The health condition in the Sami population of Sweden, 1961-2002
Causes of death and incidences of cancer and cardiovascular diseases

Sven Hassler

Umeå 2005
Det omöjliga tar bara lite längre tid.

*The impossible just takes a little longer.*

to Nathan!
ABSTRACT

The Sami people are the natives of northern Scandinavia and the Kola Peninsula. The knowledge of the demography, health and living conditions of the Swedish Sami is extremely limited. Over the last decades, only a few studies have been published addressing health and disease in this population. The overall shortage of knowledge on the health situation of the Sami population, not only in Sweden but also in Norway, Finland and Russia, is in contrast to the large amount of detailed information on health, demographic and socio-economic issues that is available for indigenous people in e.g. North America, Greenland and Australia. The encounter with the western society has for many native populations had dramatic health consequences. Early contacts brought infectious diseases such as smallpox and tuberculosis, while western influence during the last five decades have had more profound effects on the lifestyle causing a dramatic increase of lifestyle related western diseases such as cancer, diabetes, stroke, obesity and hypertension. The mental health has also been negatively affected in many native populations due to the western influence with dramatic increase of suicide rates and drug abuse.

The relationship between acculturation and health has been of longstanding interest when studying the health situation among indigenous peoples. In circumpolar peoples the processes of acculturation and adaptation has often been manifested as dramatic, unfavourable changes in health. Although the role and status of the Sami population in Sweden has been described in a historical context, these aspects have not been thoroughly evaluated in relation to health.

The overall objective of this thesis was to investigate the health conditions of the Sami population of Sweden using causes of death and incidences of cancer and cardiovascular diseases as health indicators, and to evaluate their possible association with demographical and acculturative factors such as assimilation, integration, separation and marginalization.

In order to establish a large database for epidemiological studies of the Swedish Sami population, an attempt was made to reconstruct the Sami population by using the available national population registers where the Sami population can be extracted in one way or another. A Sami cohort was constructed departing from a group of index-Sami identified as either reindeer herding Sami or Sami eligible to vote for the Sami parliament. Relatives to index-Sami were identified in the National Kinship Register and added to the cohort. The cohort contained a total of 41 721 persons (7 482 reindeer herding Sami and 34 239 non-herding Sami) and selections from this population were used for the different studies. A four times as large demographically matched non-Sami control population was compiled the same way.

A study of causes of death in the Sami population of Sweden 1961-2000 showed that the differences in overall mortality and life expectancy of the Sami, both reindeer herding Sami and non-herding Sami, compared to the control population were relatively small. However, Sami men showed significantly lower SMR for cancers but higher for external cause of injury. For Sami women, significantly higher SMR was found for diseases of the circulatory system and diseases of the respiratory system. An increased risk of dying from subarachnoid haemorrhage was observed among both Sami men and women. The observed differences might be due to lifestyle, psychosocial and/or genetic factors.

Male reindeer herding Sami showed a significantly increased risk of dying from accidents such as vehicle accidents and poisoning. No increased risk of suicide was observed. A comparison between the periods of 1961-1980 and 1981-2000 showed non-significant differences in risk although a trend towards increased risks were observed for most types of external causes of death, except suicide. It is suggested that the increased socio-economic pressure and the extensive use of terrain vehicles have increased the risk for fatal accidents among Swedish reindeer herders. It is concluded that commercial reindeer management is one of the most dangerous occupations in Sweden.

The cancer risk in the reindeer herding Sami population of Sweden was studied between 1961 and 1997. In comparison to non-Sami living in the same area, the reindeer herding Sami showed a statistically significant lower risk of contracting cancer of the prostate and of malignant
lymphoma, whereas the risk of stomach cancer was significantly higher. Although there were no statistically significant changes of cancer risks over time, temporal trends were indicated toward a decreased risk of cancers in the stomach and prostate. The results suggest that the explanations of the low cancer risk of the reindeer breeding Sami, in relation to the non-Sami in the same environment, are to be found among lifestyle and/or genetic factors.

The biomedical, behavioural and psychosocial risk factors for cardiovascular diseases among Swedish Sami where studied in a controlled cohort study. It was found that the Sami and the non-Sami showed similar risk factor-patterns. The main differences were related to working conditions and lifestyle factors of the reindeer herding Sami. The men had lower blood pressure, were more physically active and had higher job demand and decision latitude while the women showed more negative scores on the indices of the job strain variables.

Incidence ratios of stroke and acute myocardial infarction in the Sami population of Sweden where studied between 1985 and 2002. The results partly confirmed the mortality pattern. Higher incidences of stroke where seen among Sami men and women compared to their non-Sami neighbours while the mortality rates of stroke were similar. Mortality ratios of acute myocardial infarction were increased for Sami women while the incidence ratios were on the same level. Also, a higher risk of subarachnoid haemorrhage was observed among all groups of Sami. No major differences in the levels of income and education were observed between the Sami and the non-Sami population. It is suggested that the differences in incidence rates of stroke between herding and non-herding Sami men and between Sami women and non-Sami women, are to be found among psychosocial risk factors rather than among traditional socioeconomic factors.

As has been shown, only minor differences in health were found when comparing the health situation of the Sami with their non-Sami neighbours. This is in clear contrast to several other native populations for which the health situation is largely unfavourable in comparison to that of the general population.

Two lines of acculturation could be identified when interpreting the Sami policy of Sweden. One of separation or segregation, that has been acted upon the reindeer herding Sami, and one of assimilation of the other Sami. In conclusion, the similarities in health between the Sami and the non-Sami are probably a result of centuries of close interaction that has caused mixed marriages, similarities in culture, attitudes and lifestyle, as well as equal accessibility to the health care services and the social security systems.

**Key words:** Sami, Health, Epidemiology, Reindeer herder, Cardiovascular diseases, Cancer, Causes of death, Acculturation, Sweden
ORIGINAL PAPERS

This thesis is based on the following papers:


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<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tr>
<td>AMI</td>
<td>Acute myocardial infarction</td>
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<tr>
<td>BMI</td>
<td>Body mass index</td>
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<td>CI</td>
<td>Confidence interval</td>
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<td>CVD</td>
<td>Cardiovascular diseases</td>
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<td>HDL</td>
<td>High-density lipoprotein</td>
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<tr>
<td>LDL</td>
<td>Low-density lipoprotein</td>
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<tr>
<td>SAH</td>
<td>Subarachnoid haemorrhage</td>
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<tr>
<td>SIR</td>
<td>Standard incidence ratio</td>
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<td>SMR</td>
<td>Standard mortality ratio</td>
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## Glossary

<table>
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<th>Term</th>
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<tr>
<td>Acculturation</td>
<td>Culture change which results from continuous, first hand contact between two distinct cultural groups.</td>
</tr>
<tr>
<td>Ethnoculture</td>
<td>Used as a common term for concepts dealing with both ethnic and cultural issues such as ethnic/national identity, acculturation, ethnic language, ethnic parentage and ethnic context.</td>
</tr>
<tr>
<td>Culture</td>
<td>The values, norms and material goods characteristic of a given group. In relation to time and change. Culture could also be defined as a process through which man creates his living environment and is able to improve it progressively by retaining and modifying advances made by previous generations, teaching the whole to subsequent generations, borrowing innovations which are capable of perpetuations.</td>
</tr>
<tr>
<td>Follow-up</td>
<td>Observations over a period of time of a specified population.</td>
</tr>
<tr>
<td>Incidence rate</td>
<td>The number of new cases during a given time period in a specified population.</td>
</tr>
<tr>
<td>Person-years</td>
<td>The denominator when calculating the incidence rate. The length of time measured in years at risk.</td>
</tr>
<tr>
<td>Risk factor</td>
<td>Any type of characteristics that causes an increased risk of getting a certain disease. Risk factors could for instance be found in the lifestyle, personal behaviour, genetics, and environment.</td>
</tr>
<tr>
<td>Sápmi</td>
<td>The home of the Sami. Stretches over four countries – Norway, Sweden, Finland and Russia.</td>
</tr>
<tr>
<td>Sociocultural</td>
<td>A concept which aims at explaining the behaviour of an individual or a group in cultural terms.</td>
</tr>
<tr>
<td>Socioeconomy</td>
<td>A combination of social and economical conditions such as income, education and profession.</td>
</tr>
<tr>
<td>Standard mortality ratio</td>
<td>The ratio of the observed number of deaths to the expected number of deaths.</td>
</tr>
<tr>
<td>Standard incidence ratio</td>
<td>The ratio of observed number of incident cases to the expected number of incident cases.</td>
</tr>
<tr>
<td>Validity</td>
<td>The extent to which a study measures what it is intended to measure.</td>
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INTRODUCTION

Health in relation to acculturation

The concept of acculturation offers a framework for studying the health of the Sami population of Sweden (Berry 1990). Defined as culture change which results from continuous, first hand contact between two distinct cultural groups (Berry 1990), acculturation brings about psychological changes that in many circumpolar regions have been manifested in a variety of psychological and physical health problems. New diseases, changes of diet, accidents due to new technology and new substances such as alcohol, tobacco and drugs are all examples of possible health consequences related to acculturation (Berry 1985). On a psychosocial level changes in attitudes, culture and identity may also cause stress-related risk factors when original political, linguistic, religious and social institutions become altered or new ones take their place. A concept that has been employed to refer to these negative consequences of acculturation on the health condition is acculturative stress.

Berry introduces four modes of acculturation. These four modes are based on the attitude toward the ethnic group and toward the larger society and are considered to be an acculturation option, and as such constitute both a strategy and an outcome for individuals or for groups (Figure 1).

Figure 1. Four modes of acculturation (modified after Berry 1985).

The health status may be expected to vary across these four modes both as a function of the mode itself and as a function of the congruence of the mode preferred and the mode desired by the larger society (Berry 1990). Assimilation means giving up the cultural identity and moving into the larger society. Integration implies some maintenance of the cultural integrity of the group but also a movement to become an integral part of the dominant society. Separation refers to a withdrawal from the larger society while maintaining some of the traditional life, and finally marginalization means a lack of contact with both the traditional culture and the larger society. Integration, assimilation and separation all represent various forms of adaptation, while...
marginalization tends to represent alienation and is the mode where the poorest health might be expected. Separation maintains some conflict with the majority society suggesting that relatively poor health might be found in this mode as well. Assimilation represents cultural loss why health may be expected to be more negatively affected in this mode than in the integration mode, which is likely to constitute the most supportive sociocultural base for health.

In this study the concept of acculturation will be employed to partly describe and analyse the health effects of the long period of cultural contact and change that the Sami population of Sweden has experienced with the Swedish society. Rather than to empirically study the relationship between acculturation and health, which has been done by others (e.g. Koch et al. 2004; Kvernmo & Heyerdahl 2003), interpreting the health situation of the Sami in a context of acculturation in this study is more a choice of perspective. To interpret different aspects of the Sami health situation in acculturative modes is an attempt to understand the health situation in a context familiar to most other native populations in the circumpolar region. In this thesis, applying the concept of acculturation is therefore a matter of identifying ‘the wood rather than the individual trees’.

Applying the concept of acculturation as a meta perspective for understanding the health situation of the Sami population, is partly about using a new vocabulary to identify risk factors and health issues that seldom have been studied other than included in the dominant culture. As health status linked to acculturation experiences in a culturally plural society is expected to be better than in a culturally monistic one, which often pursue a assimilationist ideology, the outcome of the acculturative process is obviously dependent on the ideology of the dominant culture (Berry 1990).

In the studies of the Sami health included in this thesis, culture in relation to health and health risks is mostly used as a collective term or as a concept representing aspects of lifestyle, attitudes or traditional behaviour or a combination of all three. Culture is often defined as the values, norms and material goods characteristic of a given group (Giddens 1993). Adding ethno- or socio- as prefixes may say something about how that group is defined but most probably without making the concept more clear or specific. Depending on the context, the group of Sami could be referred to in ethnical-, professional-, social- or even in geographical terms why a functional definition of culture need to be broad an inclusive. Culture in relation to acculturation would also suggest a more evolutionary concept depending of course on what modes of acculturation (integration, assimilation, separation and marginalization), that is referred to. A functional definition for such conditions might be a concept defined as a process through which man creates his living environment and is able to improve it progressively by retaining and modifying advances made by previous generations, teaching the whole to subsequent generations, borrowing innovations which are capable of perpetuations (Uppman 1978).
Swedish Sami policy – a brief historical description

The Sami are the natives of Scandinavia. As early as relevant historical documents can take us there are evidence for that. Since the first taxation lists from the mid 16th century the Sami was recognised as the minority people of Sweden (Sköld 1998). When the Swedish state began to grow and a society took form, the Sami were still in the periphery of that society. In Sápmi (the land of the Sami) they were practically alone up until the 17th century when the first wave of settlers came.

Figure 2. Sápmi, home of the Sami, stretches over four countries - Norway, Sweden, Finland and Russia.

At this time the interest of the king and his authority was largely focused on collecting tax. In order to claim the right to land and resources in the northern part of Sweden, the government have all up until recent times referred to the letter of king Gustav Vasa from the year of 1542 where he stated that all unsettled land belong to the Swedish crown and no one else ('att sådana ägor, som obyggde ligga, höra Gud, oss och Sveriges krona till och ingen annan'). Gustav Vasas son King Carl IX worked hard to outstretch his power northwards in the early 17th century and titled himself ‘the king of the Lapps in the northern land’ ('Lapparnas i Nordanlandens konung', see Sjölin 2004).

As soon as the number of settlers started to grow and the need for more land and resources increased, the Sami become an obstacle for the expansion. According to the assimilationist idea of that time the Sami were expected to be absorbed by the expanding civilisation (Sjölin 1996).
During the 17th and 18th century the Sami were referred to as the tax-Sami (‘skattelappar’) and they were obliged to pay tax for their use of land (‘lappskatteland’) and mountains (‘lappskattefjäll’). But integrating (or assimilating) the Sami into the Swedish society was also manifested through Christian missionary efforts. The christening of the Sami started as early as medieval times, but it was in the 16th and 17th century that a more extensive missionary movement resulted in that the majority of the Sami abandoned the old shamanistic religion in favour of the Christian beliefs (Ruong 1982).

According to estimates based on the register for land use (‘Jordeboken’), 13 048 settlers and 2 500 Sami lived in the northernmost part of Sweden (corresponding to the current counties of Västerbotten och Norrbotten) in the mid 16th century (Sjölin 2004). The settlers lived for the most part by the coast and the Sami in the inland. But it was not until the 18th century that the settlers came in numbers and by the 19th century the Sami were outnumbered in many of the municipalities in Sápmi. By the turn of the 19th century 5 113 Sami were recorded to live in the Sápmi together with 6 049 settlers. At that time the Sami constituted 7 % of the total population of Västerbotten (Sjölin 2004). The interest of the Sami and the settlers often interfered and conflicts over land, fishing- and hunting rights emerged. But conflicts also appeared over issues as language, religion and other cultural matters (Sköld 1998). In order to further regulate the land-use, a border of cultivation (‘odlingsgräns’) was introduced in the late 19th century. Noth-west of the border the reindeers were allowed all year but south-east of the border, only from October to April (Ruong 1982).

