', 'involuntary migration', 'displacement' or 'forced displacement'. An asylum journey is considered an irregular means of mobility, as it usually occurs through the backdoor of the new society (Khosravi, 2010a). In turn, 'migration' and 'migrant' are often politically loaded terms, depending on where the journey begins, how it is taken, and by whom. Terminologies around migration, even when the intentions are right, often represent the process as a problem and subsequently some groups who migrate are *recreated* as "problem people"<sup>4</sup> with race and class as determinants of whether they constitute a 'problem'. The journey and those who undertake it are referred to by terms like *illegal, undocumented, non-documented, and unauthorised*<sup>5</sup>. Such terminologies, in turn, create and recreate a division not only between the status of 'migrant' and 'citizen', but also between the *hierarchies of migration* (Anderson, 2020). Such divisions come with consequences, especially when it concerns identification and confrontation of barriers to receiving health and care services among public health providers and receivers of care services, which differ depending on the migrant category that individuals are placed in (Wenner et al., 2019).

Ethnologists in Sweden have investigated everyday experiences, routines, and habits to capture cultural patterns and practices that shape and are shaped by health and migration within different settings (Fioretos, 2009; Hörnfeldt, 2005; Nilsson, 2015; Öhlander, 2005). In this dissertation, I focus on the implications of health among a group of individuals who

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4 During her visit at Malmö University as a guest professor in sociology, Bridget Andersson talked about terminologies of migration and the role of race and class in how they create assumptions about migration as a social problem: <https://mau.se/en/news/common-talk-about-migration-maintains-harmful-assumptions/>

5 [https://home-affairs.ec.europa.eu/networks/european-migration-network-emn/emn-asylum-and-migration-glossary/glossary/irregular-migration\\_en](https://home-affairs.ec.europa.eu/networks/european-migration-network-emn/emn-asylum-and-migration-glossary/glossary/irregular-migration_en)

arrived in Sweden in and after 2015, the year when Europe witnessed one of the, at the time<sup>6</sup>, greatest refugee inflows since the Second World War (UN, 2015). In 2015, over one million people took refuge in Europe, followed by slightly less than a million in 2016. The majority of those who reached the continent had escaped political conflicts, war, poverty, and unsustainable life conditions, mainly within countries in the Middle East and West as well as Central Africa (Crawley, 2016). In 2015, Sweden received 162,877 applications for asylum with Syria, Afghanistan, and Iraq, the main countries of origin for most applicants (Migrationsverket, 2022; SCB, 2024a). The rapid influx of people who needed safety and sanctuary put most EU Member States under unforeseen challenges (FRA, 2016). In Sweden, one of the concerns circled around how the refugee situation may exacerbate already-existing disparities in health between some migrant populations and the rest of the society (Folkhälsomyndigheten, 2023). At the same time, there was little knowledge about how the incoming groups of people related to health, what experiences they had navigating previous healthcare systems, what healing strategies they practiced, and how they would relate to the healthcare system and to social welfare in Sweden. Although attention has been paid to the sociopolitical and socioeconomic aspects of forced migration of the time, these and similar questions are just as much rooted in the complex sociocultural processes at play in such multidimensional means of human mobility. In other words, the situation required a better understanding on how the notions of health, unhealth, and inequalities in health may be assessed in the context of forced migration and in accordance with which health parameters. Approaching this inquiry requires a parallel understanding of how the concepts of 'health' and 'a healthy body' are perceived, interpreted, and made meaning of by those who undergo involuntary international migration and in relation to both the social and cultural determinants of health and unhealth within asylum contexts. Investigating the interrelationship between health and migration requires a sociocultural approach. While the cultural perspective centres

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6 As a result of the recent invasion of Ukraine by Russia in 2022, it is estimated that at its peak, 3.5 million people took refuge in Poland, which exceeded the former refugee influx that occurred in 2015 and 2016: <https://www.unicef.org/eca/stories/hope-amid-crisis> (accessed 3 November 2023)



around the “significations” of one’s experiences, the social aspect is about the “relations, institutions, and norms” that are involved in processes of making meaning of experiences (Fornäs, 2017, p. 55). A combination of the two analytical perspectives—while being complimentary—can reveal the significance of some social events on health outcomes.

But, why is it central to approach inequality in health in a context like Swedish society, where there is a consensus on provision of equal health for all, within and without the country’s national borders? Nordic countries, including Sweden, are known for their welfare model, comprised of a general commitment to social equality (Dahl & van der Wel, 2015). When it comes to decreasing or eradicating health inequalities, however, Nordic countries have not fared all that differently from other western European countries (Lundberg, 2018). Although overall health in Sweden has improved over the years, health differences among some groups, including those within the categories of foreign born and migrant, persist (Folkhälsomyndigheten, 2021a). To address this issue, one of the main objectives of Swedish public health policy is to establish social conditions which provide opportunities for the entire population to equally generate good health (Folkhälsomyndigheten, 2021a). Following the UN General Assembly’s agenda for global Sustainable Development of Agenda 2030<sup>7</sup>, Sweden has set the additional objective of providing equitable health by reducing and eliminating avoidable inequalities in health on a national and international scale (Irwin, 2019). While the goal of implementing the Agenda 2030<sup>8</sup> in Sweden includes providing equalities in health, a report published in 2019 by Central Statistics Agency of Sweden (SCB) has revealed that disparities in health between different groups in Sweden are widening (Larsson, 2019; SCB, 2019).

The outbreak of the COVID-19 pandemic in 2020 revealed a new feature of inequalities in health by showing how a global health crisis may

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<sup>7</sup> <https://sdgs.un.org/2030agenda>

<sup>8</sup> ‘Agenda 2030’ refers to the UN Federation’s focus on the global goals of socially, economically, and environmentally sustainable development to be achieved by the year 2030. More information at: [https://fn.se/vi-gor/utveckling-och-fattigdomsbekampning/agenda-2030/?gad\\_source=1&gclid=EAIaIQobChMI6s63pNC6hAMVRVWRBR3CpQoKEAAYASAAEgJZE\\_D\\_BwE](https://fn.se/vi-gor/utveckling-och-fattigdomsbekampning/agenda-2030/?gad_source=1&gclid=EAIaIQobChMI6s63pNC6hAMVRVWRBR3CpQoKEAAYASAAEgJZE_D_BwE)

impact different social groups unevenly. The pandemic uncovered and amplified already-existing health disparities, which was reported to have led to unjust morbidity and mortality rates among the socioeconomically disadvantaged, minority ethnic groups, refugees, and asylum seekers in different countries (Clark et al., 2020; Johnson-Lans, 2023; Mishra et al., 2021). Emergence of the pandemic in Sweden, like other countries, demonstrated the significance of addressing such avoidable health differences in the society.

Increase in migration has led researchers from different fields, including ethnologists, to follow this intensification by investigating the cultural processes that are influenced by the conditions and consequences of human mobility and their impacts on migrants' health and well-being (Fioretos, 2009; Fioretos et al., 2013; Geschwind et al., 2023; Nilsson, 2015). While social inequalities resulting in the formation and aggravation of health inequalities are recognised, empirical approaches to understanding perceptions of health and well-being while dealing with social disparities among those who are forcibly displaced are limited.

## Aim and research questions

The aim of this dissertation is to provide a cultural analytical account of the ways in which people who undergo an asylum process in Sweden relate to, navigate, and negotiate health. The ambition is to empirically explore a group of asylum seekers' perceptions of health and body, and how they make meaning of their embodied experiences of practicing self-care while living in a transitional state. Taking the COVID-19 pandemic as an empirical case, I investigate how the children and adults who participated in this research perceive and negotiate the notion of health while reflecting on and re-evaluating their care practices before and during the asylum life. I also explore in what ways perceptions of health and of the body are contested and reconstructed while contesting the terms of membership established at the doorstep of the new society. The following research questions are posed and investigated in correspondence with the three articles and the one book chapter that are included in this dissertation:

## INTRODUCTION

- How are the embodied experiences of health, unhealth, and inequalities perceived and enacted by asylum seekers in response to circumstances within an asylum context and in relation to other members of the new society?
- In what way does experiencing an asylum process influence individuals' perceptions of the body and of the meaning of its biological responses?
- How are the interpretations of health and health practices negotiated, contested and turned into strategies to meet the assumed requirements of membership and belonging during the transitional asylum procedure?
- What methodologies need to be applied to approach, access and assess notions of health, practices of care, and responses to societal hazards among asylum-seeking populations, and why is it important to include this aspect in health research?

This dissertation is an investigation into experiences dealing with underlying contributing factors to the inequalities in health among displaced populations in the multicultural society of Sweden. By doing so, this study explores how different health recommendations, guidelines, and strategies in the new society are interpreted, internalised, problematised and incorporated by asylum seekers into their everyday life decisions. The participants are families from Afghanistan and Syria. Besides the adult members, children have also joined and contributed equally to this study. It is a conscious decision to focus on experiences of health and displacement regardless of the participants' age and gender, while remaining aware of the relevance and importance of familial and gendered aspects.

### Setting the scene: framing the nexus between migration and health in Sweden

International migration has a multidimensional character and comes in varied forms and lengths. People step into a migratory journey for manifold reasons. For some, migration is a choice to relocate while for others, it comes in the form of forcible dislocation, making migration a consequence rather than a preference. Migratory moves take place inter-regionally, trans-continently, or intercontinentally, depending on one's circumstances

and available opportunities. The International Organisation for Migration (IOM) has estimated that by 2020, around 281 million people lived outside of their countries of birth, equalling 3.6% of the world population (IOM, 2022). In 2015, the number of international migrants reached 244 million, which was a considerable increase in comparison with 173 million in 2000 (UN, 2015). As of 2023, it was estimated that over 110 million people were forcibly displaced worldwide, of which 36.4 million sought refuge across national borders (UNHCR, 2023). In 2015, over one million people sought refuge in EU member states, and because of this striking inflow, managing the intake of international refugees was placed on top of nation states' political agendas (FRA, 2016).

Europe has a rather long record of receiving displaced populations of refugees and asylum seekers, some of whom experiencing statelessness (Crawley, 2016; Eliassi, 2021). In response to the aftermath of the first and second World Wars, the United Nations established the 1951 Convention<sup>9</sup> on the Status of Refugees and the right to seek asylum in other countries when in need of safety. The Convention, which at first mainly recognised the rights of European citizens to seek asylum in other countries within Europe, was later expanded and removed the geographical limitations in an enhanced 1967 Protocol, which made the 1951 Refugee Convention a universal agreement (UNHCR, 2024). Through this internationally recognised treaty, Europe and its member states agreed to offer safety and essential services such as shelter and healthcare to those who seek refuge and protection from within and without the European territories (UNHCR, 1967). The 1951 Convention has been the cornerstone of refugee's legal rights to this day. However, the challenges caused by escalated political conflicts and socioeconomic instabilities of 2015 put its execution to test.

Some described the refugee mobility of 2015 and 2016 as a so-called 'European refugee crisis'. This was principally a reference to the large

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<sup>9</sup> The 1951 Refugee Convention, also known as the 1951 Geneva Convention, is a set of international agreements stated in the 1967 Protocol in which the universal definition of terms such as *refugee*, legal human rights, and the internationally recognised standard of protection is documented. The protocol is the key legal document that forms the basis of the UNHCR's work on provision and execution of these agreements. More information available at: <https://www.unhcr.org/about-unhcr/who-we-are/1951-refugee-convention>

number of incoming individuals and the often-deadly attempts to reach their destination, besides fear of the impact that the situation could have on the receiving country's welfare regimes in the short and long run (Panebianco, 2019). Other critical voices, instead, called it a "crisis of political solidarity" in Europe, partly due to the lack of an agreement on a new political narrative about refugee rights, and partly because of disagreement over distribution of refugees among the member states (Crawley, 2016, p. 13). In the hope of finding safety and a better life, people took every possible route forward either by ground or by sea. In the immediate aftermath of the refugee situation of 2015 and 2016, the media often referred to the situation with terms such as 'refugee crisis', 'wave of refugees', 'refugee flood', or 'refugee problem'. In the meantime, the world news of the time showed how merciless these irregular passages were by reporting recurrent fatalities among asylum seekers who were trying to reach a destination (Panebianco, 2019; Spencer & Triandafyllidou, 2020). By the end of 2015, it was estimated that over 3692 refugees drowned on their way to Europe, including children (IOM, 2015). The casualties worsened the year after, when 5079 people lost their lives while trying to move to gain a second chance in life (IOM, 2017).

The asylum arena of the time accentuated the irregularity of this mode of migration by fuelling the already existing debates over legality, illegality, legitimacy, and the illegitimacy of such "desperate journeys" (UNHCR, 2017). This, in turn, resulted in the formation of new and the re-emergence of old notions of risk and security via the *securitisation* of forced migration and asylum seekers as a threat to societal stability (See Engblom, 2023). Through human mobility, it is not only people that move across and beyond borders, but also the organisms within their bodies. When it comes to an asylum move, the arrival of bodies literally and metaphorically becomes a matter of national security (Wemrell, 2021) by challenging our understanding of bacteria and the immune system with reference to collective and personal security, national borders, surveillance and migration. In the "immunitary" landscape, where reviewing the risks and rewards of living with bacteria and viruses is a daily concern (Brown, 2019), an asylum journey appears to be a biological risk not only to those who arrive from beyond geographical borders, but also those who live within

them. Most countries within the EU, including Sweden, offer medical screening upon asylum seekers' arrival (Norredam et al., 2006). These health controls not only intend to provide urgent healthcare services to those in need, but also to detect and defuse contagious diseases that the migratory bodies may carry which can pose a threat to society (Sveriges Riksdag, 2004; Socialstyrelsen, 2023).

With an increase in the number of people who sought safety and sanctuary, a majority of countries within and without EU, including Sweden, took in people in need of asylum. Although Sweden, without hesitation, opened its door and welcomed the newly arrived populations with open arms, refugee receptions of the time oscillated between notions of hospitality and hostility when opposing open immigration policies was placed against the preservation of a humanitarian agenda (see Farahani, 2021; Povrzanović Frykman & Mäkelä, 2019; Zackariasson et al., 2022). As a member state of the EU with a long history of migration, Sweden has been engaged in both European and International fora and contributed to international refugee protection and resettlement over the past decades (UNHCR, 2022). When people from Germany, as well as other Nordic and Baltic countries took refuge in Sweden during and after the Second World War, Sweden started to transform from the country to emigrate from into a country to immigrate to (Geschwind et al., 2023; Migrationsverket, 2022). Sweden has been famous for its generous migration policy and for being one of the main recipients of refugees among other European states. By enrolling in an asylum process in Sweden, one is entitled to free accommodation, financial support, and healthcare services, including the voluntary health assessment, emergency and dental care services, to name a few (Migrationsverket, 2023b). Despite keeping the provision of health and care rather intact, some aspects of asylum policy shifted after 2015 when 162,877 people immigrated to Sweden in the same year (Migrationsverket, 2023)<sup>10</sup>.

From the onset of the refugee mobilities in 2015, Sweden was one of the member countries within the EU that received a large number of individuals seeking asylum and protection. During a speech in Stockholm

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10 <https://www.migrationsverket.se/Om-Migrationsverket/Statistik/Asyl.html>

in 2015, Stefan Löfven, Sweden's prime minister of the time from the Social Democratic political party reconfirmed the country's stand and announced that Sweden would continue to support those in need of refuge as it had before (Malmgren & Johansson, 2015; Wiese Edeler, 2015). The situation, however, took a turn when the sudden increase in the number of asylum seekers created unforeseen pressure on, mainly, accommodation and processing of asylum applications (Jeppsson & Svensson, 2015; Krisinformation, 2015; Migrationsverket, 2024). Shortly afterwards, in November 2015, in a press conference, a change in Sweden's refugee policy in response to the circumstances of the so-called 'refugee crisis' was declared, announcing a sharp reversal in its refugee policy by restricting conditions of receiving a residence permit as the Swedish refugee reception needed "a breathing space" (Wiese Edeler, 2015). The Deputy Prime Minister of the time, Åsa Romson, added that the situation was not sustainable, and the Swedish asylum regime needed to be adapted to the EU's minimum level. The goal was that the change would encourage more people to seek asylum in EU countries other than Sweden. The announcement received different reactions. It was criticised by some as it was interpreted as an abrupt turn from a welcoming and tolerant to a closed-door refugee policy, while others considered it to be necessary (Ljungberg, 2015). This was followed by an alteration in the legal grounds for asylum in the "Alien's Act" (Utlänningslagen, 2005:716), the implementation of which changed the conditions of being approved as an asylum seeker and the requirements for obtaining a residence permit in Sweden. The introduced measures included stricter requirements for receiving asylum by limiting the length of the allocated residence permit to periods between thirteen months to three years.

As an aftereffect of the political events of 2015, the asylum procedure became longer and conditional for some groups, and chances of being granted the status of 'refugee' was based on one's nationality (Engblom, 2023). The instability of the situation, the prolonged state of uncertainty and the fear of unknown outcomes is known to be one of the reasons behind the formation and exacerbation of different lasting health conditions among asylum seekers, refugees, and even migrants (Makenzius et al., 2019; Sundval, 2021; Sundval et al., 2021). Those who are forcibly

displaced have been subjected to different complications before, during and after their arrival in their new society, with often long-term effects on their health and well-being (Tinghög et al., 2017; Solberg et al., 2020). The decline in the reception of refugees in Sweden became yet another contributing factor to the formation and aggravation of unhealth among those who had or were hoping to enrol in an asylum process (Lennartsson, 2022). As of 2023, the government of Sweden is implementing a paradigm shift in migration by changing the integration policy to a more demand-based model with an emphasis on individual responsibility (Regeringskansliet, 2023). This includes individual effort for becoming a part of Swedish society through being self-sufficient while understanding and practicing the society's norms and values.

## Disposition

The *Introduction* to this dissertation began by providing a general view of the interplay between forced migration, health, and inequalities. After introducing the *Aim* of this thesis and the *research questions* that were developed accordingly, a brief historical overview on migration and health in Europe and particularly in Sweden is presented. To continue on the topic, a background to the *Empirical Setting* of this research is given, followed by an elaboration on the *Theory* and the theoretical frameworks of this dissertation, with a focus on health as a boundary concept and the fluidity of the notion of 'care', 'risk' and 'immunity' within the liminal, transitional state of asylum life. This section is followed by presenting implications of the *Methods and Material* used in the analysis of this study. In this section, I analytically discuss the notion of field in ethnographic research before attending to a discussion on methodological approach and reflexivity. In the Method section, the research techniques utilized in this study are introduced and discussed. It includes Review of ethnographic perspectives and a discussion on the Ethnographic approach through a reflexive lens as well as Utilisation of different methods when approaching the matter of unequal health and other means of health-related studies. In the Material section, I reflect on the fieldwork and introduce the participants, including the organisation where this study is conducted and



the participating families who have joined this research. I then elaborate on the performed Interviews and observations as well as the conducted Survey that are referred to in the book chapter included in this study. Next, in the Analytical consideration I reflect on the material generated using different means of knowledge acquisition through out the research. Later, I delve into *Reflexivity* and the role of Positionality before, during, and after the research process, and the need for Rethinking language, first as a concept and then in relation to Research ethics when it involves vulnerable research topics and subjects.

In the *Previous Research* section, I provide an overview on the existing literature with focus on social and cultural conception of health, care, and inequalities in health in the context of migration. This section presents studies within the field of ethnology as well as other disciplines. Added to this part is literature on research methods when approaching inaccessibility in research, and the aforementioned inquiries. In *Research Findings*, I provide a summary of the three articles and the one book chapter included in this dissertation. In the *Concluding Discussion*, these publications will be discussed in relation to the aim and the research questions of the dissertation. This section ends with Concluding remarks on the contribution that this dissertation aims to make to the field of ethnology, as well as in medical humanities and migration together with suggestions for further research and practical steps that could be taken. The following sections, References, and Appendices provide the full list of the literature used as well as the information forms, interview guides, observation guides, consent forms, and the survey questions. The final part of this dissertation includes Paper 1-4, consisting of 3 articles and 1 book chapter.