Since the early 19th century, or since the start of the so called ‘Sami should be Sami’ policy, a regional Sami service (‘lappväsende’) was established in the northern part of Sweden which was lead by a governor (‘lappfogde’). These governors was originally installed temporarily to solve the conflicts arising in the mountain region between the Sami and new settlers. However, it soon became apparent that their foremost task was to supervise the Sami and to control and regulate the reindeer husbandry. This new control policy was further emphasised by the appointment of a Sami superintendent (‘lapptillsyningsman’) who supervised and controlled the reindeer herders in the field. The Sami service system (‘lappväsendet’) also had executive functions on Sami issues such as organising Sami eldercare and taxation of the reindeer herders. It implemented the governmental Sami policies but also proposed new laws and regulations (Lantto 2000). This organisation remained until 1971 when the functions of the regional Sami service was modified and integrated into the Department of Agriculture, where most the Sami-related issues still are decided (e.g. culture, health, language, along with reindeer herding matters).

The Sami should be Sami policy – segregation and assimilation

During the latter part of the 19th century the Sami were still considered a nomadic people who made their living from reindeer herding, and accordingly unsuitable to make their livelihood in
other areas requiring domiciled living such as farming. By this time reindeer herding was the most obvious cultural marker for Sami ethnicity, at least from a governmental point of view. As expressed in a parliamentary session in 1907: “The reindeer is made for the Sami and the Sami for the reindeer” (Lantto 2000). The connection between the two was considered to be so strong that the herding was necessary for the survival of the Sami (Lantto 2000). The view that the Sami were to be kept as reindeer herders and as nomads became the official opinion for quite some time (‘Lapp bör vara Lapp politiken’). This resulted in a policy of segregation. Sami experts expressed anxiety over too much contacts between the nomadic lifestyle of the Sami and the superior Swedish culture that would influence the reindeer herders in such a way that they would loose their ability to maintain the harsh lifestyle as reindeer herders. Too much intercultural mixture was seen as a threat against the distinct Sami culture. These segregation ideas were also expressed in the school policies and the introduction of nomadic schools with curricula suited for the nomadic lifestyle (Lundmark 2002). Even if the paternalistic ‘Sami should be Sami’ policy carried Darwinist or even racist ideas, the Sami policy of the Swedish state never suggested that the Sami should be left without support, but rather argued to keep the traditional nomadic lifestyle as a mean of survival (Lundmark 2002).

The Sami policy of the Swedish government was clearly dualistic. It strived for segregation and assimilation at the same time. The definition sanctioned by the Swedish government stated that the Sami were only those who were reindeer herders, while the non-herding Sami accordingly was not. Generally the non-herding Sami were looked upon as a troublesome middle category between the Sami and the Swedes that for the best of all should be assimilated into the Swedish society (Lantto 2004). The most important instrument for implementing this Sami policy were the laws regulating the right to breed reindeers. The laws of 1886 and 1898 were the first to specify the conditions on how the breeding was to be exercised and by whom. It was also the first step towards giving the reindeer herding the central position of the Sami policy while other aspects of the Sami culture were marginalised. This early reindeer laws indicated clearly that the only Sami to have part of the Sami rights were the reindeer herders. In the regulating laws of 1928 this was stressed even more, excluding other Sami than the reindeer herders from the Sami context and neglecting political demands outside the reindeer herding sphere. To avoid that policies were claimed to be based on racist arguments, the industry rather than the race now come to lead the way. As it earlier was a necessary condition to be a Sami in order to herd reindeers, it now became necessary to be a reindeer herder in order to be a Sami (Lundmark 2002).

Post war era – moving from monoculture towards a pluralistic society

In the introduction of the census of the early 20th century it was stated that ‘Sweden is a monocultural nation’. It was followed by a few sentences mentioning the Sami, the Finns and the Jews (Sjölín 2004). But by 1940 these sentences were gone. Following the second world war and
the nazi period, ethnic- or folk groups were not mentioned. Along with the ideas of the Peoples Home (‘Folkhemmet’) the Sami policy was more or less caught up in the big strive for modernity and economic progress. The reindeer herding was supposed to be an industry like all others - efficient and profitable. The cultural motives for the reindeer herding policy were now replaced by business considerations. But while the reindeer herders were expected to function in a modern cash economy with strong internal and external pressure to make their companies profitable, they were also implicitly given the responsibility to shoulder the Sami cultural heritage. A not altogether advantageous position. And when the reindeer herding Sami was confronted with forces of modernisation, the non-herding Sami were like the rest of the rural population in northern Sweden, expected to move to the towns and the cities to work in the fast growing industries (Sjölin 2004).

A new perspective on ethnic minorities came with immigration, and a more active Sami movement helped to put the Sami issues back on the agenda. From successfully having avoided making politics out of the Sami issue, the Swedish government now had to face more intricate questions of their responsibility towards our oldest ethnic minority (Sjölin 2004).

During the 20th century the political rights of the Sami has been somewhat strengthened. A new law regulating reindeer breeding have replaced the old Sami service system with an organisation of economically independent Sami villages (‘Samebyar’). The Sami has also been granted some political influence through the Sami parliament (‘Sametinget’) that was established in 1993. The Sami parliament act both as a political body and an administrative organisation that are supposed to look after the interest of the Sami in a number of different matters, such as protecting the Sami language and the usage of land and water for the reindeer herding.

In recent years a new Sami nationalism has germinated. The interest in old traditions, the Sami language and the heritage has increased, not least among many young Sami. The Sami also have to come to identify themselves more with other native populations that have experienced colonialism (Uddenberg 2000).

Although many Sami were against a Swedish membership of the EU (Uddenberg 2000), some positive consequences has no doubt followed with the membership. The EU has recognized the Sami as the natives of Scandinavia and funds for preserving the traditional Sami culture has been allocated. Being part of several nations, the supranational perspective in organisations like EU has also helped the Sami in finding new ways to reach recognition and attention (Uddenberg 2000).

In the dawning 21st century, Sweden still seems drowsy, newly woken up to the understanding of having an ethnic minority, a native population that can be compared to Indians, Inuits and other indigenous people. The rights of ethnic minorities are an issue in which Sweden fiercely have criticised other countries for neglecting in forums like the UN (Sjölin 2004). With the ILO convention 169, ratified by UN in 1991 and the granting of certain social and economical rights.
for the native populations, Sweden’s ambivalent posture is again obvious. Sweden has not yet ratified this UN convention.

**Sami or Lapp**

Nowadays Sami is the most used name for the natives of northern Scandinavia. It is a word from the Sami language while Lapp is a Finnish word that has come to be thought of as derogatory. In older studies and in official documents up until around 1980 Lapp is most often used. In this thesis Sami is used except in one of the studies where the older spelling, Saami, was used (Paper III).

**Sami language**

The Sami language belongs to the Finno-Ugric branch of the Uralic language family. The closest linguistic neighbours of the Sami are the Finns, the Karelians and the Estonians (Tambets et al 2004). There are three language groups and several dialects in the Sami language. In Sweden the main dialects are the Northern Sami dialect (‘Nordsamiska’), the Lule Sami dialect (‘Lulesamiska’) and the Southern Sami dialect (‘Sydsamiska’) (Uppman 1978). Pite Sami language and Ume Sami language have very few speakers left and is close to extinction. It has been estimated that close to half of the total Sami population speak at least one of the languages (http://www.sametinget.se/sametinget/view.cfm?oid=1150).

**The health conditions of the Sami in a public health perspective**

As far as the Swedish health care system and public health policies concerns, the Sami seems to be nothing less but fully assimilated. The welfare state of Sweden is often recognised as a model where the state, business and trade unions collaborate in harmony for the best of the nation. Sweden is described as a nation characterized by ethnical and religious homogeneity where the people is the asset of the nation and the feeling of affinity strong (Johannisson 1994). It is in the same spirit the health care system of Sweden developed. Egalitarian ideas had a strong impact on how the health care system and public health policies were shaped. The health care should be equal irrespective of socioeconomic status or place of living. Public health policies served political purposes such as supplying the nation with productive and reproductive labourers, overcoming class distinctions and cultivating the people (Johannisson 1994). Having a public health policy based on egalitarianism with motives such as working to limit the differences of class, gender, income and influence, left little space for differentiation for needs of ethnical minorities. The ‘equal health care for all’-policy left the Sami to be looked upon as any other Swedish citizen.
During the latter part of the 20th century, Sweden has experienced a new ethno-cultural situation with immigration from many different countries, cultures and ethnic groups. While the health situation of the immigrant groups is being increasingly recognized in policy documents and in public health reports, the Sami are still not mentioned. Why then has it been so hard for Sweden to acknowledge the health and living conditions of our native population? It is beyond the scope of this dissertation to fully answer this question but the answer might partly be found in the best of intentions of not stigmatising certain groups due to ethnicity in the aftermath of the second world war’s racial misdeeds.

In a recent public health report for Sweden, published by the National Board of Health and Welfare (‘Socialstyrelsen’), it is stated that the public health constitutes the sum of the health of all individuals, but as the population is made up of different social groups with different socioeconomic and cultural properties, the public health is also about how the health is distributed between different groups (Folkhälsorapport 2001). With Sweden’s high ambitions in the field of public health, as expressed in a plethora of policy documents, it is somewhat peculiar that the interpretation of these general phrases does not lead to the recognition of the health of the Sami. Although it is stated that the National Board of Health and Welfare should make visible different aspects of the health such as the distribution of health and welfare between groups (SOSFS 2000:3), the Sami are in fact not mentioned separately in any of the policy documents or reports from the National Board of Health and Welfare or from the Institute of Public Health (‘Folkälsoinstitutet’).

For example, a national policy document presenting the aims for the future public health work in Sweden was presented in 2000. It was titled “Health on equal terms” and discussed how Sweden should overcome the differences in health that still exists within the country (SOU 2000:91). Under the heading “Ethnical differences in health” the health situation of different immigrant groups are discussed, while nothing is said about the Sami.

In the report “A finger on the pulse” from the National Board of Health and Welfare the public health of the nation is again discussed without separately acknowledging the Sami (SOSFS 2003:11), although the list of references of the report includes several native people oriented titles such as “Long term illness among indigenous and foreign born people in Sweden” (Hjern et al 2001), and “Is there equity in access to health services for ethnic minorities in Sweden?” (Sundquist & Johansson 1997).

The governmental Delegation of the Indigenous People (‘Urbefolkningsdelegationen’) has since 1995 worked with issues regarding the rights and the status of the Sami population of Sweden. Just recently their final report was presented where it is recommended that Sweden as soon as possible facilitate a ratification of the UN convention ILO 169. The Sami health situation or other public health issues is not covered by the recommendations, other than in very indirect
terms of protection and support of the rights of indigenous peoples (Urbefolkningsdelegationen 2005).

Just recently the Public Health report of Sweden for 2005 was presented, again without any separate writing concerning the native population of Sweden. Although the distribution of health in the population is discussed under labels such as regional differences or foreign descent, the health conditions of the Sami are only indirectly referred to in writings such as, "behind the regional differences, differences in culture and traditions could also be found influencing for instance the diet" (Folkhälsorapport 2005).

It is obvious that the Sami is not on the agenda for neither the Swedish health planners and policy makers nor for the medical- and public health research departments. And if the Sami are considered, they are treated as nothing else but fully assimilated Swedes.

**How large is the Swedish Sami population?**

Estimates of the size of the Sami population of Sweden have been done based on different sources and definitions of the Sami identity. Through the database (see “Construction of a database” under Method) from which the study cohorts of the present studies are extracted, a possibility is given to reconstruct the Sami population of Sweden (Hassler et al. 2004a).

As with the database, the definitions of reconstructed Sami populations are described by the method by which they are generated. In the example shown in Figure 3 the definition is built on strict kinship relations with index Sami, who then served as the departure from which their relatives were identified.
In order to reduce the risk for inclusion of non-Sami in the population, index persons were excluded if they were members of the register of the reindeer herding companies but not in the register of persons owning reindeer marks (‘Renmärkesregistret’). This ‘filtering’ of the index registers was supposed to exclude most of the reindeer herders of non-Sami origin who were employed by the breeding companies on a seasonal basis.

The extension of the population was achieved by identifying all relatives (i.e. forefathers and forefather’s siblings, siblings and children) and spouses to the index Sami. Of the 10 730 persons detected as forefathers, 43 % were already part of the index registers. Thus, 6 091 forefathers were added to the population (Figure 3). Furthermore, a total of 7 678 siblings of the index persons and the forefathers were added to the population, and an additional 19 661 persons were added as descendants of the index persons, their forefathers and of the index persons and their forefathers siblings. Finally, the spouses of the selected individuals were added. Altogether this method of reconstructing the Sami population results in a selection of 50 493 individuals who were alive after 1941 (Figure 3). For a given year the size of the Sami population is smaller of course. For instance, in 1998 approximately 44 000 individuals of the reconstructed Sami
population were alive (Hassler et al. 2004a). This is more than twice as many as the official estimate of the Swedish Sami population.

Comparison with earlier estimates

In the early 1970\textsuperscript{th}, Henning Johansson made an attempt to reconstruct the Sami population of Sweden (SOU 1975:100). He used the official registers of the Swedish reindeers, for the period 1965-1971, to extract the reindeer herders. Then the parish registers were used to find and include the family members of the reindeer herders as well as of their birth families. By adding information on deaths, births and other family changes, the reconstruction resulted in an estimated Sami population of about 17 000 persons. This is the origin of the size of the Swedish Sami population still officially used by the government and various authorities.

The database (see “Construction of a database” in Material and Methods) described by Hassler et al. (2004a), admits reconstruction of a similar Sami population as the one constructed in the early 1970\textsuperscript{th}. In Johansson’s study the 2 749 reindeer herders found in the historical parish registers was the starting point for the reconstruction. The corresponding cohort constructed from our database by identifying the reindeer herders, together with their family members, from the censuses of 1960 and 1970 contained 2 744 individuals (Hassler et al. 2004a). The gender distribution of the two cohorts was almost identical, \textit{i.e.} 56 % males and 44 % females in the Johansson cohort, and 57 % males and 43 % females in the database cohort. However, when the cohorts were expanded to also include non-herding family members, Johansson’s and the database cohort differs slightly. By tracing family members and relatives in the parish registers, Johansson reaches a total number of non-herding Sami of about 13 000 individuals. The equivalent extension done through the database resulted in a total population of about 4 700 non-herding Sami. The discrepancy is largely an effect of the limited power of the extension procedure applied to our database, which lacks historical records of relatives who died before 1941, and was based solely on kinship data from the censuses of 1960 and 1975. However, when Sami from more recent sources are included among the index persons, the population adds up to a total of 13 300 individuals, a figure close to that reported Johansson in 1975. Since the index persons of the present database and those used by Johansson were identified from different sources, this comparison constitutes a valuable indication on the validity of the database.

Although the database used in the present thesis has been constructed primarily for epidemiological studies, its content may also be used in the discussion of how large the Swedish Sami population actually is (Hassler et al. 2004a). The size of the population is dependent on the Sami definition, and accordingly, the sources being used to extract the index Sami. By using a generous definition of the Sami identity, including relatives of both reindeer herding and non-herding Sami, the Swedish Sami population could consists of as many as 40 000 to 50 000
individuals. If the definition is restricted only to reindeer herding Sami and their relatives, the population will contain approximately 16 000 individuals.

Health and diseases among Sami

During the last decades the health situation of the native populations has come under an increasing attention as it has become clear that their encounter with the western society in many cases have resulted in an dramatic increase of lifestyle related diseases such as cardiovascular diseases (CVD), diabetes and lung cancer. Drastically altered sociocultural conditions have also caused severe mental problems among many native populations with increased risk for suicide and drug related accidents. Many countries have allocated resources to increase the knowledge of the health situation of their Natives and to improve their health situation and quality of life. For most native populations in USA, Canada and Greenland, socioeconomic conditions and the prevalence of major diseases are quite well recognized (Bjerregaard et al. 2004b; Bjerregaard & Young 1998; Young 1994; Indian Health Service 1995; Blum et al. 1992; Højgaard Nielsen et al. 1996). Although the Sami are the Natives in countries which early developed extensive health care systems, the knowledge of their health and living conditions is still very poor. Except for the establishment of the Center for Sami Health Research (‘Senter for Samisk Helseforskning, University of Tromsø’) in Norway, there is a lack of national initiatives with the purpose of studying and monitoring the health situation of the Sami. In the absence of long-term strategic initiatives the available knowledge is anecdotal, which makes the overall picture defective and hard to capture. The poor interest in research on the health condition of the Sami is also in contrast to the great amount of scientific articles that since long have been published on health issues regarding the native populations of USA, Canada and Greenland (e.g. Bjerregaard et al. 2004b; Mahoney & Michalek 1998). According to a recently published compilation of health related research in the circumpolar area during the last 35 years, it is evident that the studies from the Nordic countries have been focused on the biology and epidemiology of diseases in the general population (i.e. the mix of indigenous and non-indigenous people). The proportion of articles on circumpolar health in Canada that were related to the health of indigenous peoples was 89 %. The equivalent figure for papers from Sweden, Norway and Finland was 20 % (Bjerregaard & Young 2004a).

Genetics

The genetical landscape of Europe is characterized by relatively short distances between individual populations (Tambets et al. 2004). Through genetical markers some populations that clearly deviate from the rest of Europe has been identified. Those are the Sardinians, Greeks, Basques, Finns and particularly the Sami (Cavalli-Sforza & Piazza 1993; Tambets et al. 2004; Beckman et
al. 2001; Fan et al. 1993). Even if the genetical composition of the Sami regarding certain markers resembles some Asiatic-Mongoloid populations, the Sami is believed to have their genetical roots in a small, distinctive European subpopulation.

Originating from a small group of individuals where marriage to non-Sami were uncommon (Sköld 1998), the genetical variations within the Sami population are relatively small (Kaessmann et al. 2002; Kauppi et al. 2003; Johansson et al. 2005). One implication of the homogenous genetical composition of the Sami is that they are exceptionally well suited for studies of interactions between heritage and lifestyle in the development of multifactorial diseases such as cancer, diabetes and CVD (Johansson et al. 2005).

Despite that the relatively distinctive genetical character of the Sami could indicate a deviant riskfactor pattern per se, most genetical studies have focused on genetical markers of small or unknown health impact. Knowledge of the genetical character of the Sami has bolstered possible genetical explanations behind the differences between Sami and non-Sami in the prevalence of diseases such as cancer, CVD and certain rheumatological diseases (Tverdal 1997; Paper III, Paper IV; Grundt et al. 1976; Johnsen et al. 1992). For instance, it has been suggested that the high prevalence of Sami with lowered lactose tolerance could be explained by a genetical predisposition (Kozlov & Lisitsyn 1997, Sahi & Tamm 1994).

The knowledge of genetical risk factors for various diseases among the Sami is still rare. One exception is the so called Leiden mutation which presumably increases the risk of thrombosis, which is found more commonly among Sami than among non-Sami (Kuismanen et al. 1999). A gene, connected with the development of certain cancers, have been observed to be less frequent among the Sami (Fan & Sikström 1994), a condition that could contribute to the explanation of the low cancer risk among the Sami (Wiklund et al. 1990; Paper III; Soininen et al. 2002; Haldorsen & Tynes 2005).

**Diet**

The diet as a health determinant among Sami has been investigated, often with a focus on the content and the nutrients of the traditional diet (e.g. Håglin 1991; Nilsen et al. 1999). Over the last decades the diet has been under strong influence of the food habits of the western society. The meat and fish consumption have decreased while the intake of fruit and vegetables, but also sugar, have increased. This transformation has, for instance among Swedish reindeer herders, resulted in a diet with less protein, zinc, phosphate, vitamin B12 and selenium and more of carbohydrates than before (Håglin 1999). A Norwegian study have shown that the diet among the Sami is characterized by a similar trend regarding the intake of fruit, vegetables and sugar, but it was also shown that the Sami still consumed a relatively large amount of meat, fat and coffee (Nilsen et al. 1999; see also Paper IV). As reindeer meat contains large quantities of selenium but
very little beta-carotene and vitamin C, factors that together could reduce the cancer risk (Leo & Lieber 1999; Ringstad et al. 1991; Luoma et al. 1992), a high intake of reindeer meat could contribute to the low cancer risk among the Sami (Wiklund et al. 1990; Paper III; Soininen et al. 2002; Haldorsen & Tynes 2005). It has also been discussed whether high consumption of wild fish and meat, rich in omega-3 fat, could contribute to the reduced cancer risk (Haldorsen & Tynes 2005).

Smoking and alcohol

In a study of CVD in northern Norway in the 1970\textsuperscript{th}, it was observed that the number of daily smokers were lower among the Sami than among the Norwegians in the same region (National Mass Radiography Services 1979). However, subsequent studies based on self-reported information have not shown any difference in smoking habits between the Sami and the non-Sami (Reijula et al. 1990; Spein et al. 2002, 2004; Paper IV).

Regarding alcohol consumption small or no differences were observed between the Sami and the non-Sami, even though reindeer herders in Finland of Sami origin were reported to drink more than their Finnish colleagues in the late 1980\textsuperscript{th} (Poikolainen et al. 1992; Paper IV). In a Norwegian study it was also indicated that the Sami might have different drinking habits with a more periodic intake of alcohol compared to Norwegians (Larsen & Nergard 1990). On the other hand, young Sami of today appear to show less risk taking behaviour, as far as substances and drugs are concerned, in comparison with other young people in northern Norway (Kvernmo 2004). It should be pointed out, however, that the studies on smoking and drinking habits among the Sami are based on small study groups with self reported information. Except for the youth studies in Norway and Paper IV in the present thesis, there are no recent studies on smoking and drinking behaviour among the Sami. It is therefore difficult to draw any safe conclusions regarding the smoking and drinking habits of the Sami.

Physical activity

Although the reindeer herding industry has been motorized during the last decades it is still a physically demanding occupation. In the past most of the herding activities were done on foot or on skies while today, they are carried out on motorbikes, snowmobiles, cars, helicopters and airplanes. Therefore it is reasonable to suspect that the physical demands have changed during the last decades, possibly affecting the health condition of reindeer herders negatively.
Figure 4. Reindeer herding husbandry is a hazardous occupation and most accidents occurs during slaughtering, separation and during gathering for separation (Paper II; Pekkarinen et al. 1992).

Self-reported data from non-herding Norwegian Sami show that both men and women are more physically active during work, and report a higher level of overall physical activity, than the non-Sami in the same region (Hermansen et al. 2002). However, Sami women were found to be less active during leisure time than their non-Sami neighbours. According to self-reported data presented in this thesis there seems to be no major differences in the level of physical activity between Sami and non-Sami (Paper IV).

Accidents and injuries

Among reindeer herders in Finland it has been reported that accidents are most common in the late autumn during slaughtering, gathering for separation and during separation work (Pekkarinen et al. 1992). The everyday use of motor vehicles in the reindeer herding industry has caused intensified exposure to static work in seated positions often in combination with head rotation and extensive exposure to vibrations and heavy lifts (Rehn et al. 2002; Daerga et al. 2004). These working conditions have caused a high prevalence of musculoskeletal symptoms and hearing loss among reindeer herders in Finland and Sweden (Anttonen et al. 1994; Rehn et al. 2002; Daerga et al. 2004). Due to the motorisation, the location of the musculoskeletal pain complaints have changed from being most prevalent in the back, hips and knees, to being most pronounced in the back, neck, shoulders, elbows (cf. Anttonen 1994; Hemborg et al. 1987; Rehn et al. 2002; Daerga et al. 2004).
Mental health and psychosocial health factors

Contrary to the poor mental health reported in many native populations in the circumpolar regions of USA and Canada, only small differences in mental health and psychological problems has been reported among adolescents of different ethnicity in Northern Norway (Heyerdahl et al. 2004; Kvernmo & Heyerdahl 1996, 1998). The mental health of Sami children and adolescents seems to be similar to that of non-Sami children. Yet, the Sami seem to be less inclined to take risks regarding drug use and they have been reported to have less eating disorders and a stronger body satisfaction (Kvernmo 2004). The Norwegian studies also indicate that there is a gender difference regarding how marginalisation and integration affects the mental health. Sami men seem to be more affected by ethnocultural factors than the Sami women (Kvernmo & Heyerdahl 2003).

Studies on Skolt Sami show similar indications. That is, that the changes in economy, ecology and acculturation during the last decades have affected the family- and professional roles of the Sami community differently. It seems as if the changes were less confounding for the Skolt women than for the men whose role underwent a radical shift. These processes have also led to increased responsibilities, power and influence of the Skolt Sami women within the family (Seitamo 1995). In the present thesis it is indicated that the women’s responsibility for the family economy has gradually increased over the last decades, particularly in the reindeer herding families (Paper V).

Causes of death

Several studies on specific causes of death have been conducted on the Sami populations of Norway, Sweden and Finland. Differences in aims and quality of the cause of death data make them difficult to compare. In the Finnish studies the Sami was one population among others in a general health survey of northern Finland. In another paper from that survey it was reported that lethal accidents and suicide were more common among the Sami while the prevalence of acute myocardial infarction (AMI) was lower, in spite of an unfavourable riskfactor pattern (Näyhä 1997, Näyhä & Järvelin 1998). In Norway similar observations on CVD have been made (Tverdal 1997). Studies in Sweden have shown lower cancer mortality among the Sami and higher mortality of external causes of death among reindeer herding Sami (Wiklund et al. 1991, Paper I), and that Sami women show higher risks for CVD (Paper I).

Cancer

The fact that the knowledge of cancer among the Sami is relatively good is probably related to the tests of nuclear weapon on the Kola peninsula during the 1950-60th and the Chernobyl accident in 1986, i.e. that the greater part of Sápmi was heavily contaminated by nuclear fallout products.

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The studies show great concordance regarding the relative risk ratio of cancer. Apart from an increased risk for stomach cancer, the cancer risk among the Sami is lower than in the general population, as well as in the non-Sami population of the same region (Wiklund et al. 1990; Paper III; Soininen et al. 2002; Haldorsen & Tynes 2005).

**Cardiovascular diseases**

In Norway and Finland a lower risk for CVD among Sami has been observed (Njølstad et al. 1998; Tverdal 1997; Utsi & Bønaa 1998; Thelle & Forde 1979; Luoma et al. 1995; Näyhä et al. 1994). But while the relative risk is lower among Sami men, Sami women show similar risk levels as the surrounding population. This gender difference has also been found among Swedish Sami (Paper I) indicating that the relative risk to suffer from CVD is higher among Sami women than Sami men (Tverdal 1997; Utsi & Bønaa 1998; Thelle & Forde 1979). Despite these studies, the knowledge of CVD among the Sami is still incomplete. A somewhat striking circumstance since CVD is the most common cause of death among Sami as well as among other Europeans.

**Asthma and allergy**

In Northern Norway, the incidence of asthma and allergies seems to be high among Sami schoolchildren (Kavli et al. 1985; Falk & Vandbakk 1993; Selnes et al. 1999). The prevalences of immediate and contact allergies and skin diseases among reindeer herders have been observed to be roughly the same as that of other Finns (Larmi et al. 1988). Except for these reports, there is a lack of epidemiological studies on the prevalence and incidence of asthma and allergies in the Sami population, and there are no studies of these diseases on Swedish Sami.

**Infectious diseases**

Compared to other native populations, the prevalence of infectious diseases appears to be low among the Sami. In several native populations of North America infectious diseases like tuberculosis is still a serious source of unhealth and has therefore been monitored and studied for a long time (Nguyen et al. 2003, Hoeppner & Marciniuk 2000). Even though the knowledge is quite incomplete, the Sami does not seem to suffer from infectious diseases more than Swedes in general. The most important reason for this is probably that the Sami left this group of diseases behind some 40 –50 years ago, together with the rest of the Scandinavians.
**Suicide**

Along with an increasing influence of the western society, many native populations in the arctic have experienced a deteriorating mental health (Sampath 1974; Bjerregaard 2001). A dramatically increased risk for suicide has been reported from several native populations around the world (Mao et al. 1992; Mahoney et al. 1989; Bjerregaard et al. 1988). In Sweden there are substantial geographic variations in the risk for suicide, and the incidence is particularly high among young men in sparsely populated areas (Jacobsson & Renberg 1986; Lindqvist & Johansson 2000), a group to whom many of the reindeer herding men belong.

**Health care system**

The access to health care for minorities like the Sami is discussed in a Norwegian study that indicate that Sami women, for instance, use the available drug and alcohol treatment facilities in northern Norway to a lower extent compared with others (Larsen 1992). In an effort to reduce the high suicide rates in the Karsjok region of northern Norway, a youth office was opened in the early 1990s where children and adolescents could meet and get professional help and therapy (Kvernmo 1995). When the project was evaluated it was noticed that the youth office was utilized mostly by the girls. However, whether the youth office actually reduced the number of suicides in the region could not be confirmed in the study.

Preventive measures to reduce work-related musculoskeletal pain among reindeer herding Sami have been evaluated in a Swedish study (Daerga et al. 2004). The results show that it is possible to reduce the number as well as the severity of the musculoskeletal pain through physiotherapeutic treatment, individual training, information and technical improvements of the vehicles. Also, a Finnish study that evaluated written guidelines aimed at preventing accidents and injuries in the reindeer herding industry indicated positive results (Pekkarinen et al. 1992). Two years after the introduction of the guidelines, the number of work related accidents was reduced from 21 to 12 per 1000 work days.
STUDY OBJECTIVES

The overall objective

The overall objective of this thesis was to investigate the health conditions of the Sami population of Sweden using causes of death and incidences of cancer and CVD as health indicators, and to discuss their possible association with demographic and acculturative factors such as assimilation, integration, separation and marginalization.

Specific objectives

The specific objectives were:

- To construct a database for epidemiological studies of the Sami population of Sweden between 1961 and 2002.
- To analyse the mortality pattern in a large cohort of Swedish Sami and to enable gender and cause specific comparisons of mortality data for reindeer herding Sami, non-herding Sami, and non-Sami (Paper I and II).
- To study cancer incidences in the reindeer herding Sami population of Sweden and to discuss possible environmental, lifestyle and genetical causes (Paper III).
- To study the incidences of cardiovascular diseases in the Sami population of Sweden and to evaluate the impact of biomedical, psychosocial and socioeconomical risk factors (Paper IV and V).
MATERIAL AND METHODS

Construction of the database

In order to establish a large database for epidemiological studies of the Swedish Sami population, an attempt was made to reconstruct the Sami population by using the available national population registers where the Sami population can be extracted in one way or another. The database is described in detail elsewhere (Hassler et al. 2004a), so this section is restricted to a brief summary of the basic elements of the reconstruction.