### Author contribution

This dissertation includes four papers, consisting of three articles and one book chapter, which are presented in chronological order of inclusion in this study. Talieh Mirsalehi is the single author of Article 2 and 3. Article 1 and Book chapter 4 are co-authored. Authors' contributions of the

publications that are co-authored are presented in accordance with Elsevier's CReDiT Author statement<sup>11</sup>, as follows:

*Paper 1:*

*Talieh Mirsalehi:* Conceptualisation, methodology, formal analysis, investigation, data curation, writing—original draft, writing—review and editing. *Kristofer Hansson:* Conceptualisation, methodology, writing—original draft, writing—review and editing.

*Paper 4:*

*Talieh Mirsalehi:* Conceptualisation, methodology, formal analysis, investigation, data curation, writing—original draft, writing—review and editing. *Kristofer Hansson:* Conceptualisation, methodology, writing—original draft, writing—review and editing.

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<sup>11</sup> <https://www.elsevier.com/authors/policies-and-guidelines/credit-author-statement> (accessed 22 April 2023)



## The Empirical Setting

This research is rooted in Swedish society and explores cultural processes through which asylum seekers navigate and negotiate health while undergoing different stages of the asylum procedure. To operate this empirical study, I conducted ethnographic fieldwork between 2019 and 2021 in collaboration with a non-profit organisation in one of the southern cities located in Scania country, southern Sweden. This organisation, which is politically and religiously unbound, targets asylum-seeking families and unaccompanied child migrants who have either newly enrolled in the asylum process or have received a decision on their application which allows them to reside in Sweden, either temporarily and conditionally, or permanently. The people who are involved in the asylum process are usually referred to this organisation by the city's municipality in an attempt to introduce newcomers to Swedish society while connecting them to others in society with or without similar asylum experiences with the help of the organisation's humanitarian initiatives. This organisation is run by a leading group and volunteers from different geographical, educational, and career backgrounds. The motivation behind volunteers' participation varies. They can either be in their post-retirement stage and wish to support those in need while remaining socially active and engaged or join the initiative to perform an internship as a part of their education, gain work experience, develop a network for future career goals, or improve their Swedish language skills. Although the organisation's staff have

consented to join this study, I have decided to keep all information about the organisation's name and location confidential<sup>12</sup>.

The organisation was first established in 2004 in collaboration with the Church of Sweden (*Svenska kyrkan*). They, like several other NGOs in the country, aim to support children who move to Sweden with their families or caregivers as asylum seekers. By offering a pedagogical course, the organisation intends to give children the emotional and psychological support that they may need during different stages of the asylum process. The challenges that one may encounter before arrival—as well as the uncertainties imposed by the procedure before and after receiving a decision—can impact children's well-being (Eastmond & Ascher, 2011; Kim et al. 2020; Smith et al., 2021; Wahlström Smith, 2018). Children may experience emotional neglect, not feeling seen or heard by those surrounding them due to the complexity of the situation, or be forced to assume demanding responsibilities during a refugee journey. As stated at the organisation's webpage, the aim of their pedagogical activities is to provide children with an opportunity to better understand their surroundings both within and without their homes. They also intend to provide children with pedagogical tools to reflect on their experiences during migration so they can support, rather than hinder, them as they build their new lives. As a form of additional support, the children's parents or caregivers are also offered a chance to join the course together with their children, albeit in a separate group with different topics and activities designed to assist them in addressing the individual and familial situations that may arise in the new society. The same attention is paid to unaccompanied child migrants, who undergo the asylum procedure alone, both before and after they potentially reunite with their families.

The organisation offers their course twice a year. The participants meet with staff once a week for 12–14 weeks at a location where the intended

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12 This dissertation has been received and approved by the Swedish Regional Ethical Review Board (2019–03501). The Ethics Review Authority (*Etikprövningsmyndigheten*) is a state authority under the Ministry of Education in Sweden which began operations on January 1, 2019. Their mission is to review research applications to ensure the presence and quality of ethical considerations in research involving humans and human biological material.

lectures and workshops are held. Besides the indoor meet ups, the organisation's leading group also plan different outdoor leisure activities for all participating groups. The arranged indoor sessions designed for adults, among others, introduce Swedish society with an intentionally historical overview on the country's development and how different institutions—particularly those relevant to the asylum procedure—operate. They also inform discussions on how the democratic system of government in Sweden operates, and how different institutions, like, for example, healthcare and education are run. Among the often-discussed topics which receive the most attention from both course leaders and participants are the sociocultural norms that are shaped and practiced surrounding the Swedish healthcare system, child-rearing, and family structure. At the time I was conducting my ethnographic fieldwork, Syria and Afghanistan, respectively, made up the largest registered groups of asylum seekers in Sweden (SCB, 2016), which contributed to the choice to focus on asylum-seeking families from these countries in my research.

From the beginning of the fieldwork, I got to attend different activities arranged and run by the organisation's leading staff for groups of both children and adults. I divided my attendance between the lectures that were designed for adult participants while joining in, and at times, assisting in the activities that were planned for the group of children. As I am able to speak Dari, one of the official languages in Afghanistan, I often supported the rest of the volunteers as well as the participants as a language assistant. I will further reflect upon my role and unintended responsibilities in the *Reflexivity* section.

In total, I performed semi-structured interviews, focus group discussions, and observation with 18 children between the ages of 9 and 12, as well as semi-structured interviews and observations with 12 adults—the parents of some of the child participants. The presence of children in interdisciplinary research with focus on migration has increased over the past two decades. This includes studies on children's conditions when left behind in the absence of one or both parents due to migration (Asis, 2006; Graham & Jordan, 2011). They also comprise studies on children who are the ones who leave their family and enter into an asylum journey unaccompanied during and after arrival at their destination (Herz & Lalander, 2017; Lems,

2016; Wernesjö, 2014). During the events of 2015 and 2016, children had a noticeable presence among those who crossed borders toward Europe, and in the case of this dissertation, Sweden. In 2015, 70,384 children applied for asylum in Sweden, of which 35,369 were unaccompanied minors younger than 18 years old (Migrationsverket, 2024). Being a part of such procedures can force children to adopt different roles, while negotiating their social position and transitioning between different stages of a migratory childhood (Mirsalehi, 2021). Being a child can encompass different sets of roles and expectations before and after such migratory moves. Children's active participation in migratory procedures has already been noted. They may take on the role of interpreter for their parents or caregivers after arriving at the destination, as they often learn the spoken language of the new society more quickly than older adults (Al Masri & Abu-Ayyash, 2020; Baghdasaryan et al., 2021). This, in turn, may require children to learn how to distinguish between being a child prior to and *after* migration. Children, like adults, enrol in the resettlement process and use their own strategies to find entryways into the society of which they wish to be a part. The children who joined this study revealed how they strategically use their embodied experiences of health, care, and healing in conversation with me to show their tactics in building a sense of belonging to the new society (Mirsalehi, 2021). Not only they are involved in the transition from childhood to adulthood, but they also negotiate their sociocultural position from non-citizens to citizens, or potential candidates to rightful members of the new society. One way to do so, as the children in this study shared, is through learning the 'dos and don'ts' of health and care in their new society, regardless of whether they practice them. In the following sections, I will reflect on how the empirical material is collected and analysed with reference to the theoretical perspectives used in this study.

## Theory

The theoretical perspectives informing this dissertation approach health as a negotiable concept in relation to the transitional nature of the asylum procedure and the cultural practices that take place within it. While the included three articles and one book chapter each follow a different conceptual and theoretical framework, they all stem from the processual, situational, and constructed meaning of health and the body in an asylum context. Notions of health and unhealth—as partly reflected in Paper 1—are interpreted in relation to socially, culturally, and contextually influenced perceptions of the body. In the context of asylum, the meanings of health are shaped and reshaped in relation to the state of other bodies and in response to the logic of care within society. This can include maintaining the body's immunity against hazards, which in turn, depends on recognising and avoiding risks. Considering risk and immunity as boundary concepts, as referred to in Paper 2, problematises the notions of risk and responsibility and unravels the fluid and negotiable meaning of health and immunity when practiced under liminal, uncertain, and unequal circumstances. The following theoretical perspectives of boundary concepts and liminality intend to unpack the trajectories of health and unhealth within asylum procedure in Sweden. The selected theories consist of concepts that are closely connected and complementary, which allows us to approach the phenomenon in question from different angles.



## Boundary concepts

I relate to 'health' as a cultural concept to explore how it is perceived and practiced as a social and cultural process. My entry point to the cultural conception of health is inspired by ethnological research on socioculturally framed perceptions of the body and its biological processes (Fioretos et al., 2013; Lundin & Åkesson, 1996). The notion of health has evolved and diversified throughout time and within different social, cultural, and theoretical contexts. In ethnology, health is approached through the lens of time, space, and society to provide insight into how the body and bodily responses have been experienced, perceived, and negotiated in different social and cultural contexts (Lundin, 1996). From a cultural analytical perspective, health and illness are states beyond a biological distinction between life and death. Health, from this view, emerges in practices of gaining control over one's body, investigating ideas of steering the body's biological processes, or managing symptoms when illness strikes (Hansson, 2007; Idvall, 2011; Lundin, 2012; Lundin & Åkesson, 1996). This perspective is inspired by research in medical anthropology (Kleinman, 1989; Sachs, 1983; Sachs, 2012) and studies on health and illness as culturally framed and socially constructed concepts. As defined by the constitution of the World Health Organisation in 1948, health is "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity" (WHO, 1995). Medicine, as a discipline, has often recognised health as a lack of disease or the management of clinically diagnosed symptoms. Declaring health or lack of it as such has largely left it up to medical science to determine what is health, who is healthy, and to define the prerequisites of maintaining a healthy body. However, the definitions of health and unhealth are also prone to change, even from a medical perspective. Boundaries between health and unhealth become imprecise when advanced methods of investigation detect signs and symptoms of a disease that was not detectable or diagnosable at first. Thus, the definition of health lies in the experiences of living with a body that may be identifiable as healthy or not in accordance with varied descriptions of health and well-being (Sartorius, 2006).

The immunologist and philosopher of science Ludwik Fleck argued that scientific concepts, such as health, are defined in accordance with socioculturally constructed ideas within different groups of “thought collectives” (Fleck, 1979)<sup>13</sup>. A thought collective, as Fleck elaborated, is a “community of persons mutually exchanging ideas or maintaining intellectual interaction” who not only adopt but also alter their ways of perceiving and practicing different phenomena within their groups (Wojciech, 2021). Fleck (1979) elucidated that the meaning of scientifically influenced ideas within a thought collective derive from an exchange between “a small esoteric circle” or group of “professionals”, and “a larger exoteric circle” or groups of “laymen” (Fleck 1979, p. 105). In other words, the knowledge initiated by a group of the scientific ‘elite’ is interpreted, practiced, and reproduced by a group of laymen, while both are influenced by the characteristics of the *thought style* within that group (Wojciech, 2021). The scientific and scientifically influenced terms that arise within a thought collective are therefore malleable and imprecise. Due to the potential varied meaning of a phenomenon among different thought collectives, a constructed interpretation of an idea may be perceived as ‘wrong’ by others with dissimilar socially and culturally composed thought styles.

Following this argument and implementing it into the discussion of immunology, the historian of biomedical sciences Ilana Löwy (1992) calls scientific terms “boundary concepts”. By referring to immunology as an imprecise and loosely defined notion, Löwy (1992) argues that boundary concepts are negotiable entities that can simultaneously delimit or facilitate the exchange of knowledge between different disciplines. As Löwy further clarifies, immunological terms do not always result in confusion or misperception of scientific concepts, but they can also lead to adaptability in shifting between social and relational environments. Boundary concepts and their meanings are open to interpretation, negotiation, and adaptation. This variability and negotiability of the meaning, as Löwy suggests, is “the

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<sup>13</sup> The book was originally published in German in 1935. The first translated version in English was published in 1979. The theoretical perspectives above are taken from (and refer to) the English version of his work.

strength of loose concepts” (Löwy, 1992, p. 371). Inspired by the theoretical perspectives around the negotiability of scientific terms among different thought collectives, I approach health and unhealth, risk and reward, and immunity and resistance as boundary concepts with situational and fluid meanings, bound to the surrounding conditions (see Mason, 2012). The boundary characteristic of immunity, defence, and management of risk, besides the biological and sociocultural perspectives, also reveal different sociopolitical aspects of these concepts (Ajana, 2021). The COVID-19 pandemic exposed how immunity paradigms not only were interpreted differently, but also acted upon in various ways among different groups. Immunity and assessment of risk during the COVID-19 pandemic, as has been seen in previous pandemics and other times of health crises, became a matter of biological response to the risks imposed by the quickly spreading virus. At the same time, the outbreak reintroduced a division between the self and the others by dividing society into groups of immune and ‘at-risk’ individuals (Petryna, 2004), against groups of non-immune and ‘risky’. As illustrated in this dissertation, those placed in the category of ‘asylum seeker’ were positioned in a liminal stage where, while being considered both vulnerable and at-risk, were also considered as risky *Other* (Lévi-Strauss, 1969) with a presumably deviant approach to the situation. The *correct* response to the COVID-19 pandemic that was introduced by the health authorities of Sweden—like other groups in society—was interpreted, contested, and altered by the families who participated in this study. However, the fluid meaning of immunity, risk, and protection of the body was made in accordance with the ambiguities of their liminal migratory lives.

The negotiability of scientific terms is central to the discussion of health among different groups, and, as is the case in this study, the group of asylum seekers. While an asylum procedure can cause new or exacerbate already-existing health vulnerabilities among asylum seekers, experiences of living an asylum life can also trigger the formation of new or reformation of previously practiced care strategies. An asylum life, in other words, is a continual process of creating new and recreating previous knowledge about one’s body, its abilities, and practices of keeping it operative. The encountered situations within the process, therefore, are assessed and

responded to by asylum seekers and based on the opportunities or limitations within an asylum context. Undergoing an asylum process, from this view, is not a matter of “either suffering or resilience” (van Eggermont Arwidson et al. 2022, p. 12). Instead, it can be viewed as a sociocultural process of maintaining a balance between one’s former health-related knowledge and coping strategies and those of the new society. The communicated result of scientific investigations, such as the science of medicine, has been perceived and practiced by people in accordance with their life conditions, influenced by social structures within different societies. This includes the realisation of healing strategies as a response to socioculturally influenced ideas about the nature of a disease, the meaning of health, and the methods of caring for one’s body. Approaching health and care from this perspective can illuminate the boundariness of these notions by showing the distinction between different health and healing performances among different groups. It can also reveal how these perceptions and practices are made meaning of within varied contexts. The medical anthropologist Anita Hardon’s (2002) research among mothers with young children in an urban settlement around Metro Manila, in the Philippines, is an example of such collective practices of shared thought styles. Based on her study on self-care practices and treatment strategies among the households in the area and by following practices of the thought collective about healing and responsible motherhood, Hardon (2002) discusses how the mothers self-diagnosed their children’s symptoms and provided suitable treatments accordingly. Despite having limited resources to cover the basic needs of living, the mothers ensured they were able to purchase medicines when their children had visible signs of illness. It was, as Hardon (2002) explores, both a practice of care and performative act of good motherhood recognised by the thought collectives.

I have received similar responses from the participants in my research<sup>14</sup>. Like what Hardon terms “fixed treatment strategies” (Hardon, 2002, p. 26), the participants in my study shared some of the health and care techniques that they practiced in their pre-migratory life. They knew what kind of medicine they had to take and in what quantities to reduce or eliminate which symptoms of what illness. The acquired knowledge of the past, as they described, is prone to alteration, following the common *logic of care* (Mol, 2008) which can be seen as requirement for accomplishing the migratory project and obtaining membership in the new society. In her study with focus on patients with diabetes, the anthropologist Annemarie Mol (2008) explores the nature of care practices while attending to the question of what good care means and should entail. Approaching care as a right and responsibility, Mol argues that taking responsibility for one’s health by choosing the right care practices does not oppose the collective effort of care provision. From this perspective, the logic of taking responsibility for one’s health through the choice of care practices should not be a dichotomy between active care ‘practicers’ and passive care receivers. Putting it in the context of asylum, it can be argued that while having the right to care may be conditional and dependent on one’s status, the responsibility of practicing the same logic of care remains. This, in turn, highlights the boundary notions of health, care and responsibility and how their meaning and practice are negotiable with reference to contextual and situational conditions.

In relation to health, immunity is central to cultural analysis, as immunity can relate to more than the body’s biological responses. Put in the context of migration, immunity becomes a biosocial matter, as it involves “ideas about the body and society” (Martin 1994, p. 65). Immunity, as the anthropologist Emily Martin (1990) argues, has been used to convey

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<sup>14</sup> In a conversation with one of the participants, he explained how in the past, he visited physicians to receive a prescription for antibiotics (Penicillin) when he had a particular set of flu-like symptoms. According to his self-diagnosis, some conditions needed to be treated with antibiotics while others were manageable with home remedies. As a casting worker with long work hours and limited financial resources, he needed to be back on his feet quickly to not to lose his job, which was something expected from a responsible father within his community. These excerpts are taken from the fieldnotes (27 April 2021).

“social differences – between men and women, managers and workers, or citizens and foreigners... [when] written metaphorically into the character of various immune system cells” (Martin, 1990, p. 410). From this point of view, while immunity refers to biological properties of immune system, as a cultural construct, it may denote the presence or lack of security. As Martin (1990) argues, immunity, both as a biological term and metaphorically as a sociocultural construct, distinguishes and “discriminates” between the *self* and the *non-self* by not letting outsiders in before their identity is proven and approved (Martin, 1990, p. 414). Considering the receiving societies as nation states, some individuals and groups are considered as cells belonging to the body of the society—those who are morally and economically included and contributing—while others can be seen as intruders of unknown conduction and potential bearers of harmful entities. On the one hand, the meaning of immunity is shaped in accordance with collective interpretations of this scientific concept among different groups, situated in individual embodied experiences. On the other hand, these meanings can be contested when contrasted with counter ideas within different contexts. This is the ‘boundaryness’ of immunity as a concept, which leaves it open to interpretation by both those who *belong* and others who are *citizens* pending.

The participants who joined this study reflect over the concept of immunity through their embodied experiences of health and unhealth, but also their biosocial projects of acquiring membership in the new society through learning its mutual language of immunity and community (Martin, 1990). The matter of biosecurity and the boundary between self and non-self that were exposed during the COVID-19 pandemic also points to the questions of “bio citizenship” (Petryna 2002 & 2004). In her study on the aftermath of the Chernobyl disaster in Ukraine in 1986, the anthropologist Adriana Petryna investigates how new “norms of citizenship” were framed, negotiated, and resisted in response to the circumstances caused by the new definitions of body and biology (Petryna, 2004, p. 250). The response to people’s demand for access to social welfare based on their biological status as sufferers and the degree of their radiation injury, as Petryna shows, is selective and only granted to evaluated, confirmed, real

victims. Biological citizenship in an asylum context, as I argue in this dissertation, can reveal how the emergence of the pandemic as a biological hazard became a case of negotiation of membership by those who are in the asylum, refugee, or migrant categories in relation to the ‘majority’ group. Migrant populations were reported to be among the most at-risk for infection and were among the most affected groups during the COVID-19 pandemic. Although their vulnerability as a result of poor health status, exacerbated by socioeconomic factors and life conditions was recognised, they were expected to follow the health recommendations and take equal amount of responsibility to practice the presented logics of care during the pandemic. This often under unequal circumstances. The boundary notions of health, care, risk, immunity, and responsibility, thus, are open not only to interpretation but also to negotiation and strategic response suitable for their transitional state.

## Liminality

With a focus on health, this dissertation examines people’s experiences, but also how they meet with a new way of thinking about health while going through the transitional process of joining the body of the new society. In the book *Les rites de passage*, the folklorist and anthropologist Arnold van Gennep (1909)<sup>15</sup> explored how the life of individuals in all societies consists of a sequence of transitions between the time of birth to the moment of death. Calling it the “rites of passage”, van Gennep described the transition from one phase to another as the passage from one rite to the next. Any rite, as van Gennep claimed, includes inevitable phases of “separation”, *liminal (or threshold)*, and incorporation into a new *postliminal* period (van Gennep, 2019, p. 21). By enrolling in a transitional process, one departs from what was once known and defined, and enters the process of achieving a new status. Thus, with the previous states being eroded and the future ones not being realised, the transient enters a liminal period of in-

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<sup>15</sup> The book was first published in French in 1909. The first English version of this book was published by the University of Chicago Press in 1960. In the citations, I refer to the date of publication of the edition that is used in this dissertation.

betweenness where the process demands one to conform to new codes of conduct to be qualified for the new status. Following van Gennep's line of thought, the anthropologist Victor Turner (1970) called the rite of passage both a transitional and transformative process (Turner, 1970, p. 94). The transitional characteristic of the process, as Turner clarified, locates the "ritual subject" in an ambiguous position between the *state of being* and "becoming" (1970, p. 95). Once the passage is consummated, Turner elaborated, the transient "has rights and obligations of a clearly defined and 'structural' type and is expected to behave in accordance with certain customary norms and ethical standards" (Turner, 1970, p. 94). As I discuss in Paper 2 and 3, succeeding the asylum process and being granted the title of refugee, and later migrant, requires fulfilling the assumed requirements of membership in Swedish society, including practices of health and care (Mirsalehi, 2021; Mirsalehi, 2023).