In Sweden it is not possible to separate different ethnic groups directly in national population registers. This implies restrictions on how the Sami identity could be found, and means that the description of the method of finding the Sami in the national registers can be used as the definition of the Sami identity. Generous selection criterion were chosen in order to get a functional definition of the Sami origin that enabled construction of a large database with a high content of Sami with different lifestyles and from different occupational, environmental and geographical contexts. The strategy was to identify as many individuals as possible that according to one definition or another could be regarded as being of Sami origin, i.e. the selection was made to minimise the risk for excluding Sami.

![Diagram showing the construction of the database](image)

**Figure 5.** The construction of a database for epidemiological studies of the Swedish Sami population (from Hassler et al. 2004).
The construction of the database emanates from the two definitions of Sami identity that are found in Swedish law. The first definition being used for the right of registration to the electoral register of the Sami parliament, and the second being used to regulate the right to breed reindeers (see below). Based on these definitions, contemporary and computerized electoral and reindeer breeders registers have been established from which individual information can be extracted through the unique personal identification numbers. The Sami parliament holds the electoral register, and the registers of reindeer breeders and reindeer breeding companies are administrated by Statistics Sweden and by the Department of Agriculture (‘Jordbruksverket’), respectively.

Electoral list of the Sami parliament

In 1993, the first electoral register of the Sami parliament was established. Since then the register has been updated every fourth year at the time for the election. The electoral registers are the only current official registers in which non-herding Sami can be directly identified. The right to vote is regulated in the law of the Sami parliament (SFS 1992), where it is stated that this right is owned by those who consider themselves as Sami, and speak a Sami language, or have lived in a Sami speaking household, or have a parent or grandparent who speaks, or spoke, a Sami language. In 1993, about 5 400 people were registered in the electoral register. Four years later the register had grown to almost 6 000 persons. For the election of 2001, yet another 700 had signed up on the register. The electoral registers from 1993 and 1997 were used as index registers in the construction of the present database (Figure 5).

Reindeer breeders

The register of reindeer breeding companies is based on information provided by the reindeer breeding communities (‘Samebyarna’), and contained about 4 800 individuals in 1998. It was established as a digitised register in 1994 and has since then been updated annually. The right to breed reindeers in Sweden is restricted to Sami according to the following definition: a person who is listed in a previous official register of entitled reindeer breeders, or has a forefather who had this right, or is married to someone who owns this (SOU 1975:99). The register of reindeer breeding companies from 1998 was used as an index register in the present database (Figure 5).

Occupational and census registers

From Statistics Sweden’s population and census registers it is possible to extract information on e.g. occupation and main source of income. These registers are digitised since 1960 which enable construction of study populations with an ‘old’ Sami identification. From these registers one can identify reindeer herders, reindeer breeders and to a certain extent family members of reindeer
breeders. In these registers about 2 600 such persons were identified between 1960 and 1990 (Figure 5). Out of these, approximately 800 individuals were not found in any of the other index registers, and were hence added to the database.

The above registers were used as index registers in the sense that they served as the origin from which the expansion of the database emanated. Since the index registers to a large extent are contemporary, the expansion is supposed to work its way back in time. This was done by using the information in all the censuses that are computerised, which are the censuses of 1960, 1970, 1975, 1980, 1985 and 1990 (Table 4). By identifying all household members of the household of an index person, the database was expanded from about 10 000 individuals to a total of more than 150 000 individuals (Figure 5). It should be pointed out though, that although the individuals in the index registers are Sami by definition, this is not necessarily the case for the individuals collected in the expansion of the database. The criteria used for expanding the database was, ‘all the persons that once have lived in a household together with a person registered as Sami in the index registers’.

The Swedish kinship register, compiled and held by Statistics Sweden, is a register that is useful when family relations should be traced. The register is based on data from the censuses, and it is growing due to regular additions of older relatives. Thus, it is not complete in the sense that all relatives at all times are included in the register. When data from this register was extracted for inclusion in the database, Sami who were alive after 1941 could be found in the register.

**Control population**

In order to relate data from a given portion of the Sami population with equivalent information from a comparable population, a control population of non-Sami was constructed. The Sami index registers were used to match the non-Sami control population with regard to sex, age and living area (Figure 5). For every person in the Sami index registers, at least four matched control individuals were picked. This index register of control persons was then extended in exactly the same way as the Sami population. It should be noted that the Sami part of the database and the control part have a great deal of overlap (Figure 5). This should come as no surprise since the Sami index registers do not constitute a complete coverage of the contemporary Sami population of Sweden, implying that the control population is likely to include a few Sami too, especially in the most sparsely populated areas. This is due to the fact that the selection criterion for inclusion in the control population was that a person was not included in any of the Sami index registers. An additional reason for the occurrence of Sami within the non-Sami control population, and vice versa, was the choice to include all persons who lives, or have lived, in the same household as an index person.
The overlap between the Sami and non-Sami parts of the database is a problem – should it be excluded, included in the Sami part or added to the non-Sami part? Although there are rational motives for both options, it seems generally most valid to include the overlap in the Sami part of the database. The controls are defined by a passive exclusion criterion, ‘not included in the Sami index registers’. In contrast, the definition of Sami, regardless of definition applied, is affirmative, implying that the extension of the Sami index register should take precedence over the control equivalent. That is, as most definitions of Sami are likely to be found in the total Sami extension of the database, it should in most cases be kept on the Sami side (cf. Figure 5). It should also be noted that a total exclusion of the overlap, which would have been a preferred alternative in many studies, would result in a 40% reduction of the Sami part of the database.

**Table 1. Registers on health and living conditions in the Sami database (from Hassler et al. 2004).**

<table>
<thead>
<tr>
<th>Register</th>
<th>Register holder</th>
<th>Time period</th>
<th>Data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population and housing census registers</td>
<td>Statistics Sweden</td>
<td>1960-1998</td>
<td>Year of birth, Gender, Marital status, Living area, Occupation, Socioeconomic status, Hours of work, Geographic coordinates of home addresses</td>
</tr>
<tr>
<td>Kinship register</td>
<td>Statistics Sweden</td>
<td></td>
<td>Forefathers (alive no earlier than 1940), Siblings, Descendants, Spouses (marriages since 1968)</td>
</tr>
<tr>
<td>Cause of death register</td>
<td>The National Board of Health and Welfare</td>
<td>1952-2002</td>
<td>Date of death, Cause of death and contributing factors, Autopsy data, Work related injuries</td>
</tr>
<tr>
<td>Swedish hospital discharge register</td>
<td>The National Board of Health and Welfare</td>
<td>1985-2003</td>
<td>Main and contributing diagnosis, Hospital or clinic, Date of enrolment and length of the stay</td>
</tr>
<tr>
<td>The cancer register</td>
<td>The National Board of Health and Welfare</td>
<td>1958-2003</td>
<td>Type and site of tumour, Date of diagnosis</td>
</tr>
<tr>
<td>Västerbotten county’s cardiovascular disease prevention register</td>
<td>The County Council of Västerbotten</td>
<td>1990-2000</td>
<td>Blood pressure, lipids and BMI, Glucose loading data, Education and physical fitness, Lifestyle, including dietary habits and psychosocial conditions</td>
</tr>
</tbody>
</table>
For the purpose of conducting epidemiological studies on the Swedish Sami population, health related information has been added to the database. By linking the population register in the database with major national health and disease registers, such as the Cancer Register, the Cause of Death Register and the Swedish Hospital Discharge Register, the database has been extended to contain information on the health and living conditions of the Swedish Sami population (Table 1). In addition to the national health and disease registers, data from the Västerbotten County’s Cardiovascular Disease Prevention Project, has also been added to the database (Weinehall et al. 2001).

Validity of the database
In order to evaluate the validity of the Sami content of the database, it was compared to other sources of identified Sami (Hassler et al. 2004a). The results of two different validation tests are presented below.

Comparison with parish registers
One way of evaluating the sensitivity of the Sami identification, i.e. the probability of a person being correctly classified as a Sami in the database, is to use old parish registers for comparisons (Table 2).

Table 2. Sami births between 1935 and 1940 in the parishes of Tärna, Vittangi and Dikanäs (from Hassler et al. 2004).

<table>
<thead>
<tr>
<th>Year of birth</th>
<th>Tärna</th>
<th>Vittangi</th>
<th>Dikanäs</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>1935-1940</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>All births</td>
<td>280</td>
<td>788</td>
<td>210</td>
<td>1278</td>
</tr>
<tr>
<td>Sami</td>
<td>104</td>
<td>28</td>
<td>21</td>
<td>153</td>
</tr>
<tr>
<td>% Sami</td>
<td>37</td>
<td>4</td>
<td>10</td>
<td>12</td>
</tr>
</tbody>
</table>

These registers are the only historical source of information on the Sami identity. From about 1750 until about 1950-60, these registers contained notes on tribes, and ‘Lapp’ or ‘nomad’ marked people with Sami origin. The classification was based on the living conditions of the individual (i.e. nomadic or not), the heritage and the language, as perceived by the vicar in charge of the notification.

Three parishes in Sápmi were randomly selected – Vittangi, Tärna, and Dikanäs. From the birth register of these parishes, all births recorded between 1935 and 1940 were registered (Table 2).
Out of these children, the ones who were registered as Sami and those who had parents classified as ‘Lapp’ or ‘nomad’ were selected for comparison with the Sami population of the database.

Between 1935 and 1940 a total of 1,278 births were registered in the three parishes (Table 2). Out of these, 81 were recorded as Sami in the parish birth register. Additionally, 72 children had at least one parent who was recorded as either ‘Lapp’ or ‘nomad’ in the tribe column of the register. This makes a total of 153 persons, born between 1935 and 1940, who had a Sami heritage according to the parish registers. Out of these 153 births, 107 (70 %) were classified as Sami in the database (including 74 births identified in both the Sami and the control part of the database). Twenty births (13 %) were not included in the database at all, and 26 births (17 %) were included in the database as control individuals (Table 3a).

Table 3. Distribution within the database of (a) Sami born 1935-40 in three parishes in Sweden, and of (b) new members of the electoral register of the Sami parliament of 2001 (from Hassler et al. 2004).

<table>
<thead>
<tr>
<th>a) Sami births 1935-1940 in the parishes of Vittangi, Tärna and Dikanäs</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not included in the database</td>
<td>20</td>
<td>13</td>
</tr>
<tr>
<td>Included in the Sami population of the database</td>
<td>107</td>
<td>70</td>
</tr>
<tr>
<td>Included in the control population of the database (non-Sami)</td>
<td>26</td>
<td>17</td>
</tr>
<tr>
<td>Total</td>
<td>153</td>
<td>100</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>b) New members of the electoral register of the Sami parliament</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not included in the register</td>
<td>118</td>
<td>12</td>
</tr>
<tr>
<td>Included in the Sami population of the database</td>
<td>676</td>
<td>70</td>
</tr>
<tr>
<td>Included in the control population of the database (non-Sami)</td>
<td>167</td>
<td>17</td>
</tr>
<tr>
<td>Total</td>
<td>961</td>
<td>100</td>
</tr>
</tbody>
</table>

Comparison with the latest electoral register to the Sami parliament of 2001

Since the electoral register to the Sami parliament is one of the two contemporary sources of Sami identity accessible, another point of departure for testing the validity of the database would be to use the new members of the electoral register. As the extension of the database departs from the members of the electoral register of 1993 and 1997, the new members of the 2001 electoral register constitute a group of Sami who could serve as a validation population, since they have not entered the database through the index registers but should ideally be included in the database through the extension.
In 1997 there were 5,990 members in the electoral register to the Sami parliament. In the new electoral register to the Sami parliament, compiled for the election in 2001, there are altogether 6,723 members. Of these 6,723 members, 961 had not been included in any of the two previous electoral registers. Of the new members, 676 (70%) were classified as Sami in the database (Table 3b). This figure includes those 415 individuals from the electoral registers who were identified in both the Sami and the control portion of the database. Twelve percent were not included in the database at all, and 18% were included as control individuals (Table 3b). As the construction of the study cohorts introduced additional selection criteria, the density of true Sami in the study cohorts is higher than indicated by the validity tests.

The study cohorts

From the database described above, various study cohorts were extracted for the different studies.

The Sami population of Sweden - Paper 1, II and V

The most elaborate reconstruction was undertaken for the cause of death study as it aimed at capture the majority of the Sami population. Analogous to what has been described above, the reconstruction emanated from a group of index-Sami. By starting with the 1,045 reindeer herding Sami identified in the Occupational Register of 1960, relatives (forefathers, full siblings and descendents) were identified in the National Kinship Registers of Statistics Sweden (Table 4). Thus, 3,870 relatives to the index-Sami of 1960 were added to the total population. Then the 115 reindeer herding Sami of the Occupational Register of 1970 that had not been identified in the previous kinship runs, and their 611 relatives, were added to the Sami cohort. The same procedure was then used to identify relatives of the index-Sami identified in the Occupational Register of 1975 and onwards (Table 4).
Table 4. Reconstruction of a Swedish Sami population using national occupational registers, registers of reindeer breeding enterprises, electoral registers of the Sami parliament, and kinship registers.

<table>
<thead>
<tr>
<th>Index-Sami identified as:</th>
<th>1. Index-Sami</th>
<th>2. Forefathers</th>
<th>3. Siblings</th>
<th>4. Descendants</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reindeer herders or reindeer owners in the occupational register of:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1960</td>
<td>1 045</td>
<td>166</td>
<td>305</td>
<td>3 399</td>
<td>4 915</td>
</tr>
<tr>
<td>1970</td>
<td>115</td>
<td>55</td>
<td>72</td>
<td>484</td>
<td>726</td>
</tr>
<tr>
<td>1975</td>
<td>40</td>
<td>35</td>
<td>48</td>
<td>264</td>
<td>387</td>
</tr>
<tr>
<td>1980</td>
<td>75</td>
<td>89</td>
<td>99</td>
<td>369</td>
<td>632</td>
</tr>
<tr>
<td>1985</td>
<td>50</td>
<td>65</td>
<td>79</td>
<td>307</td>
<td>501</td>
</tr>
<tr>
<td>1990</td>
<td>55</td>
<td>107</td>
<td>158</td>
<td>419</td>
<td>739</td>
</tr>
<tr>
<td>Reindeer herders in the Register of reindeer breeding enterprises</td>
<td>1 290</td>
<td>1 437</td>
<td>2 302</td>
<td>9 206</td>
<td>14 235</td>
</tr>
<tr>
<td>Voters in the electoral register of the Sami parliament of 1993</td>
<td>2 761</td>
<td>2 292</td>
<td>2 258</td>
<td>9 660</td>
<td>16 971</td>
</tr>
<tr>
<td>Voters in the electoral register of the Sami parliament of 1997</td>
<td>268</td>
<td>376</td>
<td>404</td>
<td>1 567</td>
<td>2 615</td>
</tr>
<tr>
<td>Total</td>
<td>5 699</td>
<td>4 622</td>
<td>5 725</td>
<td>25 675</td>
<td>41 721</td>
</tr>
</tbody>
</table>

1 Index-Sami. Start of follow-up: January 1, following the year of identification.
2 Parents, grandparents and forefathers alive 1941 or later. Start of follow-up: 1961 or birth of Index-Sami if later than 1961.
3 Siblings to index-Sami (1) and forefathers (2). Start of follow-up: 1961 or year of birth if later than 1961.
4 Descendants to index-Sami (1) and forefathers (2) and siblings (3). Start of follow-up: 1961 or year of birth if later than 1961.
5 Also identified in the census of 1993 (Årslys 93)
6 Also identified in the census of 1998 (RTB 98)

The total study cohort of Paper I contained 41 721 persons (21 867 men and 19 854 women). To enable comparisons of potential differences in mortality pattern between Sami with a more traditional lifestyle and Sami with a more westernised lifestyle, the cohort was divided into two sub-populations: (1) reindeer herding Sami, containing 4 451 men and 3 031 women and (2) non-herding Sami, containing 17 416 men and 16 823 women (Table 6). The study cohort of Paper II consisted of the 7 482 reindeer herding Sami.

In order to reduce the non-Sami influence in the Sami cohort, spouses were only added to the cohort if they were related to an index-Sami. In Paper V the same cohort as described above was used but with the restriction that only those born before 1960 and being alive January 1, 1985, were included. The cohort of Paper V contained a total of 15 914 Sami (8 271 men and 7 643 women)(Table 6).

The reindeer breeding families of 1960 and 1980 – Paper III

For Paper III, two study cohorts were constructed. One comprised of 2 033 persons (1 289 men, 744 women) who were recorded as reindeer breeders or members of households of reindeer breeders in the 1960 Population and Housing Census. The other consisted of 1 988 persons (1 116 men, 872 women) who were recorded as reindeer breeders or as husbands, wives or children to reindeer breeders in the 1980 Population and Housing Census. In 1980, the overlap between
the two cohorts comprised of 864 individuals (590 men, 274 women). The overlap was included in both cohorts.

Sami in Västerbotten – Paper IV

From the database, a cohort of Sami was constructed containing participants of a regional CVD preventive programme between 1990 and 2001. A total of 611 (276 men and 335 women) Sami were identified, of whom 170 were reindeer herding Sami and 441 non-herding Sami. This selection constituted 20 % of the total number of non-herding Sami in the age groups in question, and 45 % of the reindeer herders.

Control population

In all studies a demographically matched non-Sami reference population was used as the standard and it was constructed the same way as the Sami cohorts (Figure 6 and Table 5).

Figure 6. Schematic illustrations of the method by which the Sami cohort and the non-Sami control population were constructed (for details, see text).
For each index-Sami four non-Sami persons were randomly selected from the National Population and Housing Census Registers, to match the index-Sami regarding age, gender, area of residency (i.e., by parish or municipality) and date of identification. Forefathers (23 657), full siblings (23 764) and descendants (74 713) of these non-Sami index-persons were identified in the National Kinship Register, thereby creating a reference population that was demographically similar to the Sami cohort and contained a total of 144 930 persons (Paper I) (75 899 men and 69 031 women). To refine the Sami cohort and the reference population regarding Sami heritage, persons being relatives to both index-Sami and non-Sami index persons were excluded from the study. The overlap comprised of a total of 5 690 persons (Paper I). For Paper II-V various selections from this demographically matched non-Sami reference population were used.

### Statistical methods and follow-up

Follow-up periods, gender distributions, size of study cohorts and the age groups included in each of the study cohort are presented in Table 6.

#### Table 6. Size of study cohorts, follow-up periods and age of the study cohorts of the different studies included in the thesis.

<table>
<thead>
<tr>
<th>Size of study cohorts (persons at risk)</th>
<th>Follow-up</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Reindeer herders</td>
<td>Other Sami</td>
</tr>
<tr>
<td></td>
<td>Men</td>
<td>Women</td>
</tr>
<tr>
<td>Paper I</td>
<td>4 451</td>
<td>3 031</td>
</tr>
<tr>
<td>Paper II</td>
<td>4 451</td>
<td>3 031</td>
</tr>
<tr>
<td>Paper III</td>
<td>1 289</td>
<td>744</td>
</tr>
<tr>
<td>Paper IV</td>
<td>93</td>
<td>77</td>
</tr>
<tr>
<td>Paper V</td>
<td>2 793</td>
<td>1 672</td>
</tr>
</tbody>
</table>
The earliest start of follow-up was January 1, 1961 and the end of follow-up was December 31, 2000 (Paper I and II) (Table 6); January 1, 1961 to December 31, 1997 (Paper III); January 1, 1985 to December 31, 2002 (Paper V). Follow up was also ended at the time of death or emigration. Standard mortality ratios, SMR (Paper I, II and V), and standard incidence ratios, SIR (Paper III and V), were calculated using age, sex and cause specific distribution of all incidences that occurred over the entire follow-up period. The control population was used as the standard for all comparisons and expected deaths or incident cases were calculated by multiplying the mortality- and incidence rates from the control population with the Sami population within annual sex specific, five-year age categories.

SMR was calculated for the main groups of cause of death and for some sub-groups, such as stroke (ICD10: I60-I69), ischemic heart diseases (ICD10: I20-I259), acute myocardial infarction AMI (ICD10:I21), subarachnoid haemorrhage SAH (ICD10: I61), diabetes (ICD10: E10-E149), suicide (ICD10: X60-X84) and vehicle accidents (ICD10: V01-V89). SIR was calculated for stroke, AMI, SAH and all main cancer sites. Re-coding of diagnoses between ICD7, ICD8, ICD9 and ICD10 has been done according to the relationship of categories produced by Statistics Sweden and the World Health Organization (Classifications of causes of death in Swedish statistics 1990). In Paper IV, Chi-square test was used to explore differences between groups of dichotomous variables and one-way analysis of variance (ANOVA) to compare numerical variables. For all statistical tests, p<0.05 was considered significant. Life expectancy at birth was calculated from cohort life-tables consisting of age adjusted death rates derived from the deaths that occurred during the follow-up period (Chiang 1984; Armitage 1971). For statistical comparisons of life expectancy the Mantel-Haenzel log rank test was used. A P-value < 0.05 was considered as significant. Statistical comparisons between time-periods were based on Poisson regression model adjusting for age and gender difference (Breslow & Day 1987).

**Ethical considerations**

Epidemiological studies of the Sami population of Sweden is one part of a project that was initiated by the Southern Lapland Research Department in 1998 with the general purpose of increasing the knowledge on the health and living conditions of the Sami population of Sweden. The project and the individual studies have been scrutinized and approved by the ethical committee of Umeå University (dnr. 98-340, 99-315 and 04-144M). No data on personal identity is included in the database and all analyses are at group level. The studies included in this thesis have been carried out in close cooperation with Sami organisations, the Sami parliament (‘Sametinget’) and Sami villages (‘Samebyar’).
RESULTS
Causes of death – Papers I and II

Between 1961 and 2000 a total of 4,576 deaths occurred in the Sami cohort, 3,546 among the non-herding Sami and 1,030 among the reindeer herding Sami. The three most common causes of death were diseases of the circulatory system, cancers and external causes of injuries. Life expectancy at birth was 74.9 years for Sami men (74.6 years for men in the reference population) and 80.0 years for Sami women (80.3 years for women in the reference population). No statistically significant difference of life expectancy was observed between any of the populations.

Table 7. Observed number of deaths among 41,721 Swedish Sami 1961-2000, together with standard mortality ratios (SMR) with 95% confidence intervals (95% CI) in comparison to a demographically matched reference population of non-Sami.

<table>
<thead>
<tr>
<th>Cause of death</th>
<th>Men</th>
<th></th>
<th>Women</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Obs.</td>
<td>SMR</td>
<td>95% CI</td>
<td>Obs.</td>
</tr>
<tr>
<td>All Sami</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Diseases of the circulatory system</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.1 Ischemic Heart disease</td>
<td>1,373</td>
<td>1.00</td>
<td>0.94-1.05</td>
<td>786</td>
</tr>
<tr>
<td>1.2 Cerebrovascular disease</td>
<td>265</td>
<td>1.02</td>
<td>0.90-1.15</td>
<td>209</td>
</tr>
<tr>
<td>1.3 Subarachnoid haemorrhage</td>
<td>24</td>
<td>1.60</td>
<td>1.02-2.38</td>
<td>27</td>
</tr>
<tr>
<td>2. Diabetes</td>
<td>52</td>
<td>1.17</td>
<td>0.87-1.53</td>
<td>51</td>
</tr>
<tr>
<td>3. Cancers</td>
<td>476</td>
<td>0.87</td>
<td>0.79-0.95</td>
<td>375</td>
</tr>
<tr>
<td>4. Diseases of the respiratory system</td>
<td>172</td>
<td>1.03</td>
<td>0.88-1.20</td>
<td>116</td>
</tr>
<tr>
<td>5. Diseases of the digestive system</td>
<td>70</td>
<td>0.89</td>
<td>0.69-1.13</td>
<td>60</td>
</tr>
<tr>
<td>6. External causes of injury</td>
<td>353</td>
<td>1.24</td>
<td>1.11-1.37</td>
<td>83</td>
</tr>
<tr>
<td>6.1 Suicide</td>
<td>96</td>
<td>1.17</td>
<td>0.95-1.43</td>
<td>18</td>
</tr>
<tr>
<td>6.2 Vehicle accidents</td>
<td>91</td>
<td>1.31</td>
<td>1.06-1.61</td>
<td>22</td>
</tr>
<tr>
<td>Total</td>
<td>2,834</td>
<td>0.99</td>
<td>0.96-1.03</td>
<td>1,742</td>
</tr>
</tbody>
</table>

The overall SMR for Sami men was similar to that for men of the control population, while a slightly higher overall SMR was observed for Sami women (Table 7). Sami men showed significantly lower SMR for cancers but higher for external cause of injury. For Sami women, higher mortality rates than expected was found for diseases of the circulatory system, ischemic heart diseases and diseases of the respiratory system. A significantly increased risk of dying from subarachnoid haemorrhage (SAH) was observed among both Sami men and women.

A comparison of reindeer herding Sami and non-herding Sami men revealed that the non-herding Sami showed mortality rates similar to their non-Sami neighbours, with the exception of significantly lower cancer mortality, while the reindeer herding Sami demonstrated significantly higher SMRs for SAH and external causes of injury. Among the reindeer herding Sami men, a significantly lower SMR was observed for diseases of the digestive system.
Among the Sami women, the non-herding Sami showed higher SMRs for diseases of the
circulatory system, ischemic heart diseases and SAH, whereas the reindeer herding Sami women
demonstrated only non-significant differences in mortality ratios.

Table 8  Observed and expected number of externally caused deaths for reindeer herders, 1961 to
2000. Standard mortality ratio (SMR) based on a comparison with a population of
demographically matched non-Sami controls. Confidence intervals (CI) are shown at 95%
-level.

<table>
<thead>
<tr>
<th></th>
<th>Men</th>
<th></th>
<th></th>
<th>Women</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Obs</td>
<td>Exp</td>
<td>SMR</td>
<td>CI</td>
<td>Obs</td>
</tr>
<tr>
<td>1. Vehicle accidents</td>
<td>29</td>
<td>17</td>
<td>1.74</td>
<td>1.16-2.49</td>
<td>4</td>
</tr>
</tbody>
</table>
| 1.1 Snowmobiles and
terrain vehicles | 8   | 1   | 7.34 | 3.16-14.46    | 0   | 0   | 0.00 | 0.00-9.80     |
| 2. Drowning     | 15  | 8   | 1.80 | 1.01-2.97     | 1   | 1   | 1.53 | 0.02-8.52     |
| 3. Falling      | 10  | 10  | 0.96 | 0.46-1.77     | 1   | 1   | 0.83 | 0.01-4.61     |
| 4. Poisoning    | 7   | 2   | 4.32 | 1.73-8.90     | 0   | 1   | 0.00 | 0.00-5.96     |
| 3. Suicide      | 33  | 24  | 1.38 | 0.95-1.94     | 5   | 5   | 1.03 | 0.33-2.41     |
| 4. Other causes | 42  | 19  | 2.18 | 1.57-2.94     | 3   | 2   | 1.23 | 0.25-3.61     |
| Total           | 136 | 80  | 1.69 | 1.42-2.00     | 14  | 13  | 1.10 | 0.60-1.85     |

The excess risk for external causes of death among reindeer herders was further investigated in
Paper II using a demographically matched control population more closely matched to this
particular Sami cohort. Over the entire follow-up period, a total of 150 externally caused deaths
occurred among the reindeer herding Sami (136 among men, 14 among women). Of the cause-
specific mortality, men showed an increased risk of dying from vehicle accidents, snowmobile
accidents, drowning, poisoning and ‘other causes’ (Table 8). Although the incidence of suicide
was higher among the reindeer herders, the increased risk was not significantly increased.

Comparison of the deaths that occurred in the periods of 1961-1980 and 1981-2000, revealed an
increase of externally caused deaths over time, non-significant however. This trend was most
pronounced for accidents directly or indirectly caused by vehicles (i.e. cars, snowmobiles,
motorcycles and helicopters) and for poisoning. The number of deaths caused by snowmobiles
and terrain vehicles, tripled between the two time periods.
Cancer – Paper III

Over the entire follow-up period, 1961 to 1997, the reindeer herding Sami showed a statistically significantly lower total cancer risk in comparison to the Swedish general population. The risk was lower both for men and women (Men: SIR 0.56; 95% CI: 0.47-0.67; Women: SIR 0.68; 95% CI: 0.53-0.86). A significantly lower risk was found for cancer of the colon, respiratory organs, female breast, male genital organs, kidneys, urinary bladder and skin, and for malignant lymphoma. A statistically significant increased risk was observed for stomach cancer only.

In comparison to the demographically matched control population, the total cancer risk of reindeer herding Sami was statistically lower, but less pronounced. A significantly lower risk was found for cancer of the male genital organs and for malignant lymphoma. An increased risk for stomach cancer was also evident, but only half as pronounced as when the comparison was based on incidence data from the general Swedish population.

Between 1961 and 1997, the relative number of cancer cases diagnosed at autopsy, as well as the number of cancer cases incidentally found at autopsy, was about the same for the reindeer herding Sami and the demographically matched control population. (autopsy rate: 8 and 9%, respectively; cancer cases incidentally found at autopsy: 2.6% and 2.9%, respectively).

![Figure 7](image-url)

**Figure 7** Mortality and migration between 1960 and 1997 within the Swedish reindeer breeding Sami populations of 1960 and 1980, and the corresponding reference populations of geographically matched non-Sami. The denominator for the relative figures of ‘Mortality’ and ‘Remaining’ is the size of the study cohorts and the corresponding reference population in 1960 or 1980. ‘Migration’ contains persons who at the end of the follow-up period lived in a different municipality than at the start of the follow-up period. The denominator for the relative figures of ‘Migrated’ is the number of survivors in 1960 or 1980.
Of the reindeer herding Sami, 24% moved to a new municipality between 1961 and 1997 (Figure 7). The corresponding number for the demographically matched control population was 50%. To disclose potential biasing effects of the different migration patterns, the cancer risk was separately analysed for those who stayed and those who migrated during the follow-up period. The cancer risk, in relation to the general Swedish population, was significantly higher among the reindeer herding Sami who moved outside the reindeer herding area, than within the stationary part of the cohort: ‘migrators’, SIR: 1.63; 95% CI: 0.95-2.62; ‘stationary group’, SIR: 0.55; 95% CI 0.45-0.67. For the demographically matched control population, there was virtually no difference in the relative cancer risks between the stationary group and the group of migrators, as compared to the whole Swedish population (migrators, SIR: 0.84; 95% CI: 0.71-0.98; stationary group, SIR: 0.81; 95% CI: 0.74-0.89). Thus, the higher cancer risk within the demographically matched reference populations does not seem to be caused by differences in environmental exposure as a result of migration.