Migration, regardless of cause or type, can be considered as a liminal state (Hartonen et al., 2022; O'Reilly, 2018), and different stages of the process are a part of the *ritual of migration* (Khosravi 2010a, p. 62). As a transitional process, migration begins with deciding, imagining, preparing, and stepping on a journey, separating from what is familiar with an ambition to transit to an intended destination and state of being. A migratory passage requires crossing geographical borders as well as social and cultural barriers, becoming actualised when the *transient* arrives and achieves what has been desired. The liminality of forced migration, however, may not lead to the same outcome in a similar manner. Those who enrol in an asylum process from the back doors can end up at the "threshold" of society (Turner, 1977), waiting and wanting to join fully and rightfully (Engblom, 2023; Hall, 2023). Forced migration brings about uncertainty of different sorts and degrees, as the transient enrolls in a fluid locus while complying, contesting, and negotiating the terms of admittance. There is a tendency that the liminality of an asylum process is translated to a lack of agency and choice (Khosravi 2010a, p. 5). Forced migration can put formation of an individual identity on hold while the migrant is placed into the liminal categories of an asylum process. By succeeding in proving legitimacy and "authenticity of their refugeeness", asylum seekers move one step further in the process by being granted the title of a *real* refugee,



## THEORY

to be later upgraded to being a, sometimes, the forever *migrant* (Khosravi, 2010a, p. 72).

The transitional characteristic of a migratory move is not wholly centred around geographical relocation, but it can also involve different processes of cultural pluralism and cultural conversions. The ambiguity of slipping through socioculturally recognised positions in the receiving society can result in the formation of new opportunities (Thomassen, 2009, 2018) where transients, through “practices of improvisation”, create and reframe their coping strategies to face the demands and challenges of the new world (Bigger, 2009; Norström, 2004). The recognition, internalisation, and practice of collective norms of health and care to be practiced by permanent, potential, and conditional members of a society are some examples of such socioculturally constructed expectations. Liminality of the asylum life, as explored in this dissertation, is experienced, contested and responded to by the participants through navigating and negotiating terms of reference within their projects of familiarisation.

## Method and Material

Ethnographically approaching experiences of health, care, and belonging among those who are categorised as asylum seekers requires methodological, analytical, and ethical reflections both during and after completion of the research. Asylum seekers and refugees are mobile communities; not only due to geographical displacement, but also because of internal emplacements after arriving at a destination. Research on sociocultural phenomena with mobile subjects can involve what the anthropologist George Marcus calls “multi-sited ethnography”, where the focus is divided between the events that take place within different contexts rather than in single field sites (Marcus, 1995). Research subjects who are categorised as asylum seekers move between localities within and beyond national borders while navigating through different “states of being” (Turner, 1970). Investigating social phenomena with people who are involved in such compulsory international migration encourages the researcher to apply ethnographic methods due to their flexible, intimate, and descriptive characteristics (Davies, 2008; Falzon, 2020). From the beginning of this study, I was reminded of the complexity of research with mobile subjects and the need to adopt a reflexive approach.

I start this section by elaborating on the field (where things happen), followed by reviewing ethnographic methods of research with subjects who are categorised as unreachable via the utilisation of qualitative and quantitative methods. What follows next is a description of how the collected empirical material used in this dissertation is analysed. I then reflect on research ethics and the different aspects of reflexivity at play in research on health with social groups categorised as asylum seekers.

## The field

Conducting fieldwork among those who undergo an asylum process demands a multidirectional approach, starting with defining the ‘field’ where complex social phenomena occur (Amit, 2004). Debates over practice of fieldwork and where ethnographic research takes place have been a growing and continuous topic. One of the overarching concerns about the ‘field’ stems from its fluid boundaries, given that ‘the field’ is not always an identified location that can be visited but a space with malleable and often undefinable margins (O’Dell & Willim, 2011). Establishing ‘the field’ becomes an even more intricate task in research with displaced groups. In the context of migration, the field is habitually mobile, dispersed, and spread between different points in time and space (Vogt, 2011). As Markus (1995) puts it, the “circulation of cultural meanings, objects, and identities” requires exploring the phenomenon in question within extended localities by shifting the focus from single sites to multiple contexts (Marcus, 1995, p. 96). Researching a phenomenon in various settings, in turn, is an indication of a manifold of realities that are situated within each setting (Mol, 2002). To reach the multiple actualities in ethnographic research with different migrant populations, the field often needs to be reconstructed and co-constructed throughout the research process, together with the research subjects (Huot, 2019).

As mentioned earlier, exploring experiences of life that are shaped in multiple contexts and over time requires the researcher to distinguish where things, naturally, take place (Hout, 2019). Even during the design phase of this study, I was reminded that conducting research among different migrated populations can become a transnational attempt which extends across geographical and cultural borders. This form of cross-border investigation is different from the earlier ethnographic fieldwork in ethnological research which in the past circled around the ethnography’s colonial history (Lamphere, 2018). Before, and even now to some extent, the researcher was required to travel across the globe and stay in another geographical location, somewhere distant, preferably exotic, to study practices of people who appeared different and perhaps communicated in a language unknown to the researcher. The shift in methodologies of

ethnographic research combined with advancement in communication technologies, however, has brought the field where things happen closer to home and—seemingly—more accessible.

This should not be interpreted as an argument against the importance of having a sense of the places from which people's experiences originate. The context of my research is the society of Sweden. Yet, the studied sociocultural perceptions and practices in this dissertation are multi-contextual and extend beyond national frontiers. This multiplicity of factors, in turn, has necessitated methodological considerations. The participants in this study have moved across continents to reside in Sweden. Investigating the research questions, therefore, demanded *being there* (Frykman & Gilje, 2003), which, in the case of this study, began by considering potential participants current localities while being recipient of the stories of their experiences from the past to present. I was well-aware of the multinational nature of my research, and the ambiguity of tracing the participants' health- and care-related experiences on a spectrum between pre- and *post*-migration states. However, the emergence of an unforeseen event influenced the notion of 'the field'. When the COVID-19 pandemic was detected in Sweden in March 2020, approaching the field, and negotiating terms of participation, took on a new turn. Before the pandemic, I conducted my fieldwork at the organisation, as well as in participants' homes or during outdoor activities arranged by the organisations' leadership team. During the pandemic and following the safety recommendations given by public health authorities around the world, including Sweden, face-to-face interactions were transferred to other means of connections. At the first glance, the shift in the ways of pursuing research questions may have seemed like a matter of damage control. Yet, it was not the first time that an ethnographic approach had to include creative strategies. The social situations that emerged after the pandemic required not only change of methodologies to meet the new conditions, but they also demanded a reflexive approach to the field and what that was happening within it during a time of crisis. Before the pandemic, I oscillated between conceptual context of migration, the geographical context of Sweden, and the sociocultural context of health, unhealth, and belonging. After the outbreak, I was faced with yet one more

context to manoeuvre, as I had to consider the dimensions of risk and reward in in the conjunctions of the aforementioned frameworks.

This brings up the question of proximity and distance in ethnographic fieldwork, where the meaning and terms of immediacy are negotiated between the researcher and research participants. Locations that were previously a place of safety and tolerance transformed to the zones of risk and resistance. The town that was once a place I had to navigate and familiarise myself with had to be avoided. From this point of view, the field became, more visibly than before, a space that needed to be contested, co-produced and resumed by me, the researcher, and the research participants (Amit, 2004; Cairns, 2013; Wilk, 2011).

## Method

### Review of ethnographic perspectives

Ethnography, through its qualitative approach, has become increasingly identified as an important methodology in health research (Goodson & Vasser, 2011; Nilsson et al., 2018). This is at least partly due to its provision of thick description of experiences and personal stories (Idvall, 2005). As ethnologists in Sweden have shown, ethnographic research can include a bricolage of methods, including both the already known and the innovative while taking up varied sources and engaging with different materials to make sense of the phenomena in question (Ehn et al., 2016; Ehn & Löfgren, 2002). Ethnology, through its qualitative and cultural analytical approach to social phenomena, unpacks the seemingly mundane and taken-for-granted cultural practices of people's everyday lives in different contexts (Ehn & Löfgren, 2002). This process, however, requires the researcher's reflexive presence to not only document what is said and shown but also reflect on the social and cultural circumstances that influence and are influenced by the situations in question. By reviewing transcriptions and fieldnotes generated while doing ethnographic research, ethnologists oscillate between interpreting the meanings expressed by the participants based on the particularity of the situation, and finding general patterns that the verbalised insights exemplify (Ehn & Löfgren, 1996).

Cultural analysis, from this perspective, is a creation, a processing of practical and moral questions in relation to conditions of everyday life (Ehn & Löfgren, 1982).

Ethnographic studies are distinguished from other means of research often due to the ethnographer's physical presence in the field (Ehn et al., 2016) while allowing for the co-creation of data with the research participants (Ingridsdotter, 2017). Choosing the methods of investigation in a research process, in turn, requires the evaluation of each method's characteristics to define at what stage in the process they are to be applied, and how they can illuminate different aspects of the phenomena in question. My research principally consisted of ethnographic research methods of semi-structured interviews, and participant observations among groups of child and adult participants, as well as with the staff of the organisation both face to face and later, at a distance. Participants in the online survey, however, consisted of adults over the age of 18. The process will be explained further in the following sections. In this section, I will elaborate on these methods and how they contributed to the empirical material that is used in this dissertation.

My fieldwork focused on how the participating families navigated situations of health and unhealth under the conditions of a shifting social and cultural landscape. Approaching the question required a thorough methodological and ethical consideration by reflecting on what questions to ask, and how, when, and where to generate what kinds of knowledge (Gunnarsson Payne & Öhlander, 2022). While there have been ongoing debates over locating the field with migrant subjects and adjusting research methods accordingly, some migration scholars have warned against "methodological nationalism" that stems from nation-state-influenced conceptualisations of migration (Wimmer & Schiller, 2002, p. 302). Methodological nationalism refers to "naturalisation" of the influence that nation-states may have on research methods when the research design takes "national population, economy and policy as their given entity of observation" (Wimmer & Schiller, 2002, p. 578-80). This can either result in approaching the field as a container of data to be harvested and those within it as the studied objects, or, in contrast, seeing it as an opportunity

“to explore how realities are constructed in particular contexts” by the subjects of the study (Cairns, 2013, p. 326).

Despite the potential, practical, and ethical challenges that the performance of ethnographic research in a context of migration may entail, the ambiguity, fluidity, and fragmented character of an ethnographic field site may contribute to not only the (re)formation of innovative research methods, but also to better understanding the social phenomenon in question (Meissner & Hasselberg, 2012). Among others, the role that technological advancement plays in the extension of the field is evident. Shifts in communication technologies have expanded the field beyond geographical locations. Although such innovative means of interaction put a demand on researchers to catch up with the ever-changing forms of interaction that happen between the physical and digital worlds, this hybridity has made it possible to address the issue of inaccessibility when close contact with research participants is either impossible or ill-advised. I experienced this shift during my fieldwork, particularly after the outbreak of the COVID-19 pandemic, as when conducting fieldwork does not necessarily require the researcher’s physical presence in the field. Instead, social phenomena can even be ethnographically investigated from a distance (Ehn et al., 2016).

### Ethnographic approach through a reflexive lens

Using the internet as a source of data is not a new phenomenon in ethnographic research (Hansson, 2023; Nilsson, 2024). The internet can be used as a tool for distributing surveys, spreading the word about a study to attract potential research participants, or doing desk research on the topic before the design and execution of a study (Davies, 2008). Called ‘net ethnography’, ‘netnography’, or ‘digital ethnography’, ethnographers have utilised cyberspace to explore social encounters that may also be approachable from a distance. Ethnologists in Sweden have benefited from this ability by investigating the diverse actions and interactions that take place between people as cultural beings within their computed spheres (Lindgren & Cocq, 2017; Johansson, 2010; Lilliequist, 2020; Willim, 2019). After the outbreak of the COVID-19 pandemic, virtual versions of

ethnography became necessities. My research was certainly no exception. Although I attempted to move my fieldwork online, I do not claim to have employed common methods of netnography throughout my ethnographic approach. Instead, I sought assistance from communication technologies to stay in the emerging field and in contact with those who agreed to join my study. To do so, the in-person interviews and observations were transferred to online meetings and video/audio phone calls. This attempt, however, became a reflexive project which demanded the field be relocated and the fieldwork be replanned, even, to a great extent, drafted anew. This was research that faced a methodological redirection, but also different essential social services. In a study on women shelters during the pandemic, the authors described the staff's attempt to reach out to women and children who lived under threat of domestic violence (Hansson & Petersson, 2021). Being confined to requirements mandating following pandemic-related guidelines, staff faced a dilemma in assessing the risk of proximity over the risk of distance from those in need of safety. Like this study, one of the first challenges that I encountered was including children in the online mode of fieldwork. The issue was not children's lack of interest or skills in managing the required understanding of new technologies. The obstacle was in fact, their lack of freedom to attend the sessions without direct observation by their parents or caregivers and away from the business of home. The children who participated in this research did not own mobile phones. This made our potential phone conversations dependent on the parents, caregivers, or older siblings' devices, in case they owned any, which entailed the challenge of having adult members of the family close at the time of discussions. As the researcher, I was accustomed to visiting families at home for interviews with the children and adult members. After the activities at the venue where the organisation arranged their weekly sessions were cancelled, the children lost an independent space where they could speak with me and other children about their daily lives, experiences of the past, and their knowledge of the research topic.

Moving the fieldwork online proved to be equally challenging when it concerned the adult participants of this study. The majority of the adults who attended this research did not have any computers at home, nor did they have the literacy skills to manage written information, which made it



difficult for them to experiment with the common technological innovations of the time, such as Zoom, Microsoft Teams, and the like. Mobile phones were the only way to reach out to them during the pandemic, however, it also introduced the challenge of including interpreters when needed. During my distanced fieldwork, I was reminded how depending on such technological advancements in research with mobile communities can be either an asset or a hindrance. Asylum seekers move where they are given permission to go, and stay where they are allowed and able to stay, and this cyclic transition which is a part of their daily lives becomes a part of the researcher's reality of the research process. Conducting online fieldwork or utilising different means of communication technologies comes with advantages when proximity or the sensitivity of the topic require a different sense of personal space during the interview (Ehn et al., 2016). The disadvantage of this mode of ethnography, as was made obvious to me during the pandemic, was the even more limited window to the participants' world. By being physically distant from participants, the researcher's access to their surroundings and having a sense of the environment is limited to what is shown over a video conversation or the sounds of the space in audio conversations (Cocq & Liliequist, 2022). At the same time, what is shown on the other side of the screen can reveal part and parcel of the participants' world, be it the way they are dressed, or the surrounding and everything that is present or absent. The possibilities and impossibilities of online research, however, are accepted and adapted in online surveys when the aim of the study is often the quantification of the phenomenon in question.

### Utilisation of different methods

Ethnographic research is commonly known for its qualitative approach. However, it is not uncommon to include quantitative methods of data collection in ethnographic processes (Phillimore et al., 2019). Quantitative methods are often recognised for their numerical attributes. They have existed side by side with qualitative methods in different disciplines; for example, sociology (Hammersley & Atkinson, 2019). Used as a tool for sampling, measuring, spotting patterns, and generalising results of diverse

statistical data, quantitative methods can provide “evidence of the absence or presence of relationships or contrasts” on a large scale (Lemerrier et al., 2019, p. 72). Although the use of statistics in data collection is not common practice in ethnographic research, they are not excluded from fieldwork processes. Ethnologists in Sweden have long been using questionnaires qualitatively by giving the participants space to share their memories, experiences, and values in a written form while responding to a set of defined questions (Hagström & Marander-Eklund, 2009). Although quantitative components may not be considered a conventional method in ethnographic research, this combination is seen as an innovative approach (Braun et al., 2021). Ethnologists in Sweden, for example, have used mixed methods in interdisciplinary research to approach cultural practices of medicine consumption and the relationship between individual agency and negotiation of health knowledge (Liu & Lundin, 2020). The amalgamation of different approaches in data collection is not a new trend in ethnographic studies, as a combination of methods may address potential weaknesses that stem from only relying on one method of data collection (Whitehead & Dahlgren, 2006). While using multiple methods may not necessarily result in a more *truthful* picture of the phenomenon in question, a combination of different methods of knowledge generation can provide more nuances and thereby provide a richer image of the investigated situations (Simonsson et al., 1998). Utilising quantitative methods in ethnographic studies can both expand and limit the extent to which a phenomenon is explored (Nelson & Spencer, 2021). Despite the potential limitations of these methods, including surveys, their usage can illuminate both the presence and absence of sought-after participants and results. Performing quantitative research with different social groups is one of the examples of how quantitative measures can come up short by, as one example, placing some groups into a “statistical limbo” in comparison to the others (Durand, 2016, p. 2). These groups, although often labelled as vulnerable and at-risk, have a more tendency to fall into the categories of unreachable or nonrespondent (Ahlmark et al., 2015; Nielsen et al., 2017). Due to the same reasons, their participation in quantitative research may be limited, and their voices, having not been granted the same platform as others, may go unheard.

The outbreak of the COVID-19 pandemic had effects reaching beyond the circulation of a potentially deadly virus. Most countries in the world experienced situations of pandemic-related ‘increase and decrease’ in different arenas. This included an increase in the online purchase of medicines and other medical products that promised protection and recovery in case of infection, and a decrease in access to some essential, generic medical supplies due to disrupted supply chains (Liu et al., 2021). To explore the online purchase of medicines and medical products for protection against the coronavirus in Sweden, together with some of the researchers from the interdisciplinary research group that I collaborated with throughout my research, we decided to perform a quantitative analysis in the Swedish context. We designed four online surveys and distributed them to the public in Sweden through the Swedish market research institute KANTAR Sifo in four rounds between September 17<sup>th</sup>, 2020, and February 2<sup>nd</sup>, 2022. Persons between 18 and 79 years of age were randomly selected by Kantar Sifo and invited to anonymously respond to the questions posed by our group. All four surveys included identical single and multiple-choice questions about their search, purchase, and experience using products that claimed protection against the coronavirus. The only difference between the surveys was two additional questions added to the fourth survey, about the respondents’ country of birth and whether any of their parents were born in a country other than Sweden. The decision was made to find out how many respondents were from the constructed categories of foreign-born and migrant. The results of the surveys are not used in the analysis of this dissertation. The findings, however, became a point of departure for the book chapter that is included in this study. I will elaborate more on the results in the following sections.

## Material

### Interviews and observations

I performed interviews, focus group discussions, and observation with 18 children between the age of 9 and 12, as well as semi-structured interviews with 12 adults—the parents of some of the child participants. The children who partook in this study were divided into two groups: the ones who

participated in semi-structured interviews, and others who did not join in any interviews due to the limitations caused by the pandemic, but attended the organisation's pre-pandemic activities, where I performed my interviews and participant observations among the children. The observations took place at the centre where the organisation arranged their weekly activities, and at participants' homes. Four of the families who joined the research independent of the organisation invited me to their home to perform the interviews.

The interviews with children took mainly the form of focus group discussions<sup>16</sup>. Most of the time, the interviews were combined with activities where we collaborated and experimented with different co-creative methods, relevant to the research questions. Before each visit, I designed games, topics of discussion, or suggestions for creative writing or storytelling relevant to the interview as well as observation guides to invite the children to share their reflexive thoughts on health- and illness-related topics. Except for two interviews with four of the children, which took place at their homes and in the presence of the children's parents, all interviews were performed at the centre where the organisation arranged their weekly activities. Besides the semi-structured interviews, I also attended different events arranged for the participating children at the organisation's centre to engage in spontaneous dialogue with them and observe the interaction between themselves and the staff of the organisation, including myself.<sup>17</sup> We played indoor football with the staff and children, baked gingerbread, made Christmas decorations, and drew stories with the theme of health and what the children considered necessary to be done if one feels unwell while listening to the playlist that we collaboratively

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<sup>16</sup> I performed some of the interviews as focus group discussions in response to the children's request. Each session took between around 18 to approximately 120 minutes, depending on the children's availability, tolerance, and interest. The interview discussions took place at the venue where the organisation held its weekly lectures and activities for the participants.

<sup>17</sup> Participant observation lasted for over 208 hours between September 2019 and January 2020. Fieldnotes were taken immediately after each observation.

made, to name a few<sup>18</sup>. All interviews, observations, and focus group discussions with the children that took place before the outbreak occurred face-to-face. After the emergence of the pandemic, as mentioned earlier, I realised that having access to children via phone or other digital means of communication could not be a suitable substitution for meeting them in person. Children showed a sense of independence during the in-person individual and group interviews by expressing their opinions freely, something that proved to be a challenge when having one or both parents present in the room during an audio or video conversation. After reviewing the possible options, I decided to direct the focus toward the adult members of the family.

Interviews with the twelve adult participants that took place before the pandemic were performed mainly in their homes. After the outbreak of the pandemic, interviews were conducted only over the phone. In the sessions with families from Syria before the pandemic, an interpreter attended the interviews to assist me with the language barrier. The discussions with adult participants, too, were audio recorded with their permission. In total, I performed 12 interviews with adult participants throughout the course of my fieldwork, of which 4 were conducted after the outbreak of the pandemic over the phone as video and audio calls. The average time that each interview took, both before and after the outbreak of the pandemic, varied between 60 minutes to slightly over 120 minutes, depending on the participant's availability and interest in continuing the discussion. Three of the interviews were follow-up discussions which took between 10 minutes and 120 minutes. Both children and adult groups gave written consent to confirm their awareness of the research aim and their rights throughout and after the process. All participants were pseudonymised and anonymised in the transcriptions to protect their confidentiality.

The observations started early autumn 2019 when I took part in a kick-off meeting with the organisation's leading group and volunteers. During that meeting, they reflected on their experiences of offering the same

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<sup>18</sup> I decided not to save or include any of the material that we created with children for two reasons: first, the material created through these activities was not meant to be used as research findings, but their role was to initiate discussion. Second, the decision was made in response to the ethical considerations that this thesis has followed.

course to former participants, and discussed what needed to be improved and how they would respond to potential upcoming, unexpected situations if they arise. Attending this meeting was a starting point to a nearly two-year on and off-site field work. Shortly after this meeting and during my next visit, I was introduced to the new participating families who showed up for two separate introductory sessions to the course, arranged for both Dari and Arabic speaking groups. I attended this course as a researcher and unexpectedly, a volunteering staff twice a week<sup>19</sup> and participated in the extracurricular activities arranged by the leading group, besides visiting the participating families at their homes<sup>20</sup>.

Although I was approached with curiosity and scepticism at first, the families and I succeeded at building the type of relationship required for an ethnographic fieldwork; a relationship built on what the ethnologist Billy Ehn calls a “sympathetic art which is based on a humanistic and hermeneutic (understanding) perspective”(Ehn & Löfgren, 1996, p. 121). While formation of this connection was initiated by me and as a part of my research, it was mutually shared and nurtured by everyone involved throughout the fieldwork. Despite reminding participants of my role and the aim of the meet-ups, I was warmly welcomed to their homes not only as a researcher, but also as a guest. I was invited to home-baked cake and drinking coffee in their best coffee set that was saved only for guests while being shown the carefully preserved photo of a young child that had passed. This experience, unanticipated as it was, enabled me to see the life that was lived behind experiences of crossing borders and navigating health- and care-related arenas.

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19 The sessions and workshops took two hours; however, I usually arrived at the center between one to two hours earlier and often left the place more than two hours after each session, to both assist the staff who prepared refreshment for the participants before the start of each session, and to observe the process and be involved in the discussions and plans of the day.

20 I visited five families at their homes to conduct semi-structured interviews with the adult participants.

## Survey

From the beginning, I expected the potential absence of some social groups in public-health-related research, including the groups of asylum seekers, due to, among other factors, the studies' recruitment strategies and choice of language. This was despite being aware of the fact that the group of individuals who seek asylum are not homogenous solely due to sharing the same stages of an asylum process and being assigned similar categories in said process. However, it becomes yet more challenging to speculate about the non-participation of those who are placed in the categories of foreign-born and migrants as they refer to a large, heterogenous group of individuals with diverse backgrounds. Thus, I suggested adding additional inquiries about the respondents' background to the fourth and final survey to know how many respondents may have an international background and are generalised as someone belonging to the aforementioned categories. The fourth survey, as mentioned earlier, included two further single-choice questions about respondents' place of birth and whether any of their parents had a country of birth other than Sweden. The ambition of these questions was to assess if respondents could be considered representative of different groups in society. The anonymous responses were analysed using descriptive statistics. The quantitative data used in the book chapter that is included in this dissertation focuses solely on the responses to these two questions. The result of this quantitative research shows that of the 1041 collected anonymous responses to the fourth survey, 4% of individuals disclosed being born in a European country other than Sweden and 2% in another country outside Europe. Of the total number of participants, 8% reported that one of their parents had been born in a country other than Sweden, while 7% disclosed that both of their parents were born in a country other than Sweden.

The group of *foreign-born* individuals constitutes 20% of the population in Sweden (SCB, 2024b). The small percentage of respondents who reported their international ethnic background in the survey showed that they could not be representatives of the group of migrant and foreign-born individuals in the study. Although the findings could be interpreted as a methodological failure, they can confirm that including these groups in public health

research requires different methods, including ethnography, to bridge the limitations of quantitative studies (Mirsalehi & Hansson, 2023).

### Analytical considerations

Common qualitative and quantitative methods follow different procedures. Nevertheless, the material generated through each practice can be complementary; different datasets used to explore the same question from different angles. While qualitative ethnographic research methods leave room for flexibility and adjustability depending on the field, quantitative methods follow a steadier line from the beginning to the end.

My research is primarily built on qualitative ethnographic research, although it also refers to material generated through quantitative methods. The qualitative data was divided into two parts: the data that were collected before the outbreak of the COVID-19 pandemic in early 2020, and the ones that were generated after the outbreak. The transcriptions were read and re-read throughout the research process and the fieldnotes were checked to contextualise the interviews. I started by documenting the initial ideas, inspired by the relevant original quotations that I extracted from the interview transcripts. The same process was followed when it comes to reviewing the fieldnotes. The primary ideas were later sorted into themes by color-coding the quotations, to show the occurring patterns that appeared in the collected material. The themes that I detected in the material did not change throughout the research process, but data analysis was refined over time. This mainly occurred by revisiting the material through lenses of the theoretical perspectives that were in alignment with the themes and were later used in the analysis. It was also due to circumstances caused by the pandemic where the thematic analysis, although remained unchanged, included new conditions that appeared during the outbreak. As mentioned earlier, the COVID-19 pandemic is an empirical case and not the focus of the study.

In the quantitative study, the main focus of the analysis was laid not only on the response to the questions, but also on the number of participants who identified themselves as having an international background. The aim was to investigate whether the groups categorised as foreign born and



migrant are present as such in similar public, national health research. Thus, although the respondents' replies to the questions and their open-ended clarifying texts were given thorough attention, the numerical data generated about the participants' cultural identities, including their specifications of ethnicity and place of birth, were the focal point of the analysis. The choice was made to solely have an understanding about participation (or not) of different social groups in public, quantitative health research, and not to compare responses based on respondents' a priori categorisations.

I used both qualitative methods and results of a quantitative study in this research, but I do not consider my approach to be an application of mixed methods in data collection. As a research design, mixed methods are increasingly used in research within variety of fields, not least in health-related studies (Doyle et al., 2009). One of the reasons behind this growing interest is the complementary nature of this means of data collection, whereby a combination of the qualitative and quantitative methods shape a third method with a multilevel approach (Curry et al., 2013). The landscape of mixed methods as a research methodology has advanced in popularity over the last few decades, even though this is not the first time that combining different research procedures has taken place in a research process. Although, for ethnologists, the first and most common choice of methods, habitually, would be ethnographic systems of exploring the field, evaluating a chosen method not based on "what that method *is* but what it can *do*" remains an important inquiry to consider (Fox & Alldred, 2018, p. 191). This is the approach that I have taken throughout my ethnological research, to benefit from the diversity of empirical research methods and analytical tools.

## Reflexivity

As researchers, we are involved in our research in different forms and degrees. As the social anthropologist Charlotte Aull Davies (2003) says “we cannot research something with which we have no contact, from which we are completely isolated” (Davies, 2008, p. 3). Reflexivity in research is a quest to evaluate how the results of the study are “artefacts of researcher’s presence and inevitable influence on the research process” (Davies, 2008, p. 3). I perceive reflexivity to be an integral part of my ethnographic approach. This is due to the multilayered nature of migration and health studies, where, in this case, fluid, situational, and boundary concepts of health and care are analysed in liminal spaces lived by mobile subjects. Throughout my research, reflexivity has been a primary focus and concern, not only because of my familiarity with one of the most spoken languages of the field, but also because of the assumed knowledge and understanding of the multiple sites and topics in question. Reflexivity can refer to looking back on what methodologies are used in the research process and whether they are utilised in a way that has impacted the process and the initiated results (Mannay & Morgan, 2015). In the following, I explore my ethnographic fieldwork reflexively, where I oscillated between positions, negotiated my identity, and challenged the assumed language while stepping forward in the field.

## Positionality

In ethnographic studies, the positionality of the researcher, research participants, and others is a recurring topic (Ehn & Klein, 1994). From the “insider/outsider” status of a researcher (Zhao, 2017) to the researcher’s attitude toward the topic in question and those included in the field

(Chacko, 2004), the researchers' presence often involves critical reflexivity. Self-reflection during a research process may arise at any stage. We as researchers may assume that we step into the field prepared to face most methodological and ethical dilemmas. However, dealing with "datafication" in everyday life can bring about challenges falling outside the researcher's anticipation (Pink & Lanzeni, 2018). Thus, it is crucial to be mindful of the position of those involved in a project, and the ways it could influence both research participants and the process of such studies (Lu & Hodge, 2019; Lundström, 2010).

In research on migration-related phenomena, the focus is largely placed on the ethics of doing no physical, emotional, psychological, and social harm to the research participants (Jacobsen & Landau, 2003; Montero-Sieburth, 2020). Despite the precautions applied before, during, and after research, there will always be room for reframing strategies of how to stay within ethical frameworks, including the position that researcher and participants occupy. To approach participants, researchers position themselves within the process with regard to what Montero-Sieburth (2020) terms the 'etic' (outsider's viewpoint) and 'emic' (insider's interpretation). This was the case in my research with families who were in different stages of their asylum processes while dealing with the COVID-19 pandemic. I was aware of the different challenges that could potentially arise throughout the fieldwork, considering the unpredictability of the situations caused by not only the pandemic, but also by participants' migratory lives. I found myself in a position to not only consider the ethical dimensions of my research, but also to reflect on the etic definitions of protection, the pursuit of knowledge, and on vulnerability.

It is of vital importance to develop and hold on to "accountable positioning" (Haraway, 1988), where the researchers embody their power and shortcomings. Research involves subjectivities of those engaged in the process and unforeseen responses exchanged between them (Cunliffe, 2003). I expected such responses from collaborators and participants, which also revealed unanticipated, situational circumstances that required my reflection on how to explore the field; in other words, how I was positioned within my research. Reaching out and attracting potential participants and conducting the study in an ethical manner among those who have sought

asylum is a multifaceted task. The intersecting nature of the challenges that both researchers and participants may face place both sides in a vulnerable position (Montero-Sieburth, 2020; Zapata-Barrero & Yalaz, 2020). To tackle the uncertainties during research characterised by its *sensitive* nature, the design needs to be flexible and responsive (Davies, 2008).

The first time I met the families who joined my study was on the introductory day at the organisation's venue. It was a September day in 2019 and neither the families nor I were familiar with the order of the day and the course offered by the organisation. Observing their body language, the information that I provided about my research was first perceived as *risky* by both groups of families from Afghanistan and Syria. Their responses, although similar in characteristics, stemmed from different socioculturally, and at least in part, politically infused past experiences. Coming from Iran, I was aware of the life situation of the Afghan diaspora community who have taken refuge in the country from the ongoing violent civil war and instability in Afghanistan. Afghan undocumented migrants or refugees move to Iran either to resettle or to move to other destinations (Khosravi, 2010a). Despite sharing a cultural and historical background with Iran, the Afghan population have been affected by the migratory system over the course of many years. From the perils of taking irregular routes and crossing dangerous borders to obstacles in the way of acquiring residence permits, most of the Afghan community in Iran and those dependent on them back in Afghanistan have dealt with discrimination and various social and economic disparities. Keeping this in mind as an ethnic member of the country while approaching the families from Afghanistan, I was not certain whether the response I would have received was influenced by their experiences of the past or the familiarity of the present. In Sweden, we were all put under the umbrella of the 'migrant' population. What divided us was our social conditions and migratory status in the new society. The sense of suspicion that I sensed among mainly adult members of the families from Syria during the first meetings at the organisation, although was partly influenced by the geopolitical situation in the region, it was mainly due to uncertainties of the asylum experience.

Rodriguez and Ridgway (2023) emphasise that research is fluid and built on the intersecting social identities posed by the scientists. I experienced this claim in practice when entering the field as a young female researcher from the Middle East, who speaks most of the languages of the field (Swedish, Dari<sup>21</sup>, English) and is related to the university, which in Sweden, is a governmental institution. The fieldwork took place in one of the southern towns in Sweden, yet I was confronted with commonalities between myself as the researcher, and the research participants of different groups from different geographical locations. On the one hand, for the asylum-seeking families, I was positioned as a representative of Swedish society and an outsider. On the other hand, I was seen as an insider as I shared the language and a similar, yet different cultural background. This situation required special attention to fieldwork realities from both an etic and emic perspective, where closeness to the research participants and using my familiarity with their cultural experiences and circumstances could result in either better understanding of the phenomena in question interfere with my previously shaped perceptions during the process of knowledge acquisition. Keeping a balance between being related yet distant from the research was necessary. Although familiarity could help me view and understand the events from a place of partial-insiderness, it could also be a distraction from noticing behavioural and decisional patterns influenced by the asylum-lived experiences. From this point of view, researcher can be positioned in “spaces of betweenness” (Katz, 1994), where the line between being an observer and observed can get blurry. While I observed the participants’ actions and reactions in response to different situations, I was as much observed and analysed by them throughout the process. Being in the position of an insider, in my case, became a point of reflection as I wondered whether I could ever relate to the participants’ lived experiences when all I could do was speak the language of those emigrating from Afghanistan. At the same time, I questioned my outsider position in this situation and how I could completely consider myself to be detached from social and cultural

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21 Dari is one of the two official languages spoken in Afghanistan.

fluencies while I grew up with people of Afghanistan and Syria in the same city or region.

Besides the relationships of power between researcher and participants, issues of language and interpretation, expectations from the process, trust, ownership of findings, and consequences of participation (Hugman et al., 2011; Mahalingam & Rabelo, 2013; Pittaway et al., 2010) are some of the questions that I was required to reflect on during my research.

## Rethinking language

Beginning fieldwork, for a researcher, can be compared to stepping into a new world with a road map and some tools to navigate the way. Engaging in fieldwork, besides discovery, also demands consideration of how the research process before, during, and after its completion is negotiated and communicated. In other words, how knowledge is going to be acquired and transferred. One of the important steps is defining the research language. The language of the field goes beyond the rhetorical concerns, as it also contains socioculturally constructed codes of communication. I experienced different, partly unexpected situations before and throughout my fieldwork where I was required to reassess and rethink the perception and performance of language. When doing ethnographic research in a multicultural context, the researcher is often expected to consider the language of communication before entering the field. My research was no exemption. I, as a non-native yet fluent speaker of Swedish and English, which I presumed to be the languages of my fieldwork, stepped into a process where the majority of those who joined my study could not communicate in either of these languages. Due to my familiarity with Dari, and due to the accessibility of interpreters for participants who had Arabic as their first language, I was not (at first) concerned about any potential miscommunication barriers that could occur. However, I was soon reminded of the multidimensional nature of language and literacy in ethnographic research.

The role of language becomes repeatedly highlighted throughout ethnographic research. From defining the literal language of communication with the target group, to ways of negotiating the terms of participants and

explaining the research aim and questions, language has an immediate impact on the way an ethnographic procedure is carried out (Crang & Cook, 2007). Like other ethical aspects of ethnographic migration research, I assumed I was prepared to face both expected and unexpected situations in this regard. However, I was repeatedly reminded that there are other, sometimes unforeseen, contributing factors in research that can influence the process and outcomes beyond language complexities in a multicultural context.

At the beginning of the fieldwork, it came to my attention how my knowledge of Dari was going to be both an advantage and disadvantage for my research process. My research focus was primarily on children's knowledge and experiences of health and care, including their perception of medicines and medication. My focus, as discussed in the method section, was shifted due to the pandemic, and was more heavily focused on adults. Being able to speak Dari made my fieldwork with the group of participants from Afghanistan multifunctional, involving different—and sometimes contradictory—roles. Among the Dari speaking families, I was a researcher who happened to know their language, was familiar with the countries where some of them began their migratory journeys from and could relate to some shared collective memories. In those instances, I was, almost, *one of them*, and could be let in. While some of them called the cities in Iran where they were born, resettled in and still connected to because of families, relatives, and friends as home, sharing their experiences of health and unhealth reminded them of the discrimination and social injustice that they were exposed to in the past. My familiarity with the language in those moments resulted in a combination of trust and mistrust. Nonetheless, I was seen as connected to the staff at the organisation and the Swedish authorities due to my position at the university by both groups of Dari- and Arabic-speaking families. Being reminded of my role as a researcher, however, made me yet another form Otherness (Lévi-Strauss, 1969). While I was approached as an image of post-migration era, the result of an accomplished migratory project or as, an encouragement for fighting for a better future, I was also a reminder of the hardships of the process and the long journey that awaited. They, in other words, viewed the possibilities and precariousness of their migratory journeys and outcome of their experiences

against mine—*the other*—who, they assumed, had shared some, if not all, their experiences of migration.

Ethnographic research can require the researcher to learn new languages; not only to communicate the research with the participants, but also to analytically review and understand the collected material afterward (Gibb & Danero Iglesias, 2017; Tremlett, 2009). In my research, I received assistance from interpreters when communicating with Arabic-speaking participants. But I also received help from the staff at the organisation who spoke the language—not as language interpreters, but as translators of the cultural codes that I would have otherwise missed. A lack of knowledge in both literal and metaphorical language of the field can put the researcher in a vulnerable position, dependent on the version of the stories narrated by the participants and described by interpreters. In the literature, the role of interpreters in ethnographic research and their influence on the empirical material has been explored in great depth. The role of an interpreter in a research process can expose both researchers' and participants' limitations (Engblom, 2023; Keselman et al., 2010; Määttä et al., 2021, p.63; Norström et al., 2011). Other studies, on the other hand, refer to the challenges that are faced by interpreters and how the systematic confusion of migration processes can impact the different parties involved (Nikolaidou et al., 2019; Wadensjö et al., 2021). The situations that emerged during the course of this research reminded me of some of these already explored encounters. I experienced moments of outsidership when I was given only a brief interpretation from a few-minute long conversation between the interpreter and the participants, or when I had to distinguish between the interpreter's personal opinion and the interpreted material. These situations reminded me of unpredictability of ethnographic fieldwork “dimensions of researcher vulnerability in qualitative research” (Sterie et al, 2023) with focus on strategies to address “the power and role asymmetries between researchers and participants” (Woodby et al., 2011).