**Figure 8.** Comparison of cancer risks for members of Swedish reindeer breeding Sami households between 1961-1980 and 1981-1997. Only cancer sites with more than five observed cases during the first period are included. The risk is expressed as standardized incidence ratio, calculated using Swedish general data as the standard.
The low cancer risk among the Sami has been quite constant between 1961 and 97, both in relation to the general Swedish population and to the demographically matched control population. No statistically significant differences in the risk to get cancer were found between the periods 1961-80 and 1981-97 (Figure 8). However, the relative risk for stomach cancer seems to have decreased from being significantly elevated in 1961-80, to being close to the Swedish average during the later follow-up period.

**Cardiovascular diseases – Papers IV and V**

*Risk factors*

The risk factors for CVD show that the Sami and the non-Sami control population demonstrated similar risk factor patterns (Paper IV). Yet, slightly but statistically significant lower blood pressure, HDL-cholesterol and triglycerides were shown among the Sami. There were also fewer Sami who reported parents and/or siblings with CVD than among the non-Sami. A history of diabetes within the family was more common among the Sami than among the non-Sami, and the Sami assessed their quality of life as significantly lower. The Sami consumed more saturated fat and reported larger demand and intellectual discretion at work. No differences were observed regarding smoking habits, alcohol consumption and social support.

Significantly smaller social networks were found among non-herding Sami men, while job demands and the decision latitude were larger for reindeer herding Sami than for both the non-Sami and the non-herding Sami. The consumption of saturated fat was higher among the reindeer herding Sami men, but they showed significantly lower systolic and diastolic blood pressures (127/78 mm Hg vs. 134/83 mm Hg), and were more physically active. The reindeer herding Sami men also scored significantly lower on physical quality of life compared to the men in the control population. The reindeer herding Sami women reported significantly lower scores on social and physical quality of life and on emotional support than the non-Sami women. Significantly lower glucose concentrations were observed among the reindeer herding Sami women (4.8±0.8 mmol/l) as compared to both the control (5.1±0.7 mmol/l) and the non-herding Sami women (5.1±0.7 mmol/l). A comparison of the risk factors between Sami men and women showed significantly higher LDL cholesterol and alcohol consumption among reindeer herding Sami men, while the reindeer herding Sami women demonstrated lower glucose concentrations.
Table 9. Psychosocial risk factors for CVD among reindeer herding Sami.

<table>
<thead>
<tr>
<th>Psychosocial factors</th>
<th>Reindeer herding Sami</th>
<th>Women</th>
<th>Mean SD</th>
<th>Men</th>
<th>Mean SD</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality of life</td>
<td>- social</td>
<td>5.3 ± 1.2</td>
<td>5.4 ± 1.1</td>
<td>–</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td></td>
<td>- physical</td>
<td>5.4 ± 1.0</td>
<td>5.1 ± 0.9</td>
<td>–</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td></td>
<td>- mental</td>
<td>5.2 ± 1.3</td>
<td>5.5 ± 1.2</td>
<td>–</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Social support</td>
<td>- social network</td>
<td>11.5 ± 1.9</td>
<td>11.8 ± 1.9</td>
<td>–</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td></td>
<td>- emotional support</td>
<td>10.7 ± 2.2</td>
<td>10.2 ± 2.5</td>
<td>–</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Work strain</td>
<td>- work demand</td>
<td>12.3 ± 2.7</td>
<td>13.4 ± 2.3</td>
<td>0.015</td>
<td>0.015</td>
<td>0.015</td>
</tr>
<tr>
<td></td>
<td>- intellectual discretion</td>
<td>11.2 ± 2.1</td>
<td>12.0 ± 1.5</td>
<td>0.006</td>
<td>0.006</td>
<td>0.006</td>
</tr>
<tr>
<td></td>
<td>- decision latitude</td>
<td>6.6 ± 1.5</td>
<td>7.3 ± 1.2</td>
<td>0.001</td>
<td>0.001</td>
<td>0.001</td>
</tr>
<tr>
<td></td>
<td>- job strain ratio</td>
<td>0.72 ± 0.20</td>
<td>0.71 ± 0.15</td>
<td>–</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td></td>
<td>- social support</td>
<td>15.12 ± 3.10</td>
<td>16.29 ± 2.97</td>
<td>0.022</td>
<td>0.022</td>
<td>0.022</td>
</tr>
</tbody>
</table>

The work strain factors among the reindeer herding Sami were characterised by significantly higher work demand among men and significantly lower intellectual discretion and decision latitude among women (Table 9). The non-herding Sami men had significantly higher systolic blood pressure, consumption of alcohol and saturated fat than the non-herding Sami women, but lower triglycerides and glucose concentrations. A history of diabetes among parents and siblings was significantly more common for the non-herding Sami women than for the men and the non-Sami women (26% and 19%, respectively). In comparison to the non-herding Sami men, the non-herding Sami women reported higher emotional support but lower intellectual discretion and physical activity.

Incidence and mortality

Between 1985 and 2002 there were a total of 1 443 observations of AMI among 1 156 Sami (788 men and 368 women), 2 306 incidences of stroke among 1 182 Sami (684 men and 498 women) and 145 incidences of SAH among 74 Sami (34 men and 40 women).

The overall incidence ratio of AMI revealed no elevated risk for either Sami men or women compared with the demographically matched control population (Table 10). However, the mortality ratio of AMI was significantly higher for Sami women but not for Sami men. The data on stroke and SAH demonstrated the opposite pattern, i.e. significantly higher overall incidence rates among both Sami men and women but no differences in mortality rates.
Table 10. Incidence and deaths in acute myocardial infarction, stroke and subarachnoid haemorrhage in the Sami population of Sweden between 1985 and 2002 shown as standardized incidence ratios (SIR) and mortality ratios (SMR) with 95% confidence interval using a demographically matched control population of non-Sami as standard.

<table>
<thead>
<tr>
<th></th>
<th>Men</th>
<th>Women</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Observed</td>
<td>SIR/SMR</td>
</tr>
<tr>
<td><strong>All Sami</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Acute myocardial infarction (AMI)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>incidence</td>
<td>981</td>
<td>1.02</td>
</tr>
<tr>
<td>deaths</td>
<td>397</td>
<td>1.09</td>
</tr>
<tr>
<td>Stroke</td>
<td></td>
<td></td>
</tr>
<tr>
<td>incidence</td>
<td>1341</td>
<td>1.08</td>
</tr>
<tr>
<td>deaths</td>
<td>249</td>
<td>1.00</td>
</tr>
<tr>
<td>Subarachnoid haemorrhage</td>
<td></td>
<td></td>
</tr>
<tr>
<td>incidence</td>
<td>55</td>
<td>1.72</td>
</tr>
<tr>
<td>deaths</td>
<td>13</td>
<td>1.57</td>
</tr>
<tr>
<td>AMI and/or stroke</td>
<td></td>
<td></td>
</tr>
<tr>
<td>incidence</td>
<td>2272</td>
<td>1.06</td>
</tr>
<tr>
<td>deaths</td>
<td>626</td>
<td>1.07</td>
</tr>
<tr>
<td><strong>Sami – Non-herders</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Acute myocardial infarction (AMI)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>incidence</td>
<td>656</td>
<td>1.04</td>
</tr>
<tr>
<td>deaths</td>
<td>259</td>
<td>1.08</td>
</tr>
<tr>
<td>Stroke</td>
<td></td>
<td></td>
</tr>
<tr>
<td>incidence</td>
<td>969</td>
<td>1.20</td>
</tr>
<tr>
<td>deaths</td>
<td>176</td>
<td>1.08</td>
</tr>
<tr>
<td>Subarachnoid haemorrhage</td>
<td></td>
<td></td>
</tr>
<tr>
<td>incidence</td>
<td>39</td>
<td>1.87</td>
</tr>
<tr>
<td>deaths</td>
<td>8</td>
<td>1.51</td>
</tr>
<tr>
<td>AMI and/or stroke</td>
<td></td>
<td></td>
</tr>
<tr>
<td>incidence</td>
<td>1590</td>
<td>1.13</td>
</tr>
<tr>
<td>deaths</td>
<td>423</td>
<td>1.09</td>
</tr>
<tr>
<td><strong>Sami – Reindeer herders</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Acute myocardial infarction (AMI)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>incidence</td>
<td>325</td>
<td>0.97</td>
</tr>
<tr>
<td>deaths</td>
<td>138</td>
<td>1.11</td>
</tr>
<tr>
<td>Stroke</td>
<td></td>
<td></td>
</tr>
<tr>
<td>incidence</td>
<td>372</td>
<td>0.86</td>
</tr>
<tr>
<td>deaths</td>
<td>73</td>
<td>0.85</td>
</tr>
<tr>
<td>Subarachnoid haemorrhage</td>
<td></td>
<td></td>
</tr>
<tr>
<td>incidence</td>
<td>16</td>
<td>1.44</td>
</tr>
<tr>
<td>deaths</td>
<td>5</td>
<td>1.68</td>
</tr>
<tr>
<td>AMI and/or stroke</td>
<td></td>
<td></td>
</tr>
<tr>
<td>incidence</td>
<td>682</td>
<td>0.92</td>
</tr>
<tr>
<td>deaths</td>
<td>203</td>
<td>1.04</td>
</tr>
</tbody>
</table>

The incidence and mortality patterns of other Sami men and women were similar to those of the total Sami population (Table 10). In contrast, the reindeer herding Sami demonstrated rather different incidence and mortality patterns. The reindeer herding Sami women showed significantly lower incidence rates of AMI and no excess mortality rate from AMI, but higher incidence ratios of stroke and SAH in comparison with the other Sami women. The reindeer herding Sami men revealed significantly lower incidences of stroke. In similarity with the other Sami and the reindeer herding Sami women they had high, but non-significant, incidence rates of SAH. Some of these differences are likely a result of small number of cases.

There was no statistical difference in case fatality in stroke between the Sami and the demographically matched control population. For AMI, Sami women were observed to have a
higher case fatality than non-Sami women. This was also found for the other Sami women. For Sami men the case fatality in AMI was similar for that of men from the demographically matched control population.

No statistical difference was observed between the Sami and the demographically matched control population for out of hospital deaths, except for the reindeer herding Sami men who showed an increased mortality from out-of-hospital AMI.

Figure 9. Development of annual net income in Swedish currency (SEK) for Sami, demographically matched non-Sami and for Sweden, in the age-group 40-60 years.
The annual net income for Sami men and women in comparison to that for the demographically matched control population and Sweden as a whole is illustrated in Figure 9. While there were small differences of median net income between the other Sami men and men from the demographically matched control population, the income for the reindeer herding Sami men was considerably lower. In general, the income for women of the Sami cohorts, the demographically matched control population and the entire Sweden were quite similar, while the net income of the reindeer herding Sami women has increased more markedly. Since the late 1980s the reindeer herding Sami women take home more money than their men, and in 2000 the difference was considerable.

There were virtually no differences at any educational level between the women of the different populations. However, the relative numbers of reindeer herding Sami women with high level of education was significantly larger and those with low level of education smaller, compared to the other Sami, demographically matched control population as well as to Sweden as a whole. The proportion of reindeer herding Sami men was significantly different from men of the other groups at all educational levels, i.e. lower frequency of high and mid-level of education, and considerably higher frequency of basic education.
DISCUSSION
The findings of the separate studies behind each Paper are discussed under the headings, Cause of death, Cancer and Cardiovascular diseases and are followed by a general discussion on methodological considerations.

Causes of death
The main result of this study was that the mortality rates and life expectancy of the Sami and their non-Sami neighbours were quite similar. This is in clear contrast to several other native populations for which the mortality statistics are largely unfavourable in comparison to that of the general populations (Bjerregaard et al. 2004b; Mao et al. 1992; Bjerregaard & Young 1998; Hogg 1992; Mahoney 1989; Mahoney & Michalek 1998). The similarities between the Sami and the non-Sami are probably a result of centuries of close interaction that has caused mixed marriages, similarities in culture, attitudes and lifestyle, as well as equal accessibility to health care services and the social security systems.

Cardiovascular diseases
Beyond the finding of a general resemblance between the Sami and the non-Sami there were significant differences regarding some causes of death. One distinct finding was that the mortality due to diseases of the circulatory system was significantly higher among Sami women than among their non-Sami neighbours. Since diseases of the circulatory system caused almost 50 % of all deaths among Sami women, their excess risk of dying from such diseases was the main reason for their slightly higher total mortality. Male Sami, however, showed the same risk of dying from diseases of the circulatory system as did the non-Sami males. This discrepancy between men and women is basically in agreement with results from previous studies. In a study on Swedish reindeer herding Sami it was shown that the women had significantly higher mortality rates for diseases of the circulatory system as compared to the general Swedish population, while the men demonstrated significantly lower risks (Wiklund et al. 1991). The latter was substantiated by results from a Norwegian study showing that Sami men had a significantly lower risk of dying from diseases of the circulatory system as compared to the Norwegian male population living in the same area (Tverdal 1997). The Sami women, however, did not show any reduced mortality risk from diseases of the circulatory system. Thus, it might be concluded that the relative risk of dying from diseases of the circulatory system is higher among Sami women than among Sami men compared to their non-Sami neighbours.

Nutritional studies indicate that the traditional diet of the Sami, which is dominated by reindeer meat and has a low content of vegetables and fruit, could constitute a potential risk factor for diseases of the circulatory system (Håglin 1988, 1999). Although the diet could contain general
risk factors, this could not explain the observed gender difference in mortality rates from diseases of the circulatory system (see below ‘Cardiovascular diseases’).

The high SMR from CVD among Sami women might be related to their psychosocial situation. Today, most women of reindeer herding families carry a double or even a triple burden of shared responsibility for the reindeer herding enterprise together with being responsible for the household and the family’s social network and in addition also having a regular part-time work (teacher, nurse, etc) (Daerga et al. 2004). In combination with little daily physical activity and a diet low in vegetables and fruits, the unfavourable psychosocial situation of the Sami women could be a major factor responsible for their elevated mortality risk from CVD (see below ‘Cardiovascular diseases’).

It is known that the incidence of SAH is higher among Greenlandic Inuits than among Caucasian Danes, and it has been suggested that genetic dissimilarities might be the main reason (Lindgaard et al. 2003). Possible causes of the high mortality rate from SAH among the Sami, will be further discussed below (Paper V; see below ‘Cardiovascular diseases’).

The smoking habits of the Sami seem to be similar to those of their non-Sami neighbours as indicated by self-reported data collected during the 1980th and 90th (Paper IV; Lindgaard et al. 2003; Isaksen et al. 2002; Spein et al. 2002; Reijula et al. 1990). Thus, it is tentatively suggested that the increased mortality risk from SAH among the Sami, at least partly, has genetic causes. This is indirectly supported by studies indicating that the Sami constitute a genetically distinct ethnic group without strong links to other European and Asian populations (Sajantila et al. 1995; Fan & Sikström 1994; Kassermann et al. 2002).