## Research ethics

The core ethical principles of conducting research with human beings centres around reducing the risk of any potential harm to those involved



and prioritising individuals' well-being over the needs of society and science (The Swedish Ethical Review Authority, n.d.). Ethnological studies are subjected to ethical review. Ethnographic research methods bring about rich and comprehensive account of a social phenomenon. However, there is an ongoing discussion about how ethnographic approaches may present complex methodological and ethical dilemmas to researchers and research participants, both during and after the end of a research project (Imray Papineau, 2023; Ryder, 2021). To avoid any potential complications, university-based researchers are expected to obtain ethics review approval, as a proof that they have ensured the research process is designed, conducted, and communicated in a way that does not pose any harm to research subjects or other involved parties. Despite the implementation of such safety measures, ethical dilemmas are a persistent challenge. Ethical principles aim to ensure that the benefit of research is weighed against the potential consequences that the study may impose (The Swedish Ethical Review Authority, n.d.). Nonetheless, the concept of harm and adequacy of the often-abstract ethical codes are repeatedly contested (Düvellı et al., 2010), by highlighting how such formalised and pre-defined ethical guidelines and promises may clash with complex and unforeseen encounters throughout the course of research (Ansell et al., 2023; Miller et al., 2012; Pink, 2022; Redwood & Todres, 2006).

Ethnographic methods are known to be the leading means of data collection in ethnological research (Ehn et al., 2016). From its design phase to performance of the field work and presentation of the results, conducting ethnographic research requires the researcher to continuously reflect on both the *research ethics* and the *researcher's ethics*; particularly when either the topic or the participants' position (or both) is considered to be "sensitive" (Wallner, 2022, p. 2). Research with those who are deemed vulnerable, marginalised, and underrepresented, such as people who are undergoing an asylum process, is known to be an intricate task. Alongside the growth of displaced communities caused by instability, violence, and war, the amount of research with and about those who are affected by such involuntary mobilities has increased. At the same time, a call for rethinking research topics and methods to safeguard the privacy, integrity, and well-being of the research subjects has been a re-emerging topic (Manderson &

Allotey, 2003; Ellis et al., 2007; Hugman et al., 2011; Leaning, 2001). While protecting the research participants' security and confidentiality during the process is of vital importance, preserving the *truthfulness* of each study's results is the researcher's scientific and moral responsibility (Kaiser, 2009). In other words, it is the researcher's responsibility to ethically interpret and transform the collected material from words to communicable knowledge. Nevertheless, receiving and assessing intimate information shared by participants demands an ethical yet compassionate response (Wallner, 2022). Resolving these challenges calls for a reflexive standpoint throughout the process (Roth & von Unger, 2018), by asking what the goal of the study is and to what the acquired and communicated knowledge is expected to contribute.

Having these considerations in mind, I started the process by obtaining approval from the Swedish Ethical Review Authority<sup>22</sup>. My fieldwork became the point of awakening to different unanticipated aspects of a reflexive approach. I enhanced awareness of how qualitative migration research—particularly with people who enrol in an asylum process—may demonstrate challenges that, while seemingly recognised and recurrent in the literature, each include unique characteristics.

One of the crucial moments in ethnographic research, from my experience, is the presentation of the research and the research methods to the potential participants. Introducing my study to both to the staff at the non-governmental organisation where I conducted my fieldwork and the families who attended their activities became an ethical exploration of knowledge exchange between different groups involved in a research process. I was aware of the significance of “comprehensibility” when communicating my research to others (Davies, 2008, p. 55). I intended to be clear, comprehensible, and yet *convincing* of the importance of attending to the conditions that concern asylum seekers' health and well-being in the new society. Also, through verbal and written forms of clarification, I emphasised the voluntary and anonymous nature of participation. To give the process the required ethical verification, I received the participants'

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<sup>22</sup> As mentioned earlier in the text, the current study is approved by the Swedish Regional Ethical Review Board (2019-03501).

written consent to include them in the study while I guaranteed that I would safeguard their personal information.

This phase can be perceived as the beginning of the ethical journey of research. Soon after enrolling the research process, I realised that my ethical approach had already started when I proposed my PhD project and selected my research questions. An ethical exploration begins by the researcher reflecting on their choice of topic, how it is going to be examined, and where the results are going to be presented and potentially used (Davies, 2008).

It was my ambition to explore asylum seekers' embodied experiences of health and care during a migratory process. The context is Sweden, yet the investigation of care practices among a group of asylum seekers is not limited to the new location and their experiences after their arrival. Among the staff at the organisation, I emphasised the weight of attending to health-related challenges that people may experience during an asylum process. When it comes to participating families, depending on who was present in the room, I rephrased the research aim and methods to be appropriate for all family members while putting an emphasis on the mutual support that we could give one another. In other words, besides explaining the aim and the voluntary nature of their participation, I clarified the importance of their voice. Despite the attempt, there will always be room for reflection and improvement when it comes to safeguarding participants' rights.

## Previous Research

This section discusses some of the existing research output that has provided an outline for this dissertation. There has been extensive research on the correlating factors between displacement and health, as well as the challenges of accessibility in public health research within different disciplines. The ambition of this dissertation is to add a new nuance to the existing literature through an ethnographic approach to how people in an asylum process relate to and negotiate health. I begin the previous research with a focus on ethnological studies involving migration, body, health, care, and phenomenon of belonging. Next, I address earlier discussions on the methodologies of health research among people who are categorised as 'hard to reach'.

### Ethnological approach to migration and health

Migration has had a prominent presence in ethnological research for decades, not least in Swedish ethnology. These studies look into cultural meeting and confrontations between groups of migrant and Swedish society (Alsmark, 1997, 2007; Ehn, 1975, 1986, 2000) as oppose to 'typical' Swedish norms, routines and habits and the sociocultural structures behind them (Daun, 1998; Ehn et al., 1995). Earlier ethnological dissertations have explored different aspect of everyday life among individuals and groups of people who migrated from Chile and former Yugoslavia and resettled in Sweden (Lindqvist, 1991; Ronström, 1992). Migration has been approached through questions of diaspora communities and transnationality (Lindqvist, 1991; Povrzanović Frykman, 2001, 2004; Olsson, 2007) or how everyday life in dispersion have been experienced

with respect to diasporic narratives of body and sexuality (Farahani 2006, 2010, 2012) and sociocultural repositioning of the self (Ingridsdotter, 2016, 2017). In the literature among different disciplines, migration as an act of human mobility is often divided into two categories at each end of the migration spectrum—one being the voluntary move made out of free choice, and the other being a forced, non-voluntary option. While the first category indicates an agentic life choice, the second category represents an obligatory move because of unjust social structures. This view of mobility, however, is a simplified take on this complex social phenomenon. Those who are forcibly displaced through irregular passages, from this perspective, are victims of unfair social structures which are enforced on them; thus, they can be seen as lacking a sense of agency (Khosravi, 2010a); while others, the free movers, are exempted from structural circumstances involved in life decisions and migratory processes (Öhlander et al., 2016). Against the prevalent categorisation of the people on the move as passive victims, the social anthropologist David Turton (2003) argues that even in the most imposed types of migration, there are still elements of choice that are made throughout different migratory processes (Turton, 2003). This choice, however, is often influenced by factors of age, gender, and class (Khosravi, 2010b).

Migration from diverse countries to Sweden over the past few decades has resulted in the significant growth of diaspora communities in Sweden. An increase in migration has led researchers from different fields, including ethnologists, to follow this increase by posing questions about the influence that displacement and different aspects of displacement have on different migrant populations' health and well-being (Fioretos, 2009; Fioretos et al., 2013; Warsame Halane, 2005). How cross-cultural meetings between patients and medical staff are influenced by interpretations of the concept of culture, and in what way the *uncommon* health behaviours that are practiced by patients are perceived by and responded to by healthcare systems have also been investigated (Hörnfeldt, 2005; Karlsson, 2005; Nilsson, 2015). In other words, we are speaking of the objectification of 'culture' as an entity (Öhlander, 2005). Matters of conception of health and practice of care have also been reviewed in the light of Sweden's history of welfare and how the shift in welfare models has influenced ideas around

health, body, and citizenship. One of the examples is adapting to various expectations of health behaviours and conforming to the *rules* of care-seeking and medication in the new society, including care for one's body. Self-care, as a central paradigm in contemporary Western society, places major responsibility on individuals for obtaining and preserving their own health. This is done by encouraging them to, among others, adopt a healthy lifestyle by having a nutritious diet, being physically active, and continuously managing the stressors of daily life (Alftberg & Hansson, 2012), and, not least, by co-opting the common approach to medicines and medication. Care for the self is not only expected from society as an individual and social responsibility, it also functions as a distinction between *responsible* citizens and those who are not granted this status (Frykman, 1992). Self-care can be seen as one of the prerequisites of stepping forward in migration's liminal process, acquiring *real* membership and creating a sense of belonging. Familiarisation with the 'dos and don'ts' of health and care in a new society in accordance with individuals' different embodied experiences of healthcare, however, can highlight and challenge culturally constructed and socially practiced notions of health and illness, clean and dirty, safe and risky, and familiar and unfamiliar. This "culture of disbelief" around migration and the legitimacy of migrants is seen in cross-cultural meetings between doctors and patients from different international backgrounds. At the same time, in fear of rejection and deportation, as Khosravi details, the body and bodily symptoms are used as a tool to negotiate "deservingness" in being granted a stay (Khosravi, 2010a, p. 114).

Matters related to health, healing, and the body have long been investigated by ethnologists in Sweden. These studies focus, among others, on cultural performances around health and illness (e.g., Åkesson, 1997; Alver, 1980; Tillhagen, 1958) and how the body and the biological response to illness are interpreted through understanding their social and cultural influences (Alver, 1995; Drakos, 1997; Frykman, 1994, 1998; Idvall, 2007; Ljung, 2001; Lundin, 1997; Selberg, 1990). The studies have also reviewed the cultural notions of norms and normality as opposed to abnormal and deviant behaviours (Drakos, 1997; Jönsson, 1998) and how such classifications are resisted and enacted (Åkesson, 1991; Hansson, 2006; Salomonsson, 1996). The current study has also been inspired by cultural

perspectives within the expanding field of medical humanities, where narratives and the meaning of illness and care (Kleinman, 1989; Kleinman & Kleinman, 1991) and the cultural analysis of vaccination (Hammarlin et al., 2023), or the position of individuals in medicine as subjects (Cole et al., 2015) are in focus. The body has been placed in the centre of these studies to explore, as ethnologists Susanne Lundin and Lynn Åkesson explain, “why and how biological processes, desire, and not least the passion for physical exposure occupy such a large place in people’s lives... [and] what kind of ideas impel us during different historical eras and different phases of life” (Lundin & Åkesson, 1996, p. 6). The body, from a social and cultural perspective, is the holder of one’s embodied experiences, while it represents the beholder’s identity and position in sociocultural contexts (see e.g., Merleau-Ponty, 1962; Frykman, 1992). In other words, the focus of many ethnological studies has been put on the “interplay between social structure, identity, and body” to understand the socioculturally constructed meaning of health and practices of healing throughout time and space (Lundin & Åkesson, 1996, p. 7). Ethnologists in Sweden have explored the bodies’ biological time and ideas of parenthood and personhood (Lundin, 1997, 2012), how illnesses influence and are influenced by everyday life choices (Hansson, 2007; Idvall, 2020), how aging and (dis)abilities are to be managed (Alftberg, 2016; Eksam & Nilsson, 2021; Hansson, 2019; Jeppsson Grassman et al., 2012), how medicines and other substances are placed used, and misused in people’s everyday life with regards to age, gender, and class (Eleonorasdotter, 2021), or how biomedical research is extended out of laboratories to become a tool for generating hope (Hansson & Idvall, 2017; Ideland, 2002; Lundin, 1999; Wiszmeg, 2019). Ethnology takes the pulse of society to follow the change in social patterns and how they result in the formation or reformation of old and new sociocultural norms.

The correlation between health and migration is a well-investigated topic. The focus of many of these studies is on the *migrant’s* health after the migratory move (Jayaweera & Quigley, 2010). Ethnology has also attended to the interplay between different modes of migration and health-related conditions that may arise. Studies in Sweden have explored how securing health and the management of illness are intertwined with questions of

ethnicity, class, culture and social positions in a multicultural society (Öhlander, 2005; Nilsson, 2011; Nilsson, 2015). My research is built on these and other studies that have attended to the concepts of health and care in a migratory context. By the outbreak of the COVID-19 pandemic, however, my research gravitated more toward inequalities in health and how the liminality of a migratory process—in this case in an asylum context—can influence perceptions of health and unhealth among those who are categorised as asylum seekers and refugees. Approaching migration trajectories and experiences of health inequalities from a cultural analytical perspective led me to an interdisciplinary investigation into this matter to have a better understanding about the issues at hand.

According to the public health reports, although the overall quality of health among the general population in Sweden has improved over the years, there is a noticeable difference between health status of those categorised as vulnerable, including migrant populations, and the rest of the society (Folkhälsomyndigheten, 2023). Although socioeconomic factors and trauma from before, during, and after migration are introduced as contributing factors to poorer health conditions among some members of migrant populations (Fioretos, 2009; Rostila, 2021), the question of how to measure and address such disparities remains unanswered (Eyal et al. 2013). There has been a continuous attempt by researchers, health practitioners, and policymakers to address health inequalities by reducing and preventing differences in health quality among different groups (Arcaya et al. 2015). Whitehead (1992) terms these differences “health inequities” by referring to the ethical principles of health as human rights, calling systematic health differences unjust, unnecessary, and avoidable. In a not new—but growing—field, ethnologists have approached the question by examining risk and immunity across social and cultural borders (Geschwind et al., 2023; Hansson & Irwin, 2020). On the one hand, vulnerabilities, and inequalities in health among those who navigate transitional stages of their enforced migratory life require a theoretical gaze at the socioculturally constructed “immunitary logics” (Brown, 2019) and how preserving health, practicing care, managing risks, and membership are expected to be performed. On the other hand, the role of socioeconomic inequalities in health disparities need to be recognised as an influencing



factor and analysed as a result of structural injustice (Mackenbach, 2019). Measuring and addressing health disparities, as argued, depends on the elimination of systematic differences in the distribution of health (Braveman & Gruskin, 2003). Yet, addressing imbalance in health among different groups requires continual examination of the source of said discrepancies and how their unfairness is experienced among different affected groups (Eyal et al, 2013).

Addressing inequalities in health demands consideration of how asylum seekers and refugees have been viewed by the receiving society. Khosravi argues that migrants and their migratory bodies go through formation and reformation before and during a migratory journey (Khosravi 2010a, p. 1). Displaced bodies, from the point of view of nation-state systems, are border transgressors who break the *natural* mode of being as they defy the constructed relation “between ‘nativity’ and nationality” (Khosravi 2010a, p. 2). The assumed anomaly of migratory bodies, as Khosravi explains, is partly due to their irregular mode of migration in opposition to regularities of border regimes, partly because of their “violation of ethical and aesthetic norms” of a migratory process (Khosravi 2010a, p 2). The bodies of asylum seekers are in constant formation and reformation, partly during their performative acts to prove their eligibility for seeking asylum and being given the official status of a refugee, which requires one to “translate one’s life story into Eurocentric juridical language and to perform the role expected of a refugee.” (Khosravi 2010a, p. 33). This form of adaptation, in turn, demands hiding any form of agency as displaying a sense of choice may “cast the authenticity of their refugeeness into doubt” (Khosravi, 2010a, p. 72). At the same time, as those who joined this research revealed, negotiating their strength as a potential member of the new society appears to be a requirement.

## Inaccessibility in research

Previous studies from Sweden have shown that the groups who live in a post-migration state are more at-risk when it comes to exposure to infection and death caused by the pandemic (Thapart-Björkert & Villacura, 2020). One of the pre-conditions for addressing barriers to good health and

providing suitable healthcare services to the category of at-risk populations, in this case migrants, is through having knowledge about health status, determinants of health and unhealth, and use of health services among individuals placed in this category (Rechel et al., 2012). The need for more in-depth studies on disparities in health and differences in mortality and morbidity among different migrant groups has been recognised (WHO, 2010). However, current data collection systems used in most EU member states do not provide accurate information about the health experiences and needs of asylum seekers and refugees (Rechel, 2011; Bradby et al., 2015).

Put in an asylum context, accessibility becomes a multidimensional phenomenon. On the one hand, it refers to the policy of reaching out and providing health screening to the newly arrived asylum seekers and refugees (Norredam et al., 2006), and the criticism directed at the approach and results of such attempts (Nkulu Kalengayi et al., 2015). On the other hand, health screenings have been called ineffective or inefficient in accurately addressing health needs among newly arrived groups by often focusing more on infectious diseases (Norredam et al., 2006; Shedrawy et al., 2018). Although health screening in Sweden, like most other countries within EU, is voluntary and offered free of charge, asylum seekers and refugees' participation remains low. A range of factors behind the non-participation of these groups in health examinations in Sweden are listed by previous research on the question. This includes lack of access to communicated information and unmatched expectations of health examinations among the asylum seeker and refugee population (Jonzon et al., 2015; Lobo Pacheco et al., 2016; Wångdahl et al., 2018) as well as fear of the consequences of attendance (Delilovic et al., 2018).

This, in turn, brings up the question of accessibility to health care information and services among these groups. Although Sweden provides asylum seekers with emergency medical care and equal care services for children the same as the ones provided to citizens, the conflicting healthcare policies, and inconsistent information and guidelines can make examination and provision of health offered to these groups restrictive and unattainable (Nkulu Kalengayi et al. 2015; Delilovic et al., 2018). While asylum seekers are entitled to participation in health examinations within one year from their arrival, those who arrive in the country and enrol an asylum procedure

through reunification with a family member are not offered same or similar services (Socialstyrelsen, 2019). This, in turn, makes accessibility to health and care related information and services conditional both for the newly arrived members of society and those who work within the healthcare sectors. For those who are enrolled in an asylum procedure, inaccessibility can result from isolation by living in alternative accommodations and language unproficiency, as well as interpreting and practicing legal definitions, which is a shared challenge by both the groups of care receivers and providers (Delilovic et al., 2018).

Similar concerns over accessibility and participation are seen in studies on absence of some groups in research within and across different disciplines. Previous studies have shown challenges of recruiting underrepresent populations to participate in clinical trials (Hussain-Gambles et al., 2004; Ford et al., 2008), as well as barriers to participation of 'minority' groups in research on public health promotion (Deding et al., 2008; Nielsen et al., 2017). While some studies focus on the importance of cross-sectoral investigation into nonparticipation (Etti et al., 2021), others highlight the role of methodological choice as a determinant of participating in research (Zeisler et al., 2020). The anthropologist Shahram Khosravi (2010a) argues that visibility and invisibility of the so-called minority groups of asylum seekers and refugees in society goes back to the to the question of borders and formation of regular, irregular, legal and illegal bodies. As Khosravi explains, presence and visibility are two differently defined notions. While the absence of some migrants is often referred to as a negative outcome of migration, Khosravi reminds the reader that for those who are labelled 'illegal' migrants, visibility can mean being critically observed (Khosravi, 2010a, p. 77). While lack of active participation in research can be seen as a personal choice, absence from it is sometimes a consequence of not only structural factors but also methodological design (Mirsalehi & Hansson, 2023). In other words, asylum seekers and refugees may be silently visible in the numerical results of health research yet absent as research subjects. This includes children's (lack of) presence in different social research, including health. Children, too, are subjected to the questions of accessibility and participation while their presence or absence, besides ethical, conceptual, and legal dimensions,

is influenced by the research design and its methodological choice (Mirsalehi, 2021).

From a social and cultural perspective, health can be interpreted as not only a lack of constructed diagnostic criteria, but also as power and control over the body's biological responses (Lundin & Åkesson, 1996). Evaluating performances of generating good health, thus, requires exploration of the influencing factors involved in such "critical mobilities" where views of body and ideas of health cross borders, geographically, culturally, and disciplinary (Söderström et al., 2013). Critical mobility can entail situations where the mobile, migratory bodies of those who seek safety turn to biosocial projects when placed under the expectation of learning how to respond to conditions that stem from social inequalities. Thus, it is important to review the cultural processes that take place within and between them.



## Research Findings

The Papers that are presented in this dissertation review the notion of health in a context of asylum in the society of Sweden. The first paper presents a cultural perspective on health inequalities through an empirical approach to embodied experiences of health and the logics of care during an asylum process. Paper 2 demonstrates the cultural conception of immunity and risk in an asylum context, while paper 3 reveals how conventional health recommendations and practices are strategically used by the children who joined this study during their transitional asylum process. Paper 4 attends to the absence of some social groups in health research and the contribution of ethnographic methods in conducting research with ‘hard-to-reach’ populations. In this section, I summarise the papers with a discussion on how each of them responds to the aim and research questions of this dissertation.

### Paper 1: Crossing Health Borders

Embodied Experiences of Health and Inequalities Among Asylum Seekers During the COVID-19 Pandemic in Sweden

Talieh Mirsalehi and Kristofer Hansson (Submitted)

This article addresses the first research question: *How are the embodied experiences of health, unhealth, and inequalities perceived and enacted by asylum seekers in response to circumstances within an asylum context and in relation to other members of the new society?*

The article attends to the issue of embodied experiences of inequalities in health among a group of asylum seekers in Sweden. The emergence of

the COVID-19 in Sweden revealed the impact of disparities in health when public health reports showed a noticeable difference in the morbidity and mortality cases caused by the pandemic among some migrant populations (Drefahl et al., 2020; Hansson et al., 2020; Rostila et al., 2021). While the interplay between international displacement, disparities in health, and the exacerbation of poor health has been investigated in literature (Rechel et al., 2012; Çetrez et al, 2021; Sundvall et al. 2021), studies on perceptions of health and experiences of inequalities while being displaced are scarce. By contextualising how inequalities in health are perceived, experienced, and responded to by two female asylum seekers in Sweden who joined this research, the authors argue that the notions of health and unhealth are situational, contextual, and their meanings are socioculturally bounded. In a healthcare paradigm where preserving health and building a healthy body are seen as social responsibilities placed on individuals, inequalities in health can be seen as avoidable through a change of lifestyle. By evaluating their health and bodily status in relation to other bodies in society, the participants in this study presented similar in nature yet different approaches to the notion of migratory body through different approaches to their health performances as a contributing factor behind their assumed vulnerabilities in health. As we argue in this article, this is in response to a logic of care which regards responsible health behaviour as a moral percept, expected from contributing members of society. The choices made to preserve health, from this view, can reveal one's attempt to discover the possibilities and impossibilities of one's body when under consideration as a legitimate member of the new society. While attempting to reveal their awareness at how they are viewed through the eyes of "the Others" in the society and what is expected from them, the participants in this study problematised the unequal conditions under which they are to expect generate equal levels of health. As argued in this study, viewing health and generation of a healthy body from this perspective can portray inequalities in health as reversible through individual health and care practices, despite recognition of structural factors behind formation of disparities in health.

## Paper 2: Rethinking Immunity

An Ethnography of Risk and Migration in Sweden

Talieh Mirsalehi, 2023

in *Journal of Medical Anthropology*, 42(5), 493–505.

This article investigates the question of *In what way does an asylum process influence individuals' conception of risk, body and its biological responses?* Following the first article and its reflection on health inequalities and the meaning of health and unhealth among a group of asylum seekers, in this study, I have investigated perceptions of the body's biological responses to risk from a social and cultural perspective. The human immune system has biological, social, and cultural lives. Reports on the overrepresentation of the groups of foreign-born and migrant individuals among the morbidity and mortality cases caused by the pandemic highlighted the impact of pre-existing health vulnerabilities on susceptibility to disease and death among these groups (Socialstyrelsen, 2021). In addition, debates about the role of immune system in preserving one's health against the virus resurfaced (Swaminathan, 2022). Strengthening one's immunity resulted in an increase in attempts to buy products with the promise of boosting one's immune system as a preventive strategy (Lundin et al., 2020). On the one hand, immunisation against the prevailing virus was a matter of survival. On the other hand, it became an act of taking responsibility for one's health as a moral percept. Caring about one's health, from this perspective, was a social responsibility, as it contributed to society's well-being (Alftberg & Hansson, 2012). Among the group of asylum seekers who participated in this study, immunity against the disease, like the rest of society, generated questions of health and survival. However, their response to the risks that were imposed by the pandemic differed. On the one hand, they were concerned whether their migratory bodies, deemed vulnerable against the disease, could survive the health effects of the pandemic. On the other hand, they feared the impact of the pandemic on their social body by jeopardising their chances of fulfilling the requirements to obtain residency in the new society. Through referring to health as a



boundary concept, a notion suggested by Illana Löwy (1992), I argue that health, unhealth, and risk are boundary concepts with fluid definitions and thus, open to interpretation by different groups based on their experiences. This article contextualises the challenges that those who live on temporary terms may face during a health crisis such as a pandemic. The presented experiences also show how matters of immunity and health are perceived and enacted around the hope of transitioning from pending to rightful citizens of the new society. This way, as the participants in the study revealed, they could immunise their social bodies while their biological bodies may or may not be what Martin calls “flexible” (1994) in meeting the requirements of a healthy body in accordance with their new society’s parameters of health.

### Paper 3: “We Only Drink Water Here”

An Ethnological Approach to the Liminality of Childhood Migration, Health Narratives, and Negotiation of Belonging in Sweden

Talieh Mirsalehi, 2021

in *Ethnologia Scandinavica*, Vol. 51(2021). Pp: 212–230.

This article responds to the question of *How are interpretations of health and health practices negotiated, contested and turned into strategies to meet the assumed requirements of membership and belonging during the transitional asylum process?* In this article, I focus on the fluid, transitional positions within an asylum process, where notions of health, illness, and methods of healing are used as a strategy to find one’s place in the new society. The study addresses the liminality of childhood migration and the role of health narratives when negotiating social position among a group of children who have moved to Sweden with their families as asylum seekers. By using water as a cultural object, and medicine and language as building blocks, these children demonstrate how they recognise and comply with the socioculturally constructed norms around health and illness in the new society. The article takes its point of departure from the work of anthropologist Victor Turner (1970 & 1977) on the concept of liminality

to analyse the participated children's attempt to transition from migratory childhood to a state of belonging. The concept of liminality has been analysed in response to migration as a social conflict (Bigger, 2009; Norström, 2004). Children—the same as other members in society—are targeted to lead a healthy way of life by being physically active and having a healthy nutritious diet (Frykman, 1992; Nilsson, 2015). Translated to self-care, children, like adults, are encouraged to care for their bodies through adopting new and healthy habits (Alftberg & Hansson, 2012). Through a strategic use of objects of symbolic and cultural meaning such as water, the children in their meetings with me, who, from their opinion, is a representative of Swedish society, reveal their attempt to transition between different liminal stages of their migratory childhood. To confront the ambiguity of the process, they make meaning of this process through the metaphorical usage of water when narrating their experiences of the double transitory process of childhood migration that they are involved in. Through approving the healing power of water, showing familiarity with the recommended dos and don'ts of medication and health care, and negotiating language acquisition in all its forms, these children challenge the assumed requirements for being granted the full membership of the new society. Although this article was written and published before the outbreak of the COVID-19 pandemic, the theoretical perspectives and empirical discussions presented in this study, too, build on the boundary and negotiable notion of health. While reflecting on their experiences of health and illness prior to and after their migratory journeys, the children reveal how they, intentionally, enrol in cultural processes of making meaning of health and the body, considering the new society's requirements of its citizens. To avoid the risk of prolonging their liminal state of remaining as only potential citizens of the new society, the children oscillate between their knowledge of proper health from past to present.

## Paper 4: To reach the unreachable

Migratory life, health vulnerabilities, and the non-response bias in health research

Talieh Mirsalehi & Kristofer Hansson, 2023

Mirsalehi, T., & Hansson, K. (2023). To reach the unreachable: migration, health vulnerabilities, and the problem of nonresponse bias in health research. In *Medicine Across Borders: exploration of Grey Zones* (pp. 133–151).

This book chapter explores the question of *What methodologies need to be applied in health research to approach, access and assess meaning of health, practices of care, and responses to societal hazards among asylum-seeking populations?* This study is built on the results of an online survey on the response of the society of Sweden to the COVID-19 pandemic and purchase of protective products against the disease on the internet.

The COVID-19 pandemic has exposed a range of health inequalities that especially impact vulnerable groups around the world. In Sweden, the pandemic resulted in high number of hospitalisation and death cases among foreign-born individuals and migrants. Much points to contributing factors such as unequal distribution of care, these groups' socioeconomic status, and their difficulties accessing health information. In addition, there are other underlying reasons that merit examination. Some of them may be knowledge gaps in society at large as well as among experts and researchers about these groups' culturally based experiences of dealing with risks and care-related encounters. Moreover, there are knowledge gaps about these groups' practices of tackling health risks in a culturally unfamiliar society such as Sweden. Taking the phenomenon of COVID-19 pandemic in Sweden as an empirical case, the aim of this chapter is to explore the strengths/weaknesses of different methodological approaches when investigating health and care-related conditions among 'marginalised', foreign-born groups. The objective is not primarily to answer the question of why foreign-born groups are severely affected; the purpose, instead, is to present the methods that allow these groups to have their voices heard.

This, we argue, can contribute to the formation of an understanding about their lived experiences, situations, and patterns of action related to circumstances caused by the pandemic. Drawing on our quantitative and qualitative collected material, we argue that health research needs ethnography to unpack structurally voiceless groups' responses to risks especially in times of crisis.



## Concluding Discussion

This dissertation is an ethnological study of the fluid, situational, contextual, and negotiable notion of health in the asylum context. Through an ethnographic investigation into the experiences of health, unhealth, immunity and risk during an asylum process, this study explores how people navigate and respond to situations that arise from conditions and consequences of forced migration and displacement. Taking the COVID-19 pandemic as a case, the findings present an empirical account of the cultural processes through which perception of the body is contested and reconstructed in relation to the notions of health and in response to the logic of care in a new society. The meaning of health and of having a healthy body (or not), from this view, is made through constant negotiation in different contexts and between diverse actors across time and space.

The current section begins by reviewing the findings of this research in relation to the overarching theoretical perspectives—namely conception, negotiation and practices of the boundary concepts of health, care, risk and immunity in response to the conditions caused by liminality of the asylum life.

### Health and immunity, a continuous transition between responsibility, risk and reward

Care for one's body as a central paradigm in Western society requires individuals to take active and individual responsibility for generating good health through avoiding risks and maintaining a healthy lifestyle (Alftberg & Hansson, 2012). Taking responsibility for one's health has increasingly penetrated people's everyday decision-making, even when it concerns

assessing, accessing, and using medicines (Liu, 2023). In a healthcare landscape where accountability for one's well-being is seen as a social norm, actively pursuing—and morally perceiving—good health is seen as an ideal practice of care, with individuals having control over the process and not the outcome (Mol, 2008). From this perspective, inequalities in health may appear as both avoidable and controllable through making *correct* individual life choices regardless of one's life conditions (Paper 1). Maintaining a body that is fit and flexible to adapt to a changing world, from this view, becomes a part of the social and cultural construction of an ideal citizen who is contributing and reflexive over one's life choices (Martin, 1994). Following or avoiding public health recommendations such as those distributed during the COVID-19 pandemic in Sweden, in turn, can become a matter of distinction between 'accountable' citizens and the rest of society, who are placed outside of this category (Frykman, 1992). In other words, failing to live up to the expectations of acting responsibly and preserving one's health can inevitably result in being deemed socially unfit and pushed to the margins of society (Fioretos, 2009). Those who arrive in Sweden as asylum seekers are introduced from early on to this *logic of care* (Mol, 2008) by being offered a voluntary health control upon arrival and being reminded of the importance of minding one's body and health status (Migrationsverket, 2023; Socialstyrelsen, 2023). They also realise with time that health and illness behaviours are seen as a performance of membership. To evaluate their possibilities and limitations of building wellness, those who are on the borderline of the new society may, however unconsciously, take a social, cultural and "biological gaze" (Lundin, 1996, p. 31) at their bodies through the eyes of the *Others* (Lévi-Strauss, 1969) to measure their chance of constructing the ideal body (Paper 1).

In the shifting healthcare panorama, where individualisation of health has become a social norm, bodies are placed in the centre of one's life project. The emphasis on the body and health and striving to care for one's well-being is seen as an attempt at familiarisation. From this perspective, a view of the meaning of health and practices of care for the self is built on not only the former but also the current embodied experiences of generating health, in relation to the state of other members of the society within and without the asylum context (Paper 1). Those who have joined this research

self-reflexively relate to their health through their bodies, which have gone through hardship and are yet in adjustment process, in relation to the bodies of the ‘non-migrant’ population who are, from their perspective, nurtured, strong, and can withstand hazards. Constructing a healthy body and generating good health, thus becomes a part of the migratory project even though it must be done under unequal circumstances. Instead of referring to the structural factors behind health vulnerabilities, shared through stories of living with limitation and injustice before and during migratory moves, it is the ‘inability of the body in adapting to the demanded self-care that is at the centre of the narratives (Paper 1).

In the emergence of the COVID-19 pandemic in Sweden, the body, and the role of its immune system in response to the disease came to the fore. Facing the risks imposed by the pandemic, participating families found themselves cast against the “immunitary logics” (Brown, 2019) of health and care that were, sometimes, hard to grasp and follow. For asylum seekers, the demand to take personal responsibility for one’s health during the pandemic could be experienced as contradictory when the health guidelines opposed the rules and recommendations of a so-called ‘successful’ integration (Paper 2). Although the guidelines during the pandemic aimed to control the infection and prevent health threats, they could be experienced by those who lived on the threshold of the new society as a risk to constructing the required active and contributing social body. The pandemic also revealed how the ambiguity of an asylum life could multiply when it concerned the prioritisation of one risk over another. On the one hand, contracting a potentially deadly virus could jeopardise the chances of surviving and building the anticipated life, as one’s migratory body and its health and immunity status were deemed as vulnerable and at-risk in the new society. On the other hand, being encouraged to stay at home and keep a physical distance from public places could be seen as taking a step back from being present in society, which is usually considered an active integration attempt. Responding to the assumed membership requirements, in other words, may demand making sense of the often contradictory, uncommon, or nonsensical dos and don’ts of health and care by those who try to make sense of their life projects in limbo (Paper 2).



By articulating their perceptions on health, immunity, and risk, the participants in this research revealed how gaining citizenship in the new society was seen as a biosocial and biocultural project. Social, cultural, and biological factors are closely linked and mutually influential when it comes to quality and inequality in matters surrounding health. Human biology and its biosocial measures can reveal the destructive or constructive aspects of life within a social context (Harris & McDade, 2018). The cultural side, as well, demonstrates the processes through which cultural meanings around health, illnesses, norms, and morality are shaped, interpreted, and experienced in relation to one's social relationships with others and with institutions (Kleinman, 2007). Acquiring new ways of life by following the perceived requirements can be experienced as impossible due to the limitations and barriers caused by liminality of an asylum life. These limitations, however, do not equal passivity or defeat. The liminality of forced migration can influence individuals' conception of the body and its biological processes by challenging what the anthropologist Emily Martin (1994) calls its flexibility and readiness to tackle the societal challenges that must be encountered before they are allowed 'in'.

Migration, regardless of type, includes performances of liminality (Turner, 1970). It begins from the moment the heart and mind are set into motion, proceeded by leaving one place for another to reinvent a desired order of life somewhere new. However, for some, the liminality of migration has no finality. Those who have participated in this research show how the ambiguity of asylum life can be prolonged when entry into the new society appears to be conditional and dependent upon adaptation to a new way of life (Paper 3). The assumed prerequisites of entry are perceived, specified, and practiced differently by individuals within different asylum and refugee populations. Yet, what remains common is the goal of not only obtaining citizenship but also membership of the society which they have survived to reach and have been endeavouring to become a part of. This is, however, not a linear path, as the terms of full membership in the new society can appear contradictory and open to interpretation (Paper 2). The perceived health-related membership requirements are discerned, made meaning of, and acted upon in accordance with the conditions of an asylum process; at the same time, norms and normality around health and

care in the new society are contested when they clash with the conditions and consequences of displacement (Paper 2 & 3).

While participants in this study grasped the logic of care in the new society by referring to embodied experiences of living in their formerly acquired health knowledge, they considered practicing care in accordance with the new sets of norms as a life project. Health and care, from this perspective, can be viewed as turning points which could either enable or disable asylum seekers from reaching the desired migratory outcome. Put into the asylum context, maintaining health, generating a healthy body, avoiding risks, and adopting new or reconstructing old self-care practices appear to be a part of the migratory process for those involved, regardless of age. Contesting the strategies of care for one's body and negotiating the meaning of health, can therefore be seen as an act of building a common ground between one's approach to well-being and that of the new society (Paper 3). Those who cross borders in search of asylum enter new social and cultural spheres where the definition of health, being healthy, and building a healthy body may have different cultural representations, although it may share similarities to what they already know and do. Interpreting the societal norms around health and care and transforming them into new knowledge can result in practicing the presented guidelines of how to maintain health, however, often in one's own terms. They can strategically be used to bridge pre- and post-migratory life cycles as a way of building a sense of culturally manageable belonging to the new society (Paper 3). Criticising the habits of the past and problematising the order of things in the present, can therefore manifest as a performative act of departure from the liminality of an asylum life, proving one's eligibility as a potential responsible future citizen.

The participants in this study found themselves in what Turner (1970, p. 465) called "betwixt and between" different socioculturally framed perceptions of health and hazard. Their understandings of immunity and how the immune system functions were shaped in relation to not only their former conception of their bodies, but also in comparison between other bodies and bodily responses in other individuals in the new society (Paper 1 & 2). Although the participants who joined this study could not offer a full scientific description of the complex mechanism of human

immunology, they described it through referring to their bodily response to social inequalities of the past, and uncertainties and helplessness of the present (Paper 1 & 2). In a liminal asylum context, immunity can be seen as a capacity that could either be activated and nurtured, like that of the non-migrant population, or be deactivated and diminished in those who have survived the hardships of living with social disparities. For them, staying in Sweden could be seen as a chance to build a desired life away from injustice and uncertainty. Arriving in Sweden, however, proved to not to be the end of their crossing, as they faced the requirements of proving their eligibility to become a refugee. This process insisted on a journey within, as they assessed the readiness of their bodies and how they could immune themselves against the surrounding risks, the biggest of all being deported from the country and facing the dream of their anticipated life being put to an end.

In the face of a global pandemic, the boundary concepts of immunity, health, and risk may refer to aspects beyond the physicality of life and denote an interruption in the formation of one's social body (Paper 2). In an asylum journey, those who undergo the process—transients—are displaced but not passively as their migratory bodies are involved in constant formation and transformation. The body of an asylum seeker becomes the means of resistance to reach the destination or serve as evidence of suffering to legitimise their deservingness of receiving asylum (Khosravi, 2010a). Those who take the irregular migratory path become a means of border transgression and violate the *natural* mode of being by breaking “the link between ‘nativity’ and nationality and bringing the nation-state system into crisis” (Khosravi, 2010a, p. 2). By crossing geographical borders *illegally*, it is not solely one's status that is put on hold to later be changed, but also one's state of being is pending between being ‘useful’ and ‘legitimate’ or being wasted and illegitimate (Bauman, 2011, p. 33). Thus, to prevent prolongation of this illegitimacy, strategies of familiarisation and belonging seem to be essential.

The complexity of approaching health in a multicultural society, mainly in times of collective uncertainty, led me to explore how embodied experiences of health and hazard are contested against sociocultural, political, and biological perceptions of care, the body, and the self. In this

dissertation, I lean towards social and cultural studies on the meaning of immunity and the politics of resistance (Löwy, 1992; Brown, 2019) to understand how the concepts of health and care are shaped, contested, and enacted among the group of asylum seekers who joined this study. The conditionality, fluidity, and imprecision of these concepts, put in the liminal context of asylum, can illuminate the situatedness of health and strategies of self-care among the groups of minority *laymen* (Fleck, 1979). Health and care practices, although bonded by seemingly divergent thought styles among these groups, are influenced by the socioculturally constructed mainstream ideas of a society. This is one of the core arguments of this dissertation, which in turn illuminates the importance of methodological approach to access experiences of health and care among different groups (Paper 4). While some groups are deemed hard to reach, it is often the research design that contributes to formation of inaccessible communities. The literature across disciplines have been continuously attending to the pros and cons of qualitative vs. quantitative approaches, while the notion of bricolage and combination of methods is favoured yet analytically criticised by others. Despite these reflections being important elements in shaping and updating the methodological knowledge bank, a critical approach to research methodologies may go beyond well-investigated questions of advantages and disadvantages and investigate how to utilize each method to its full potential. As argued in the fourth and final Paper included in this dissertation, unpacking a complex social phenomenon such as inequalities in health requires investigation into structural factors behind formation and exacerbation of social and health disparities. However, it is as crucial to explore the seemingly casual, everyday coping strategies applied by those impacted to identify patterns of health and care practices among different groups. For the latter, ethnographic methods can illuminate such everyday practices while they may fall short because the finding cannot be generalised, if needed.