Cancer

The low mortality from cancers found among Sami men is in conformity with previous studies reporting significantly lower cancer incidences in this group than among others living in the same region (Paper III; Soininen et al. 2002). The observation that the SMR was equally low among reindeer herding Sami and non-herding Sami, together with the assumption that the non-herding Sami have adopted a lifestyle identical or very similar to that of the reference population, indicates that the low mortality rate from cancers might be a result of genetic rather than lifestyle factors. Yet, lifestyle factors cannot be excluded of course. The increasing risk of dying from cancer among non-herding Sami women might be a reflection of reduced influence of protective factors related to the traditional Sami lifestyle. That the excess risk of stomach cancer among herding Sami is caused by a large consumption of smoked and salted reindeer meat has also been suggested (Paper III; Soininen et al. 2002).
**Suicide**

Suicide among male reindeer herding Sami was at first found slightly increased (Paper I). When the same group was compared to non-Sami living closer to reindeer herding communities in the inner part of north Sweden, this higher risk was reduced (Paper II). In Sweden there are substantial geographic variations when it comes to the risk for suicide, and young men in sparsely populated areas are those with the highest risk, a group of which many of the reindeer herding men belong (Jacobsson & Renberg 1986; Lindqvist & Johansson 2000). Interestingly, the non-herding Sami did not show any increased risk of suicide, which is somewhat in contrast to findings from other native populations where the incidence of suicide often is considerably higher among the westernised/urbanised natives than among those living more traditionally (Marshall & Soule 1998; Bjerregaard et al. 1988).

**Fatal accidents**

Excess mortality among men from external causes of injury, such as accidents and suicide, has been reported for several native populations (Mao et al. 1992; Bjerregaard et al. 2004b; Mahoney & Michalek 1989; Hsianick 1994; Andrews & Krouse 1995; Marshall & Soule 1998). But whereas acculturation, alcohol abuse and socio-economic poverty are main causes of the excess mortality in most other indigenous people (Andrews & Krouse 1995; Marshall & Soule 1998; Bjerregaard et al. 2004b), fatal accidents among the reindeer herding Sami are mostly work-related. This conclusion is supported by observations that the alcohol consumption was similar among reindeer herding Sami as among Swedes and Finns in the same region (Paper IV; Poikolainen et al. 1992), and the finding that suicide among the Sami was only non-significantly increased when compared with the non-Sami in the same area of living. The high risk of dying from vehicle accidents, drowning and poisoning among the reindeer herding men, suggests that there is a strong relation between the fatalities and the herding, fishing and hunting lifestyle of the Sami.

Reindeer herding includes many hazardous tasks and environments especially during the gathering of the reindeers for migration or slaughter. During these periods the herders use vehicles to gather the reindeers (i.e. motorcycles, snowmobiles, helicopters, airplanes and boats), and the work is often executed during long working hours in a harsh climate and terrain. For instance, it has been shown that most reindeer herding men spend more than 800 hours per year on snowmobile (Daerga et al. 2004). The increasing number of work-related fatal accidents among the reindeer herders is probably also related to an increasing pressure from the Swedish society to develop profitable reindeer herding companies. This has resulted in an external socioeconomic pressure, and competition between the family companies within the Sami communities, that in turn have forced the enterprises to make costly investments in vehicles to save time and expenses on personnel.
According to self-reported data on the division of working time among reindeer herders in Finland, the slaughtering, gathering and reindeer separation in late autumn are the most labour-intensive periods (Pekkarinen et al. 1992). More than half of the annual work-related accidents occurred during those periods (Pekkarinen et al. 1988). Among the Swedish reindeer herders, the fatal accidents were fairly evenly distributed over the year, and lacked the peak of accidents during the holiday-months that was observed in the non-Sami population. This suggests that the vast majority of fatalities among the herders were work-related, a conclusion supported by the fact that more than 90% of the fatalities were observed among the men who are exposed to most of the hazardous herding operations. This is also in agreement with the herders’ attitudes, which imply e.g. that they do not make any strict distinction between labour and leisure time. For instance, hunting and fishing, as well as ‘hiking’, are regarded as natural elements of their work, but for others, these are typically leisure time activities.

**Figure 10.** Fatal work-related accidents among reindeer herders, 20-64 years of age, between 1982-1998 presented as deaths per 100 000 persons in five year moving averages. Comparison is made with equivalent values for the agricultural (includes farming, reindeer herding, forestry, fishing and hunting) and building and construction sectors (ISA 2003).

The high number of work-related accidents among reindeer herders puts reindeer herding in top among the most hazardous occupations in Sweden. A comparison of the present results and official statistics on work-related accidents in different occupations shows that work-related fatal accidents is 2-6 times as common among reindeer herders as within the agricultural (including farming, forestry, fishing industry, hunting and reindeer herding) and the building-construction sectors (Figure 10) (ISA 2003). A preliminary comparison between reindeer herders and different occupations within the demographically matched control population, strengthen the conclusion that reindeer herding is indeed a hazardous occupation.

It should be quite possible to reduce the number of both fatal and non-fatal work-related accidents by suitable adjusted preventive measures, e.g. education, modified work organisation,
technical improvement on vehicles, clothing and communication equipment. Promising attempts to bring down the number of accidents and musculoskeletal pain conditions among reindeer herders have been reported previously (Daerga et al. 2004; Pekkarinen et al. 1992). An obstacle for implementation of such measures, however, is the poor financial situation within the reindeer-herding sector, at a time when the need for investments in occupational health promoting activities is very high.

Cancer

The overall cancer risk was 40% lower among the reindeer breeding Sami than in the Swedish general population. When the observed number of cancer cases among the reindeer breeding Sami was compared to expected number of cancer cases derived from residents in the same geographical area, the lower cancer risk was reduced by about 20%. Significant differences between the reindeer breeding Sami and the geographically matched non-Sami reference population were observed only for cancer of the stomach and the prostate, and for malignant lymphoma. The results suggest that the explanation for the reduced cancer risk in relation to the non-Sami in the same environment is to be found among lifestyle and/or genetic factors.

The observations made by comparing the cancer incidence of the study cohorts and the geographically matched reference populations could potentially have been caused by differences in mortality and/or migration patterns within the different populations. A comparison of the mortality and the averaged age of death between the study cohorts and the corresponding geographically matched control populations, however, reviled only small and insignificant differences (Figure 7). Of the groups that migrated out from the reindeer breeding area during the follow-up period, there was no overrepresentation of cancer cases among the reference population, but an indication of an over-risk among the reindeer breeders. The latter indicates that migration among reindeer breeders could be caused by a need for medical attention or a lack of physical fitness to work with reindeer breeding, which in turns support the argument of lifestyle factors influencing the cancer risk of the reindeer breeders. Yet, together these findings suggest that the low cancer risk among the reindeer breeding Sami is not a result of differences in mortality or geography of residency between the Sami and the reference populations.

Under-diagnosis is one of the factors that potentially could explain the lower cancer incidence among the reindeer breeding Sami. The observation that there was no difference in cancer mortality between the reindeer breeding Sami and the geographically matched non-Sami, could indicate that under-diagnosis is a contributing factor. However, the relative number of cancer cases found incidentally at autopsy and the frequency of cases diagnosed at autopsy was about the same for the reindeer breeding Sami and the geographically matched non-Sami. Taken together, these observations suggest that under-diagnosis is not the major reason for the low cancer incidence.
The equally high cancer mortality in combination with a lower cancer incidence might be explained by the fact that the non-Sami to some extent suffer a higher risk to develop cancers with good treatment prognoses, and/or that the Sami possess a higher risk for more malignant cancers. This explanation is supported by the findings that the risk to get prostate cancer, which to a large extent is curable, is significantly higher among the geographically matched non-Sami, while the Sami suffer a significantly higher risk to get cancer of the stomach, which is a highly fatal form of cancer (SoS Report 2000).

In a large number of studies it has been evident that dietary habits are strongly related to the risk of gastrointestinal cancer (for reviews, see Palli 2002 and Weisburger 2000). Smoked food and foods rich in salt, nitrite and preformed nitrous compounds are associated with an increased risk, whereas a high consumption of fresh fruit and raw vegetables and a high intake of antioxidants are related to a reduced risk. Thus, since a high intake of smoked and salted food and a low intake of fresh fruit and vegetables characterize the reindeer breeder’s diet (Håglin 1988, 1999), it seems likely that their dietary habits have a strong impact on their high risk to develop stomach cancer (Soininen et al. 1998; Haldorsen & Tynes 2005).

During the last decades, the incidence and mortality rates of stomach cancer have been dramatically reduced in most Western countries, including Sweden (SoS Report 2000). Interestingly, the incidence rate appears to have decreased faster among the reindeer breeding Sami than within the general Swedish population (cf. Figure 8). A possible reason for this could be that the differences between the dietary habits of the reindeer breeders and those of the general population have been reduced over the last decades (Håglin 1988, 1999).

It is well established that there are substantial differences in incidence and mortality of prostate cancer within various ethnic groups. For instance, the incidence rate among black American men is about 13 times as high as that of Japanese men (Whittermore 1994). The results of the present study add to the impression that the low risk to develop prostate cancer is a common trait for native people of the circumpolar region (e.g. Mahoney & Michalek 1991; Højgaard Nielsen et al. 1996). Although it is known that dietary habits and low physical activity constitute the major risk factors related to prostate cancer, it has been shown that such factors only to a limited extent can explain observed ethnic differences (Whittemore et al. 1995). The finding that there is a considerably lower risk of prostate cancer among the reindeer breeding Sami, in spite of dietary habits that include a number of risk factors (i.e., high intake of calories and meat; low intake of fruit and vegetables), strengthen the conclusion that lifestyle factors have a limited impact on ethnic differences in prostate cancer incidence.

It has been suggested that ethnic differences in cancer risk can be due to ethnic variations in polymorphic alleles of genes that are related to modest alterations in risk (Shibata & Whittemore 1994). In previous studies of associations between cancer and the human serum protein orosomucoid (ORM), it has been shown that ORM may act as a blocking factor that protects the
tumour cells against an immunological attack (Samak et al. 1982; Mittermuller & Weidinger 1992). The frequency of the alleles controlling the production of ORM is ten times lower among the Sami as compared to the non-Sami (Fan et al. 1993; Fan & Sikström 1994). This difference could contribute to the lower cancer incidence among the Sami people.

The low and rather constant incidence ratios of leukaemia and cancer of the thyroid gland suggests that the radioactive fallout products from nuclear weapon tests and the power plant accident in Chernobyl have had a marginal, if any, impact on the cancer risk among the reindeer breeders. The lack of a significant increase of radiation sensitive cancers is in accordance with the demonstration of an unchanged risk for acute childhood leukaemia between 1980 and 1992, in areas of Sweden highly contaminated by radioactive particles from the Chernobyl accident (Hjalmars et al. 1994). These findings are also in line with results showing that exposure to low doses of radiation does not result in any increased risk to develop cancer of the thyroid (Holm et al. 1988). Although a recent study, focused on the fallout of caesium-137 in relation to cancer incidence, showed indications of a slight exposure-related increase of the total cancer incidence in northern Sweden after the Chernobyl accident (Tondel et al. 2004). This would imply that the risk to develop cancer has increased slightly both among Sami and the non-Sami population.

There is still a lack of comparative studies that study the prevalence of cancer in relation to risk factor patterns for various Sami populations with different lifestyles. Such studies could generate important findings regarding the factors that reside in the traditional Sami lifestyle and in the western lifestyle that influence the risk for cancer in positive and/or negative ways. No genetic studies has so far been done to systematically investigate if the prevalence of different 'cancer genes' is more or less common among the Sami compared to the non-Sami. Such studies could not only give important clues to the understanding of the low cancer risk among the Sami, but also shed some light on how heritage and lifestyle interact in the development of cancer.

**Cardiovascular diseases**

The incidence ratio of stroke, but not of AMI, was significantly increased for both Sami women and men who have adopted a more westernised lifestyle. Among the reindeer herding Sami, the men demonstrated a reduced risk for stroke while the women revealed an increased stroke risk and a decreased risk for AMI. Thus, the conclusion of Paper I, that the excess mortality from CVD for Sami women was due to an increased risk for developing CVD in comparison with that for Sami men (Wiklund et al. 1989; Tverdal 1997; Näyhä & Järvelin 1998; Näyhä 1997; Paper I), was partly confirmed for the reindeer herding Sami but not for the non-herding Sami. The reindeer herding women showed higher net income and educational levels in comparison with reindeer herding men, suggesting that their elevated risk for developing stroke might reflect a combination of psychosocial and lifestyle factors rather than traditional socioeconomic ones.
Morbidity and mortality

The present study substantiates previous results showing that Sami women have significantly increased mortality risks from ischemic heart diseases in comparison to non-Sami women in the same region (Paper I). However, the incidence of AMI showed no differences between the Sami and the non-Sami, neither for men nor for women. The discrepancy between the mortality and the incidence risks indicates that AMI are under-diagnosed among the Sami women or that the mortality is elevated due to long distances to hospitals. The latter seems less likely though, since it would imply a similar discrepancy for Sami men. Moreover, if long delays between the occurrence of the AMI and the emergency care are the main reason for the excess AMI mortality one would expect higher mortality rates for the reindeer herding Sami, who spend a considerably amount of time far from roads. This conclusion is also supported by other studies showing that long distances to hospitals are poorly associated with coronary mortality in Sweden (Gylleryp et al. 1992). Thus, the incidence of AMI might be under-estimated among Sami women, possibly as a result of socioculturally mediated hesitation to consult the local health care centres and regional hospitals (cf. Larsen 1992).

While the reindeer herding Sami men had a reduced risk to develop stroke, the other Sami men displayed an increased incidence rate in relation to the demographically matched control population. These results are partly in conformity with Norwegian and Finnish studies, which showed significantly decreased CVD mortality for Sami men in comparison to non-Sami in the same regions (Tverdal 1997; Näyhä & Järvelin 1998; Näyhä 1997). The reason for the higher incidence rate of the Swedish non-herding Sami is obscure since they appear to be similarly exposed to behavioural and biomedical risk factors (Paper IV). The explanation is perhaps related to the acculturation process, which has affected the non-herding Sami differently from the herding Sami (cf. Berry 1985; Kvernmo & Heyerdahl 2003). Due to governmental policy ever since the 1900-century, the privilege to use the mountain areas for reindeer herding, fishing and hunting has been restricted to a rather small group of Sami, while the majority has been expected to be assimilated into the Swedish society (Beach 1981; Ruong 1982). This segregation policy leaves the non-herding Sami without possibilities to practise a traditional lifestyle and culture despite their Sami origin. Whether this discrimination has created psychosocial conditions that contribute to the increased risk for CVDs remains to be elucidated in future investigations, however.