The outcome of the explorative approach presented in the last publication included in this dissertation suggests that investigating qualities and inequalities in health through exploring the fluid characteristic of health and care, risk, and reward demand flexible methods of investigation (Paper 4). By suggesting ethnographic methods as a means of conducting “slow

research” (Adams et al., 2014), this dissertation indicates that approaching health and inequalities demands attentiveness and depth.

## Concluding remarks

This dissertation shows how the notion of health is negotiated, problematised, and enacted by those who undergo an asylum process in their everyday life circumstances. This ethnological contribution adds to the existing literature within ethnology, medical humanities, and migration studies, besides others, on the correlation between migration and experiences of health and unhealth. It is through the analysis of embodied experiences of displacement while undergoing a liminal and not necessarily transitional asylum process. The presented empirical material that was collected during the COVID-19 pandemic shows how inequalities in health within and without a time of health crisis are experienced by those who—although considered vulnerable—are silently visible behind public health statistics. My analysis, on the one hand, reveals how health and the body’s biological response are culturally viewed and socially reconstructed and enacted during an asylum process. On the other hand, the empirical account shows how these embodied experiences are interpreted, contested and responded to by referring to the possibilities and impossibilities of one’s body in building a desired post-migratory life.

The three articles and the book chapter in this dissertation have shown that the notions of health and unhealth, as well as ways of approaching risk and strategising care are contextual, situational, and bound to the circumstances unique to each individual case, while emerging from similar patterns of sociopolitical shifts. By exploring some aspects of an asylum life before and during the pandemic, the studies included in this dissertation reveal that the meaning of health in an asylum context is fluid, and in constant formation and reformation in relation to the conditions of the process. From this perspective, health is not limited to one’s biological state, but becomes a parameter for measuring the degree of one’s social and cultural belonging. Thus, approaching migratory health requires continuous evaluation and application of relevant means of improvement. Being aware of one’s body and its biological responses is considered a

given, the norm, in a landscape where health outcomes are assessed through individual's care performance. The question to ask would be, however, what possibilities and hindrances might stand in the way of reaching this goal for those who wait to move up from being a temporary to a permanent member, a progression which ends with enrolling the category of migrant. The ambiguity of this process becomes illuminated when the asylum-seeking participants in this research oscillated between being the subject of their lives, responsible for changing lifestyle and building better health, and being the object of the asylum process, waiting for permission to begin a new life while considered vulnerable and prone to suffering the effects of health disparities by default.

Health and the body, as shown in this study, are placed at the two ends of a migratory spectrum. On one end, health is seen as a necessity to keep the participants of this study in the process of actualising their dream of remaining in Sweden and having a normal life. On the other end, health—or the lack of it—can be a tool to negotiate one's eligibility for being officially granted refugee status (Khosravi, 2010a). Navigating the new health and care landscape can therefore require negotiation of what risks need to be prioritised or avoided and what health strategies are to be replaced or modified. As shown in this dissertation, the evaluation of health and the assessment of unhealth by public health research needs to consider in what way these concepts are perceived, made meaning of, and practiced in different contexts, including different migrant populations. The analysis also illuminates how generating health and resisting unhealth has been interpreted as a form of resettlement project. Thus, the meaning of health, as investigated in this study, goes beyond the biological property of one's body and becomes a performance of belonging. The conditions under which such practices and performances take place, however, are not equally distributed. Generating health under uneven circumstances and leaving it to individuals to decide over the means of sustaining well-being can, in turn, form and exacerbate disparities in health.

This dissertation has taken an inside-out approach to the navigation of health in response to the phenomenon of inequalities in health among asylum populations. The study approaches the question by revealing how embodied experiences of health are made meaning of in face of the often-

conflicting choices available to asylum seekers throughout an asylum process. Unpacking this, in turn, can shed light on the importance of considering and incorporating the knowledge that stems from these experiences and strategies when designing health interventions to tackle health disparities in society. Those placed into these categories, although they are deemed, by default, at-risk and vulnerable, are expected to practice health and care in the same manner as the rest of society, even though they exist and have existed under unequal circumstances. Being considered at-risk is as a result of societal negotiations over what constitutes risk and who falls into this category, according to what parameters of health and unhealth (Kenen, 1996). Assessing the contributing factors behind health disparities and reviewing the already recognised structural factors behind it can normalise inequalities in health among some groups when the experiences and knowledge of those who are in the category of at-risk are not considered.

Reviewing the boundary concepts of health, unhealth, and immunity in the liminal spaces of an asylum process paves the path for the generation of knowledge about health inequalities among the groups of asylum seekers and migrants. By calling attention to the fluid characteristics of these notions, as my analysis shows, assessment of inequalities in health among these groups, besides multidimensional approach to the effect of social inequalities on their health status, requires an empirical understanding of how effect of such inequalities can be accessed, assessed, and addressed. Ethnological studies on health and health disparities are an important complementary conceptual and methodological contribution to understanding the practices that result in the presence or absence of by health, shedding light on the cultural processes within which the notion of health is perceived and practiced among different groups. Understanding such processes is particularly important in an increasingly globalised world where multiculturalism, which has been politically favoured by most countries, including Sweden, results in a diversification of approaches to both the meaning and the means of practicing health.

The ambition of this dissertation is to invite further cultural analytical research on health and inequalities in health among different migrations populations by examining into these notions from their own perspective.

Tackling a social phenomenon as multilayered and complex as health and disparities during migration requires knowledge exchange between different academic disciplines and society.





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Appendices I-X







## **Information kring doktorandprojektet ”Förfalskade läkemedel i ett mångkulturellt samhälle. Betydelsen av kunskapsutbyte mellan allmänhet och expertis”**

### **Vad är läkemedel och vad betyder förfalskade mediciner egentligen?**

De flesta människor världen över kommer i kontakt med mediciner någon gång i livet. För många av oss är mediciner ett självklart och sällan ifrågasatt inslag i tillvaron. Det är svårt att tänka sig en fungerande hälso- och sjukvård utan läkemedel. Enligt lagen är läkemedel alla ämnen som påstås kunna påvisa, förebygga, lindra eller bota sjukdom eller sjukdomssymtom.

Med tanke på denna bakgrund är spridningen av förfalskade läkemedel särskilt problematisk och innebär omfattande hälsorisker för individen. Förfalskade läkemedel är ett samlingsbegrepp för det Världshälsoorganisation (WHO) rubricerar som *Substandard and falsified medical products*. Termen avser produkter som inte når upp till den utlovade kvaliteten. Det handlar även om produkter som är avsiktligt förfalskade där läkemedel innehåller alltför lite av den angivna substansen eller saknar den. Konsekvenserna kan i samtliga fall bli utebliven effekt av profylax och behandling, ökad resistensutveckling vid infektioner etc. Det finns också exempel på att läkemedel innehållit toxiska substanser som skadat och dödat den som i god tro tagit medicinen. Förutom att förfalskade läkemedel medför hälsorisker för individer finns det, på lång sikt, andra konsekvenser i form av höga sjukvårdskostnader.

Det har framkommit att förfalskade läkemedel finns i Sverige. Den ökande förekomsten av förfalskade läkemedel i Sverige har väckt allvarliga farhågor eftersom den utgör direkt skada för människor i olika åldrar, från olika sociala och kulturella bakgrunder. Inte minst barn och ungdomar kan förväntas vara bland riskgrupperna. Fenomenet angår Sverige i högsta grad idag med tanke på att samhället allt mer omvandlas till ett multikulturellt sådant. Det är därför viktigt att få kunskap om hur människor i det framväxande mångkulturella svenska samhället förhåller sig till läkemedel.

### **Övergripande plan för forskningsprojektet**

Det övergripande syftet med forskningsprojektet är att inhämta information hos allmänheten med inriktning på barn i åldern 9 – 12 år för att ta reda på barnens uppfattningar och kunskaper om läkemedel och hälsa. Detta för att så småningom ta reda på hur barn i dessa åldrar förhåller sig till läkemedel och i vilken mån de känner till de stora risker som är förknippade med förfalskade läkemedel.



Projektet har tre målgrupper som består av barn (9-12 år), barnens vårdnadshavare, och personal på skolor, organisationer och föreningar som anordnar olika aktiviteter för t.ex. nysvenska och migranter.

### **Metoder:**

Vi vill undersöka hur barn uppfattar hälsorelaterad information och hur de skulle vilja bli informerade om hälsorelaterade frågor.

Undersökningen görs enligt följande metoder:

#### **Deltagarobservationer**

- Doktoranden följer de ansvariga på skola då de diskuterar eller undervisar om hälsorelaterade frågor med barn.
- Doktoranden närvarar i klassrummet och observerar vilka hälsorelaterade ämne som diskuteras i klassrummet, vilken typ av information som ges till barn (årskurs 4-6) samt hur informationen ges, dvs. vilken metod som används av personalen.
- Doktoranden observerar hur barn reagerar på presenterad information, t.ex. vilka frågor barnen har om den presenterade informationen och hur barnen svarar på frågor som personalen ställer.
- Doktoranden observerar de olika lärometoderna och material som används för undervisning och diskussion, hur barnen uppfattar informationen och hur de reagerar på materialet.

#### **Intervjuer:**

- Doktoranden intervjuar vårdnadshavare, barn och personal på skola, organisationer och föreningar för att så småningom ta reda på vilken typ information forskningspersonerna har om läkemedel, hälsa och medicinering.
- Intervjun omfattar även frågor om forskningspersonernas kunskaper och egna erfarenheter angående läkemedel och förfälskade läkemedel.

Genom att intervjua dig som arbetar med barn önskar jag få bättre kunskap om barns uppfattning om hälsa och medicinering. Genom att intervjua dig vill jag prata om t.ex. vilka hälsorelaterade frågor som diskuteras i skolan. Intervjun beräknas ta mellan 30 minuter till en timme. Jag kommer att spela in intervjun så att jag minns den information som du delar med dig av. Inspelningar kommer att lagras på en säker plats enligt Personuppgiftslagen GDPR (General Data Protection Regulation, Dataskyddsförordningen på svenska) och en kompletterande svensk lag, Dataskyddslagen. Om du föredrar att inte bli inspelad tar jag skriftliga anteckningar i stället. Intervjutexten är mitt material för studien och den anonymiseras genom att ditt namn och annan fakta som kan relatera till dig tas bort. I det datamaterial som arkiveras kommer personuppgifter inte finnas med. Materialet kommer att arkiveras vid Lunds Universitets arkiv.

Under och i anslutning till observationerna görs fältanteckningar som ett stöd för min kommande bearbetning av materialet. Korrekta namn på personer eller platser används inte i fältanteckningar.

Det är jag, Talieh Mirsalehi, som i egenskap av doktorand kommer att genomföra studien.

När studien är avslutad kan du få ta del av resultatet (min doktorsavhandling) genom att kontakta mig, Talieh Mirsalehi, per telefon 046-222 75 66 eller 073-766 63 76 eller e-mail [talieh.mirsalehi@kultur.lu.se](mailto:talieh.mirsalehi@kultur.lu.se). Projektet har genomgått etisk prövning.

Deltagande är frivilligt och den som väljer att delta kan när som helst avbryta sitt deltagande. Om du har frågor är du välkommen att kontakta mig, Talieh Mirsalehi, via e-post: [talieh.mirsalehi@kultur.lu.se](mailto:talieh.mirsalehi@kultur.lu.se) eller per telefon 046-222 75 66 eller 076-054 80 04. Huvudman för studien är Lunds universitet, som kan kontaktas via e-post: [lu@lu.se](mailto:lu@lu.se) eller per telefon 046-222 00 00.

### **Kontaktpersoner:**

Talieh Mirsalehi  
Doktorand i etnologi  
Institutionen för kulturvetenskaper  
Lunds Universitet  
Epost: [talieh.mirsalehi@kultur.lu.se](mailto:talieh.mirsalehi@kultur.lu.se)  
Telefon: 046-222 75 66  
Mobiltelefon: 0760- 54 80 04  
Adress: Box 192, 221 00 Lund

Kristofer Hansson  
Docent i etnologi  
Institutionen för kulturvetenskaper  
Lunds Universitet  
Epost: [kristofer.hansson@kultur.lu.se](mailto:kristofer.hansson@kultur.lu.se)  
Telefon: 046-222 83 92  
Adress: Box 192, 221 00 Lund

Susanne Lundin  
Professor i etnologi  
Institutionen för kulturvetenskaper  
Lunds Universitet  
Epost: [susanne.lundin@kultur.lu.se](mailto:susanne.lundin@kultur.lu.se)  
Telefon: 046-222 41 79  
Adress: Box 192, 221 00 Lund





## Hur hanterar du mediciner?

Hej!

Jag heter Talieh Mirsalehi och är doktorand vid Institutionen för Kulturvetenskaper vid Lunds universitet. Jag genomför en studie av barns kunskaper om mediciner och hälsa och söker deltagare – barn mellan 9 och 12 år och barnens vårdnadshavare. Jag söker även deltagare som arbetar inom organisationer och föreningar som inom ramen för integration av nysvenska och migranter driver aktiviteter för barnfamiljer.

### Syftet med studien och hur den utförs

Det har framkommit att falska läkemedel finns i Sverige. Dessa falska produkter utgör direkt skada för människor i olika åldrar och från olika sociala och kulturella bakgrunder. Inte minst barn och ungdomar kan förväntas vara bland riskgrupperna. Idag har vi liten kunskap om hur barn och ungdomar relaterar till hälsa, kropp och medicin. Enligt Läke-medelsverket, som kontinuerligt söker nå allmänheten med information, är det viktigt att barn från tidig ålder får kunskap om hälsa och om hur läkemedel ska användas. Som deltagare kommer forskningspersoner delta i en undersökning och dela med sig av sina erfarenheter av att söka vård och att köpa medicinska produkter.

Undersökningen görs enligt följande metoder:

### Deltagarobservationer

- Jag närvarar i aktiviteter som organisationen eller föreningen bedriver barnfamiljer och observerar vilka hälsorelaterade ämne som diskuteras, vilken typ av information som ges till barn (årskurs 4-6) och vuxna samt hur informationen ges, dvs. vilken metod som används av personalen.
- Jag observerar hur forskningspersonerna reagerar på presenterad information, t.ex. vilka frågor barnen och vårdnadshavarna har om den presenterade informationen och hur barnen svarar på frågor som personalen ställer.

### Intervjuer:

- Jag intervjuar vårdnadshavare, barn och personal på organisationer och föreningar för att så småningom ta reda på vilken typ information forskningspersonerna har om läkemedel, hälsa och medicinering.
- Intervjun omfattar även frågor om forskningspersonernas kunskaper och egna erfarenheter angående läkemedel och förfälskade läkemedel.

Intervjun och fokusgruppsamtal med barn tar 15 till 30 minuter. Intervjun med vuxna tar 30 till 60 minuter. Forskningspersonerna får själva bestämma tid, datum och plats för intervjun.

Jag kommer att spela in intervjun så att jag minns exakt all information som du delar med dig av. Inspelningar kommer att lagras på en säker plats enligt Personuppgiftslagen GDPR (General Data Protection Regulation, Dataskyddsförordningen på svenska) och en kompletterande svensk lag, Dataskyddslagen. Om du föredrar att inte bli inspelad tar jag skriftliga anteckningar i stället. Intervjutexten är mitt material för studien och den anonymiseras genom att namn och annan fakta som kan relatera till forskningspersonerna tas bort. I det datamaterial som arkiveras kommer personuppgifter inte finnas med. Materialet kommer att arkiveras vid Lunds Universitets arkiv.

Under och i anslutning till observationerna görs fältanteckningar som ett stöd för min kommande bearbetning av materialet. Korrekta namn på personer eller platser används inte i fältanteckningar.

#### Frivillighet

Medverkan är frivillig och du kan när som helst avstå från att delta eller avbryta ditt deltagande utan att ange några skäl. Om du väljer att avstå eller avbryta ditt deltagande kommer detta inte att få negativa konsekvenser för dig. Om du avbryter, bör du meddela om den information som redan samlats in om dig kan användas i studien eller inte.

#### Hantering av insamlat material och sekretess

All information som samlas in i studien är konfidentiell och förvaras så att obehöriga inte har tillgång till den. Enbart medverkande forskare kommer att hantera materialet. Korrekta namn på personer eller platser används inte i forskningen och om forskare eller andra myndigheter begär ut materialet, gör Lunds universitet en sekretessprövning i varje enskilt fall. I redovisningen av projektet kommer inga uppgifter att lämnas ut som kan knytas till dig som enskild person. När studien är avslutad kan du få ta del av resultatet som presenteras i min kommande doktorsavhandling.

Det är jag, Talieh Mirsalehi, som i egenskap av doktorand kommer att genomföra studien. När studien är avslutad kan du få ta del av resultatet (min doktorsavhandling) genom att kontakta mig, Talieh Mirsalehi, per telefon 046-222 75 66 eller 073-766 63 76 eller e-mail [talieh.mirsalehi@kultur.lu.se](mailto:talieh.mirsalehi@kultur.lu.se). Projektet har genomgått etisk prövning.

Om du har några frågor så hör gärna av dig till mig, Talieh Mirsalehi, eller till mina handledare vars kontaktuppgifter du finner nedan.

Huvudman för studien är Lunds universitet, som kan kontaktas via e-post: [lu@lu.se](mailto:lu@lu.se) eller per telefon 046-222 00 00.

Med vänliga hälsningar

Talieh Mirsalehi  
Doktorand i etnologi  
Institutionen för kulturvetenskaper

#### Bilaga 15.3.4 Informationsbrev till personal på organisationer och föreningar

Lunds Universitet

Epost: talieh.mirsalehi@kultur.lu.se

Telefon: 046-222 75 66

Adress: Box 192, 221 00 Lund

Kristofer Hansson

Docent i etnologi

Institutionen för kulturvetenskaper

Lunds Universitet

Epost: kristofer.hansson@kultur.lu.se

Telefon: 046-222 83 92

Adress: Box 192, 221 00 Lund

Susanne Lundin

Professor i etnologi

Institutionen för kulturvetenskaper

Lunds Universitet

Epost: susanne.lundin@kultur.lu.se

Telefon: 046-222 41 79

Adress: Box 192, 221 00 Lund





## **Information kring doktorandprojektet ”Förfalskade läkemedel i ett mångkulturellt samhälle. Betydelsen av kunskapsutbyte mellan allmänhet och expertis”**

### **Vad är läkemedel och vad betyder förfalskade mediciner egentligen?**

De flesta människor världen över kommer i kontakt med mediciner någon gång i livet. För många av oss är mediciner ett självklart och sällan ifrågasatt inslag i tillvaron. Det är svårt att tänka sig en fungerande hälso- och sjukvård utan läkemedel. Enligt lagen är läkemedel alla ämnen som påstås kunna påvisa, förebygga, lindra eller bota sjukdom eller sjukdomssymtom. Med tanke på denna bakgrund är spridningen av förfalskade läkemedel särskilt problematisk och innebär omfattande hälsorisker för individen. Förfalskade läkemedel är ett samlingsbegrepp för det Världshälsoorganisation (WHO) rubricerar som *Substandard and falsified medical products*. Termen avser produkter som inte når upp till den utlovade kvaliteten. Det handlar även om produkter som är avsiktligt förfalskade där läkemedel innehåller alltför lite av den angivna substansen eller saknar den. Konsekvenserna kan i samtliga fall bli utebliven effekt av profylax och behandling, ökad resistensutveckling vid infektioner etc. Det finns också exempel på att läkemedel innehållit toxiska substanser som skadat och dödat den som i god tro tagit medicinen. Förutom att förfalskade läkemedel medför hälsorisker för individer finns det, på lång sikt, andra konsekvenser i form av höga sjukvårdskostnader.

Det har framkommit att förfalskade läkemedel finns i Sverige. Den ökande förekomsten av förfalskade läkemedel i Sverige har väckt allvarliga farhågor eftersom den utgör direkt skada för människor i olika åldrar, från olika sociala och kulturella bakgrunder. Inte minst barn och ungdomar kan förväntas vara bland riskgrupperna. Fenomenet angår Sverige i högsta grad idag med tanke på att samhället allt mer omvandlas till ett multikulturellt sådant. Det är därför viktigt att få kunskap om hur människor i det framväxande mångkulturella svenska samhället förhåller sig till läkemedel.

### **Övergripande plan för forskningsprojektet**

Det övergripande syftet med forskningsprojektet är att inhämta information hos allmänheten med inriktning på barn i åldern 9 – 12 år för att ta reda på barnens uppfattningar och kunskaper om läkemedel och hälsa. Detta för att så småningom ta reda på hur barn i dessa åldrar förhåller sig till läkemedel och i vilken mån de känner till de stora risker som är förknippade med förfalskade läkemedel.

Projektet har tre målgrupper som består av barn (9-12 år), barnens vårdnadshavare, och personal på skolor, organisationer och föreningar som anordnar olika aktiviteter för t.ex.



nysvenska och migranter.

### **Metoder:**

Vi vill undersöka hur barn uppfattar hälsorelaterad information och hur de skulle vilja bli informerade om hälsorelaterade frågor.

Undersökningen görs enligt följande metoder:

#### Deltagarobservationer

- Doktoranden följer de ansvariga på skola, eller organisationer och föreningar då de diskuterar eller undervisar om hälsorelaterade frågor med barn.
- Doktoranden närvarar i klassrummet och observerar vilka hälsorelaterade ämne som diskuteras i klassrummet, vilken typ av information som ges till barn (årskurs 4-6) samt hur informationen ges, dvs. vilken metod som används av personalen.
- Doktoranden observerar hur barn reagerar på presenterad information, t.ex. vilka frågor barnen har om den presenterade informationen och hur barnen svarar på frågor som personalen ställer.
- Doktoranden observerar de olika lärometoderna och material som används för undervisning och diskussion, hur barnen uppfattar informationen och hur de reagerar på materialet.

#### Intervjuer:

- Doktoranden intervjuar vårdnadshavare, barn och personal på skola, organisationer och föreningar för att så småningom ta reda på vilken typ information forskningspersonerna har om läkemedel, hälsa och medicinering.
- Intervjun omfattar även frågor om forskningspersonernas kunskaper och egna erfarenheter angående läkemedel och förfälskade läkemedel.

Genom att intervjuas dig som är vårdnadshavare till barn önskar jag få bättre kunskap om barns uppfattning om hälsa och medicinering och prata om t.ex. hur du som förälder ser på familjens hälsa. Intervjun beräknas ta mellan 30 minuter till en timme. Den spelas in och skrivs sedan ut. Jag kommer att spela in intervjun så att jag minns den information som du delar med dig av. Inspelningar kommer att lagras på en säker plats enligt Personuppgiftslagen GDPR (General Data Protection Regulation, Dataskyddsförordningen på svenska) och en kompletterande svensk lag, Dataskyddslagen. Om du föredrar att inte bli inspelad tar jag skriftliga anteckningar i stället. Intervjutexten är mitt material för studien och den anonymiseras genom att ditt namn och annan fakta som kan relatera till dig tas bort. I det datamaterial som arkiveras kommer personuppgifter inte finnas med. Materialet kommer att arkiveras vid Lunds Universitets arkiv.

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### **Kontaktpersoner:**

Talieh Mirsalehi  
Doktorand i etnologi  
Institutionen för kulturvetenskaper  
Lunds Universitet  
Epost: [talieh.mirsalehi@kultur.lu.se](mailto:talieh.mirsalehi@kultur.lu.se)  
Telefon: 046-222 75 66  
Mobiltelefon: 0760- 54 80 04  
Adress: Box 192, 221 00 Lund

Kristofer Hansson  
Docent i etnologi  
Institutionen för kulturvetenskaper  
Lunds Universitet  
Epost: [kristofer.hansson@kultur.lu.se](mailto:kristofer.hansson@kultur.lu.se)  
Telefon: 046-222 83 92  
Adress: Box 192, 221 00 Lund

Susanne Lundin  
Professor i etnologi  
Institutionen för kulturvetenskaper  
Lunds Universitet  
Epost: [susanne.lundin@kultur.lu.se](mailto:susanne.lundin@kultur.lu.se)  
Telefon: 046-222 41 79  
Adress: Box 192, 221 00 Lund





## Vill du vara medforskare i ett projekt om falska läkemedel?

Hej!

Jag heter Talieh Mirsalehi och är doktorand vid Institutionen för Kulturvetenskaper vid Lunds universitet. Jag gör en studie om medicin och hälsa. Den gör jag tillsammans med en forskargrupp från Lunds Universitet. Vill du vara med i denna forskning?

### Vad är läkemedel och vad betyder falska läkemedel egentligen?

Det är svårt att tänka sig en fungerande hälso- och sjukvård utan läkemedel. Med moderna läkemedel kan vi idag förebygga många sjukdomar så att de inte bryter ut. När en sjukdom har brutit ut, kan läkemedel ofta hjälpa patienten att bli frisk eller åtminstone lindra besvären. Förr användes läkemedel främst för att man till exempel inte skulle ha så ont eller att för att sänka febern. Det är först i modern tid som läkemedel används för att hindra att sjukdomar uppstår och för att bota sjukdomar.

Visste du att det finns så kallade falska läkemedel som kan skada oss istället för att bota sjukdomar? Om man använder sådana falska läkemedel kan det leda till att behandlingen inte lyckas eller att människor blir sjuka.

Men, hur vet vi om ett läkemedel är äkta eller falskt? Forskare vill veta mer för att kunna stoppa de falska läkemedlen. Det är viktigt att ta reda på vem som gör förfälskningarna. Det är också viktigt att känna till hur människor använder olika slags läkemedel. Får man ett recept av doktorn och går sedan till apoteket eller handlar man sina läkemedel på andra sätt?

Vi är en grupp forskare vid Lunds Universitet som vill förhindra att falska läkemedel sprids. Först behöver vi få reda på vad människor i Sverige överhuvudtaget vet om läkemedel. Sedan behöver vi veta om människor har hört talas om falska läkemedel. Vill du vara med och hjälpa oss med detta forskningsprojekt?

### Hur kan du hjälpa vår forskargrupp?

För att få reda på vad människor i Sverige vet om läkemedel och falska läkemedel vill jag prata med dig. Vi kommer att träffas och samtala om vad som händer när du blir sjuk och vad du gör för att bli frisk. Dessutom vill jag tillsammans med dig läsa och samtala om en serietidning som handlar om falska läkemedel.

Jag kommer att spela in intervjun så att jag minns den information som du delar med dig av. Inspelningar kommer att lagras på en säker plats enligt Personuppgiftslagen GDPR (General Data Protection Regulation, Dataskyddsförordningen på svenska) och en kompletterande svensk lag, Dataskyddslagen. Om du föredrar att inte bli inspelad tar jag skriftliga anteckningar i stället.

Vill du eller dina föräldrar veta mer får du gärna kontakta mig!

### Bilaga 15.3.3 Informationsbrev till barn

Talieh Mirsalehi

Institutionen för kulturvetenskaper, Lunds universitet

Helgonavägen 3, 221 00 Lund

E-post: [talieh.mirsalehi@kultur.lu.se](mailto:talieh.mirsalehi@kultur.lu.se)

Telefon: 046-222 75 66

Mobil: 070-60 54 80 04

## Intervjuguide

I den här studien använder doktoranden semistrukturerade intervjuer. Intervjun inleds med att söka bakgrundsinformation och innebär frågor ställs om forskningspersonens familjeförhållanden, personliga intressen etc. Därefter behandlas följande ämnen i samtalsform:

Vårdnadshavare:

1. När var sista gången du eller någon i familjen sökte vård? Vill du berätta om dina upplevelser i samband med händelsen?
2. Vad gör du eller andra familjemedlemmar när du eller ni har problem med hälsan?
3. Hur ofta söker du eller andra familjemedlemmar vård? Vill du berätta mer om detta?
4. Vad gör du om läkaren förskriver receptbelagda mediciner till dig? Vill du berätta om detta? Kan det vara så att du inte hämtar ut medicinerna? Varför?
5. Har du upplevt situationer när du bad om specifika mediciner, men då läkaren inte ville skriva ut dem? Om så är fallet, vad gjorde du efteråt?
6. Diskuterar ni hälsorelaterade frågor hemma? Om ja, hur ofta, och vad brukar ni prata om?
7. Vad tycker du om att prata med barn om mediciner? Har du någon erfarenhet i detta avseende?
8. Hur fick du behandling som barn? Använder du fortfarande samma metoder eller mediciner som du själv fick som liten?
9. Har du provat e-läkare eller köpt mediciner på Internet? Om ja, kan du beskriva hur du upplever skillnaderna mellan e-läkare och att träffa läkare personligen samt skillnaderna mellan att köpa mediciner på Internet eller på ett apotek?
10. Har du hört talas om falska mediciner? Om ja, kan du beskriva vad det är?
11. Har du delat med dig av läkemedel med någon? Till vem? När var sista gången du gjorde det? Kan du beskriva situationen?
12. Har du köpt mediciner eller hälsoprodukter någon annanstans än på apotek? Om ja, kan du berätta om detta?
13. Var brukar du få information om hälsa och läkemedel?

Personal:

1. När var sista gången du eller någon i familjen sökte vård? Vill du berätta om dina upplevelser i samband med händelsen?
2. Vad gör du eller andra familjemedlemmar när du eller ni har problem med hälsan?
3. Hur ofta söker du eller andra familjemedlemmar vård? Vill du berätta mer om detta?
4. Vad gör du om läkaren förskriver receptbelagda mediciner till dig? Vill du berätta om detta? Kan det vara så att du inte hämtar ut medicinerna? Varför?
5. Har du upplevt situationer när du bad om specifika mediciner, men då läkaren inte ville skriva ut dem? Om så är fallet, vad gjorde du efteråt?
6. Diskuterar ni hälsorelaterade frågor hemma? Om ja, hur ofta, och vad brukar ni prata om?
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8. Hur fick du behandling som barn? Använder du fortfarande samma metoder eller mediciner som du själv fick som liten?
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10. Har du hört talas om falska mediciner? Om ja, kan du beskriva vad det är?
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12. Har du köpt mediciner eller hälsoprodukter någon annanstans än på apotek? Om ja, kan du berätta om detta?
13. Var brukar du få information om hälsa och läkemedel?

Barn:

1. När var sista gången du eller någon i din familj gick till doktorn eller en sjuksköterska? Vill du berätta om det? Blev du eller familjemedlemmen frisk igen?
2. Hur vet du att du behöver söka vård?
3. Vad gör du eller dina familjemedlemmar när du/ni inte mår bra?
4. Pratar ni om frågor som rör hälsa och medicin på skolan eller hemma? Om ja, hur ofta, och vad brukar ni prata om? Om nej, finns det andra ställe du hört talas om detta och var?
5. Har du hört talas om falska mediciner? Om ja, vet du vad det är?



**Samtyckesformulär för vuxna som deltar i doktorandsprojektet ”Förfalskade läkemedel i ett mångkulturellt samhälle. Betydelsen av kunskapsutbyte mellan allmänhet och expertis”**

Jag har informerat om studien via den skriftliga informationen, har fått innehållet förklarad för mig och jag har också getts möjlighet att ställa frågor via e-post eller telefon. Alla frågor har besvarats till min belåtenhet.

Jag godkänner och ger tillstånd till att delta i undersökningen. Jag är medveten om att deltagande är helt frivilligt, att jag kan avstå från att medverka, och att jag när som helst kan avbryta mitt deltagande.

Jag ger tillstånd till att data från studien (transkriptioner av intervjuer, fältanteckningar t ex) får användas i undervisning och forskning efter att jag har avidentifierats.

Fullständigt namn

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Kontaktuppgifter

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Datum

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Underskrift

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**Samtyckesformulär för barn som deltar i doktorandsprojektet "Förfälskade läkemedel i ett mångkulturellt samhälle. Betydelsen av kunskapsutbyte mellan allmänhet och expertis"**

Jag har blivit informerad om studien via den skriftliga informationen, har fått innehållet förklarat för mig och jag har också getts möjlighet att ställa frågor via e-post eller telefon. Alla frågor har besvarats till min belåtenhet.

Jag godkänner och ger tillstånd till att delta i undersökningen. Jag är medveten om att deltagande är helt frivilligt, att jag kan avstå från att medverka, och att jag när som helst kan avbryta mitt deltagande.

Jag ger tillstånd till att data från studien (transkriptioner av intervjuer, fältanteckningar t ex) får användas i undervisning och forskning efter att jag har avidentifierats.

Fullständigt namn

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Kontaktuppgifter

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Datum

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Underskrift

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**Samtyckesformulär för vårdnadshavare till barn som deltar i studien  
”Förfalskade läkemedel i ett mångkulturellt samhälle. Betydelsen av kunskapsutbyte  
mellan allmänhet och expertis”**

**Vårdnadshavarnas samtycke**

Jag har informerat om studien via den skriftliga informationen, har fått innehållet förklarat för mig och jag har också getts möjlighet att ställa frågor via e-post eller telefon. Alla frågor har besvarats till min belåtenhet.

Jag samtycker till att:

- mitt barn (fullständigt namn) \_\_\_\_\_

deltar i studien (intervjuundersökningar , observationer i klassrummet , fokusgruppsamtal ) samt att hens personuppgifter, insamlade data från studien (transkriptioner av intervjuer, fältanteckningar t ex) kommer att behandlas på angivet sätt och att de får användas i undervisning och forskning efter att hen har avidentifierats.

Jag och mitt barn är medvetna om att mitt barns deltagande är helt frivilligt, att hen kan avstå från att medverka och när som helst, kan avbryta deltagandet.

\_\_\_\_\_  
Vårdnadshavares namnförtydligande

\_\_\_\_\_  
Vårdnadshavares namnförtydligande

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Vårdnadshavares underskrift

\_\_\_\_\_  
Vårdnadshavares underskrift

Jag är ensam vårdnadshavare



## Observationsguide

Doktoranden följer i sitt arbete personal på skolor, organisationer och föreningar i samband med att det sker undervisning och diskussioner om hälsorelaterade frågor. Syftet med metoden är att observera bl. a. hur information ges om hälsa och medicin, vilken typ av information som ges och hur barnen reagerar på presenterad information.

Metoden består av följande steg:

Skola:

Observationen sker i skola då personal (skolsköterskan, biologilärare, idrottslärare och fritidslärare) undervisar eller diskuterar hälsorelaterade frågor med barn. Under observationen på skolor:

- Doktoranden följer de ansvariga på skola då de diskuterar eller undervisar hälsorelaterade frågor med barn.
- Doktoranden närvarar i klassrummet och observerar vilka hälsorelaterade ämnen diskuteras i klassrummet, vilken typ av information som ges till barn från olika årskurs (årskurs 4-6), samt hur informationen ges, dvs. vilken metod används av personalen.
- Doktoranden observerar hur barn reagerar på presenterad information, t.ex. Vilka frågor barnen har om den presenterade informationen och hur barnen svarar på frågor som personalen frågar.
- Doktoranden observerar de olika lärometoden och material som används för undervisning och diskussion, hur barnen uppfattar informationen och hur de reagerar till materialet.

Detta för att så småningom ta reda på om någon information om läkemedel ges till barn från respektive åldrar i skolan, och om det finns information om läkemedel, vilken typ av information det är och hur både barn och personalen reagerar på processen.

Organisationer och föreningar:

- Doktoranden närvarar och observerar då barn läser *Annie & Macs äventyr*. Detta för att så småningom ta reda på hur barn diskuterar och uppfattar informationen presenterad i serietidningens.
- Doktoranden observerar hur barnen reagerar på informationen som presenteras i serietidningen och vilka frågor eller idéer de har om den presenterade informationen.

Under och i anslutning till observationerna görs fältanteckningar som ett stöd för doktorandens kommande bearbetning av materialet. Dessa fältanteckningar renskrivs vid dator och utgör sedan data för studien. Korrekta namn på personer eller platser används inte i fältanteckningar.



## Survey by Kantar Sifo between 2022-01-28 and 2022-02-09

### Frågor:

1. Har du sökt på internet efter något skydd mot Covid-19, för egen eller närståendes räkning (t.ex. ansiktsmasker, handsprit)?
  - a. Ja
  - b. Nej
  - c. Tveksam, vet ej
2. Vilka slags skydd sökte du efter? Välj alla alternativ som stämmer.
  - a. Ansiktsskydd/ansiktsmask
  - b. Handsprit
  - c. Handskar
  - d. Medicin/kosttillskott/hälsoprodukt, nämligen:
  - e. Test för att kontrollera om jag har en pågående infektion med covid-19
  - f. Test för att kontrollera om jag har haft en infektion med covid-19
  - g. Vaccin
  - h. Annat, nämligen:
3. Har du handlat något på internet för att skydda dig själv eller någon annan mot Covid-19? Välj alla alternativ som stämmer.
  - a. Ja, ansiktsskydd/ansiktsmask
  - b. Ja, handsprit
  - c. Ja, handskar
  - d. Ja, medicine/kosttillskott/hälsoprodukt, nämligen:
  - e. Ja, test för att kontrollera om jag har en pågående infektion med covid-19
  - f. Ja, test för att kontrollera om jag har haft en infektion med covid-19
  - g. Ja, vaccin
  - h. Annat, nämligen:
  - i. Nej, jag har inte handlat något sådant från internet
  - j. Tveksam, vet ej
4. På vilket språk var sidan/sidorna som du handlade varorna från? Välj alla alternativ som stämmer.
  - a. Svenska



- b. Engelska
  - c. Annat språk; nämligen:
  - d. Vill ej uppge
  - e. Tveksam, vet ej
5. Vid inköpstillfället, kontrollerade du på något vis om det du köpte var äkta/godkänt av myndighet? Välj alla alternativ som stämmer.
- a. Ja, jag kontrollerade att det var CE-märkt
  - b. Ja, jag kontrollerade apotekssymbolen från EU eller Läkemedelsverket
  - c. Ja, genom att:
  - d. Nej, jag gjorde ingen sådan kontroll
  - e. Vill ej uppge
6. Har du, eller någon annan, använt produkten/produkterna som du beställde? Om ja, vilken/vilka produkter? Välj alla alternativ som stämmer.
- a. Ja, ansiktsskydd/ansiktsmask
  - b. Ja, handsprit
  - c. Ja, handskar
  - d. Ja, medicin/kosttillskott/hälsoprodukter, nämligen:
  - e. Ja, test för att kontrollera om jag har en pågående infektion med covid-19
  - f. Ja, test för att kontrollera om jag har haft en infektion med covid-19
  - g. Ja, vaccin
  - h. Ja, annat, nämligen:
  - i. Nej, produkterna har inte använts
  - j. Vill ej uppge
  - k. Tveksam, vet ej
7. Kommentera gärna användningen av produkterna du har skaffat. Fungerade de som tänkt? Något problem? Andra synpunkter?
- a. Tveksam, vet ej
8. Vad har du för huvudsaklig sysselsättning?
- a. Arbetare
  - b. Tjänsteman
  - c. Egenföretagare
  - d. Pensionär
  - e. Studerande
  - f. Arbetslös

- g. Sjukskriven
  - h. Föräldraledig
  - i. Annan
  - j. Tveksam, vet ej
9. Vilken är din högsta avslutade utbildningsnivå?
- a. Grundskola (el. motsvarande)
  - b. 2-årigt gymnasium (el. motsvarande)
  - c. 3-årigt gymnasium (el. motsvarande)
  - d. Högskola/universitet (el. motsvarande) upp till 2 år
  - e. Högskola/universitet (Lägre utbildning-färdig examen)
  - f. Yrkesutbildning. KY eller YH (eftergymnasial)
  - g. Folkhögskola
  - h. Ej slutfört grundskola
  - i. Tveksam, vet ej
  - j. Vill ej uppge
10. Vilken är din personliga månadsinkomst? Med inkomst menar vi inkomst före skatt. Studiemedel, hyresbidrag, pensioner m.m. räknas också som inkomst.
- a. Mindre än 8.000 kr/månad
  - b. 8.000-24.999 kr/månad
  - c. 25.000-34.999 kr/månad
  - d. 35.000-41.999 kr/månad
  - e. 42.000-54.999 kr/månad
  - f. 55.000 kr/månad eller mer
  - g. Vet ej
  - h. Vill ej uppge
11. Var är du född?
- a. Sverige
  - b. Annat land i Europa
  - c. Annat land i världen vill ej uppge
12. Vilket av följande stämmer in på din familj?
- a. Båda mina föräldrar är födda i Sverige
  - b. En av mina föräldrar är född i ett annat land
  - c. Båda mina föräldrar är födda i annat land
  - d. Vill ej uppge



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