Socioeconomic risk factors

The data on income and education do not suggest that the observed differences in stroke incidences and AMI mortality were caused by dissimilarities in socioeconomic status to any
important extent. In spite of the lowest income and educational levels the reindeer herding men demonstrated the lowest risk for stroke, and a similar risk for AMI as among the demographically matched control population men. In addition, the Sami women showed higher risks for AMI and stroke in comparison to women in the demographically matched control population, despite similar levels of income and education. Thus, for the Sami these socioeconomic factors appear to be poorly related to classical risk factors for CVD such as high unemployment rate, poor diet, and unfavourable smoking and alcohol habits (Marmot et al. 1997; Lynch et al. 1996, Paper IV). The factors that affect socioeconomic status within the reindeer herding communities are probably more associated with occupational skills and family relations (Salonen 1982; Silventoinen et al. 2005). The kind of apprenticeship used in the reindeer herding management, where the elderly teaches the younger skills of breeding and herding reindeers, is not part of the Swedish educational system and therefore not documented in official statistics. Furthermore, the dietary habits are not much influenced by the level of income since the basic elements of the Sami diet, reindeer meat and fish (Håglin 1988, 1999; Nielsen et al. 1999), are the main products of their reindeer breeding businesses. The reindeer breeding lifestyle also contain factors that could have positive effects on the risk for CVD, such as high level of physical activity, fresh air, abundance of dietary selenium, zink, vitamin B and soft water (cf. Nyström et al. 1986; Gyllerup et al. 1992; Näyhä et al. 1994; Näyhä 1997; Hermansen et al. 2002; Paper IV; Daerga et al. 2004).

Psychosocial risk factors

The most intriguing finding in Paper I and V was perhaps the differences between Sami men and women regarding CVD, particularly the risk for stroke. There are several possible explanations for the elevated risks among the reindeer herding women. It has been indicated that Sami women in Norway have higher BMI, elevated cholesterol and triglyceride concentrations, and higher blood pressure (Tverdal 1997; Njølstad et al. 1998; Hermansen et al. 2002). However, these differences were not confirmed in our study on Swedish Sami women, irrespectively of whether they were from reindeer herding families or not (Paper IV).

While there were no significant gender differences regarding the anthropometrical and biomedical risk markers, small but statistically significant disparities of some psychosocial risk factors were observed. The reindeer herding Sami women showed lower intellectual discretion, decision latitude and social support at work (Paper IV), together with lower levels of physical activity (Daerga et al. 2004). Such psychosocial and behavioural risk factors are related to increased risk for CVD (Marmot et al. 1997; Lynch et al. 1996; H Baiery Merz et al 2002; Hammar et al. 1998), and it has been indicated that women are more sensitive than men to psychosocial risk factors related to unhealthy working conditions (Hallman et al. 2001).

This might indicate that the reindeer herding women have a more stressful working situation (Daerga et al 2004). This was also somewhat supported by the observation that the reindeer
herding women assessed their social and physical quality of life as low. While the reindeer herding men are responsible for the daily management of the reindeers, the women are typically responsible for service functions related to the reindeer business (e.g. providing food supplement to the reindeers, vehicle transportation of reindeers and the meat management during slaughter), along with the responsibility for the household and the family’s social network (Amft 2000). To guarantee a reasonable family income in response to an insecure and variable profit from the reindeer breeding business (cf. Figure 9), it has become common that the women also hold a regular part-time employment (Daerga et al. 2004). It seems conceivable that the increased responsibility for the family economy has further added to the unfavourable risk factor pattern for CVD among the herding Sami women. An alternative interpretation is that the increase in net income has increased the women’s economical independence and hence has improved their psychosocial conditions. The latter is somewhat supported by the fact that deaths from CVD has decreased significantly since the 1960th (Paper I). Yet, one would expect that potentially positive effects on CVD due to increased income would appear with a longer delay, i.e. to show up within a few decades. Thus, the results support the previous suggestion that the Sami women’s high risk for CVD is caused by exposure to unfavourable psychosocial risk factors, perhaps together with insufficient daily physical activity (Paper I).

The patterns of exposure to socioeconomic and behavioural factors among Sami and non-Sami suggest that the main reasons for the differences in reported CVD mortality are to be found in other risk factors. It could be that genetic and sociocultural factors are important for the mortality differences. The observation that the prevalence of CVD within the family was more uncommon among the Sami than the non-Sami has previously also been reported among Norwegian Sami (Utsi & Bønaa 1998), and could indicate that the Sami are less genetically predisposed to develop CVD (see below, ‘Subarachnoid haemorrhage’). Finally, it should be inferred that psychosocial-behavioural parameters that are currently established as risk factors for CVD have mostly been identified through studies on Caucasian populations. These risk factors might not necessarily have the same impact on different ethnic and gender groups, depending e.g. on differences in genetic predisposition, environmental and culture exposure.
Behavioural risk factors

Smoking and large consumption of alcohol, both well-recognised risk factors behind CVD, were not more common among Sami than among non-Sami (Paper IV). This is basically in agreement with earlier studies on Finnish reindeer herders (Poikolainen et al. 1992), and shows that high consumption of alcohol is a characteristic of most men in the northern parts of Scandinavia, regardless of ethnicity and occupation. The finding of high consumption of saturated fat among the reindeer herding Sami was in conformity with earlier studies (Håglin 1999). However, it was somewhat unexpected that the large fat consumption did not induce any increased blood lipids. A possible explanation could be e.g. that the fat is metabolised due to high levels of physical activity, or that the there are different intestinal mechanisms of fat absorption. The reindeer herding Sami men had lower blood pressure than the non-Sami men. This is in agreement with data from Sami men in northern Norway demonstrating lower blood pressure and incidence of AMI than among Finns and Norwegians (Thelle & Forde 1979).

Subarachnoid haemorrhage

The incidence of SAH was significantly elevated for all Sami groups except for reindeer herding men (Paper V), which basically is in agreement with the mortality data (Paper I). It has been suggested that genetic factors have smaller effects on the risk for stroke and ischemic heart diseases in comparison with behavioural and lifestyle factors (Alter et al 1986). However, SAH might be hereditary predisposed to a larger extent. For instance, the first-degree relatives to patients with SAH run a 3-7 times larger risk of developing SAH (van Gijn & Rinkel 2001). It has also been shown that gender, ethnicity and region have a marked influence on the incidence of SAH. Women have a 1.6 times higher risk than men, and black Afro-Americans a 2.1 times higher risk than white Caucasians (van Gijn & Rinkel 2001). Alcohol consumption, cigarette smoking, hypertension and large coffee consumption are other known risk factors for SAH (Isaksen et al. 2002). Except for high coffee consumption there is no indication of these risk factors to be more common among the Sami (Håglin 1988; Nilsen et al. 1999). Thus, the data support a genetic predisposition for SAH among Sami (Paper I; Lindgaard et al. 2003) since the incidence rates were significantly elevated both among herding and non-herding Sami in comparison with the non-Sami reference population. Significantly higher frequency of the Leiden mutation, which is known to predispose an elevated risk for thrombosis, has been observed among Sami compared to non-Sami (Kuismanen et al. 1999). Whether there are any causal links between the elevated risk for SAH and the high frequency of the Leiden mutation among the Sami is yet to be studied.
Methodological considerations

The method of reconstruction that the cohorts of this thesis are based upon, allows relatively long follow-up periods with reasonably large cohorts. Together with register data of high quality from the national and regional health registers, conditions for results of reasonable statistical strength are provided for. Using a demographically matched control population with similar qualities, as the standard, also adds to the statistical relevance of the results. The major drawback of the method of reconstruction described above, that contribute to weaken the statistical quality of the results, is the mix of Sami and non-Sami that is present in the study cohorts as well as the control population.

The quality of the data from the national and regional health registers that the studies of this thesis have been based upon has been thoroughly validated (Asplund et al. 1988; De Faire et al. 1976; Rosén et al. 2000; Stegmayr & Asplund 1992). It has for instance been stressed that reliable diagnosis of CVD should be based on clinical findings, and that variations in incidences between studies often are due to different diagnostic methods applied (Alter 1986; Asplund et al. 1988). And although the quality of some registers and diagnoses is better than others it should not have affected the results of the studies undertaken since the observed and the expected cases of the incidence and mortality ratios were extracted from the same registers.

The different Sami cohorts used were obtained from a reconstruction of the Swedish Sami population based on information from national occupational, electoral and kinship registers. The validity of the reconstructed Sami population was found to be acceptable according to independent sources of Sami identity (see above, ‘Construction of a database’), which however implies that the present Sami cohort contain a small proportion of non-Sami and the demographically matched control population a number of Sami (Hassler et al. 2004a). The differences in incidence and mortality rates observed in this thesis would therefore represent minor under-estimations of the actual differences.

The demographically matched reference population of non-Sami was compiled analogous to the Sami population (Figure 6). The non-Sami index-persons were matched to the index-Sami for age, gender and area of residency while the relatives of the index-groups were added to the cohorts irrespective of each other, resulting in small differences in age and gender distribution between the Sami and the reference population (Table 5). However, this should not have had any impact on the results since the mortality risk was calculated as age, gender and time period adjusted mortality rates.
CONCLUSIONS

Major findings

In an international comparison the overall health status of the Sami population of Sweden appears to be good. Many of the health problems that native populations in the circumpolar region faces are not prevalent among the Sami, such as dramatic elevated risks for diabetes, CVD, lung cancer, various infectious diseases and suicide (Bjerregaard et al. 1988; Bjerregaard et al. 2004b; Friberg et al. 2003; Leonard et al. 1997; Mao 1992). The serious health consequences for many native populations that has followed the encounter with the western culture is not observed among the Sami in the late 1900-century. In this perspective it is the similarities in health status between the Sami and the general population of non-Sami that above all should be emphasised. There are generally small differences in risk for the major diseases and causes of death.

Regarding the differences in health between the Sami and the non-Sami, some gender differences are observed. For Sami women, significantly higher SMR was found for all causes, diseases of the circulatory system and diseases of the respiratory system (Paper I). Sami men on the other hand showed an increased mortality risk for external causes of death (Paper I) mostly due to the high number of work-related accidents among reindeer herders (Paper II). An increased risk of SAH was observed among both Sami men and women (Paper I and V). The mortality risk for cancer was lower among Sami men (Paper I) and a general lower risk for cancer among reindeer herders was observed whereas the risk for stomach cancer was significantly higher with a decreasing temporal trend (Paper III).

The mortality ratio for AMI was significantly higher among Sami women but not the incidence ratio (Paper V). For stroke the opposite pattern was observed with higher incidence ratios but similar incidence ratios for Sami women (Paper V). Higher incidence ratios for stroke were also observed for Sami men (Paper V). Gender differences in biomedical and behavioural risk factors for CVD were observed among the reindeer herding Sami (Paper IV). The men had lower blood pressure, were more physically active and had higher job demand and decision latitude while the women showed more negative scores on the job strain variables (Paper IV).

Interpretations in a context of acculturation

A possible interpretation of the Sami health situation in terms of acculturation could be that the policy of separation of the reindeer herding culture, as a result of different variants of the “Sami-should-be-Sami” policy, has helped to preserve protective factors of their traditional lifestyle and genetical heritage. This could have contributed to a generally better health status than among their non-Sami neighbours, but also than among their non-herding fellow Sami.

There seem to be a gender difference in how this acculturative process has affected the health of the reindeer herding Sami. Different effects of coping with the acculturation process could have
influenced the health of men and women in different ways. During the last four decades, reindeer herding women has experienced a dramatic change in their socioeconomic situation. Today she often have a job outside the reindeer herding management, accordingly standing with one foot in each culture. The reindeer herding man, on the other hand, seem to have remained in a more homogenous cultural context compared to the women, although there are indications that part-time employments outside the reindeer husbandry have become more common also among the men.

Gender differences in relation to assumed acculturative stress are not unambiguous, though. A strikingly increased risk of CVD among aboriginal women in the circumpolar region of Siberia is suggested to reflect gender differences in the influence of acculturation and lifestyle changes (Leonard et al. 1997). On the other hand, contrasting indications have been observed on Skolt Sami where changes in economy, ecology and acculturation seem less confounding for the Skolt women than for the men (Seitamo 1995). The higher risk for CVD among reindeer herding Sami women presented in this thesis could partly be caused by strong work demand in combination with a life-situation where the level of responsibility is high in relation to the degree of control (Daerga et al. 2004, Paper IV).

The comfort of remaining in ones traditional culture could also become a trap if there is a lack of transitory ways of changing ones life conditions. A policy of separation has made the ‘reindeer herder a reindeer herder’ but the transition from a primitive economy towards a modern industry has at the same time created new conditions for economical survival that fits badly with the traditional context. Although the studies included in this thesis do not provide any evidence for increased risks of suicide among reindeer herders, there are indications of socioeconomic stress due to the harsh economic conditions of the reindeer herding industry of today. These psychosocial effects of the acculturative process is also accompanied with the physical effects following a stressful work situation most likely contributing to the high rates of work-related accidents in the reindeer herding industry.

So, it seems as if the reindeer herding culture and industry show aspects of segregation that in some respects have had positive health effects and in other respects the contrary. Positive health effects of a traditional lifestyle have been mentioned, but improved health due to acculturative changes is also indicated. The higher risk for stomach cancer observed among Sami is probably caused by the traditional diet of smoked and salted meat and fish and a lack of vegetables and fruit. That this form of cancer has decreased over the years is probably related to a more balanced diet (Paper III).

The health effect of this acculturative process for the other Sami group should most likely be interpreted in assimilationist terms. The “Sami-should-be-Sami” policy that separated the reindeer herders from the rest of the Sami population also meant that the protective health factors of a traditional lifestyle and strong cultural identification have diminished for the other Sami,
who’s health situation has become more similar to that of the general population. Then again this transition might also have had negative health affects beyond just loosing possible protective aspects of the traditional lifestyle. Relinquishing one’s culture identity and moving into the larger society implies cultural loss and health may therefore be affected negatively (Berry 1985). But many of the other Sami most likely lost these health promoting aspects as early as maybe 100-200 years ago, when the forces of assimilation started. But it might also be that scorns of acculturative stress are apparent even today. The higher risk of stroke that has been observed among non-herding Sami men is in contrast to the significantly lower risk for stroke among the reindeer herding men (Paper V). The explanation is perhaps to be found in the acculturation process, which has affected the non-herding Sami differently from the herding Sami (cf. Berry 1985; Kvernmo & Heyerdahl 2003). The privilege to use the mountain areas for reindeer herding, fishing and hunting has been restricted to a rather small group of Sami, while the majority has been expected to be integrated or assimilated into the Swedish society (Beach 1981; Ruong 1982). This segregation policy leaves the non-herding Sami without possibilities to practise a traditional lifestyle and culture despite their Sami ethnicity.

With the proposed ratification of the ILO 169 convention, the rights of the Sami population, and who have the right, to land and to the cultural heritage again have become a political issue. This renewed interest in acknowledging the rights of our native population, could therefore very well lead to a regenerated acculturative stress with the type of negative health effects discussed above.

Finally, in very general terms, two lines of acculturation could be identified when interpreting the Sami policy of Sweden. One of separation or segregation that has been exercised towards the reindeer herding Sami and one of assimilation influencing the other Sami. In this discussion, the concept of acculturation has merely been used to relate the observed health indicators and riskfaktors to the acculturation process, based on rather schematic historical descriptions. The assimilative or separative processes or modes is of course not solely determined by the governmental policies but is also dependent on how these acculturative processes have been coped with by the Sami – individually and in group (cf. Berry 1990). How these coping strategies might have affected the health of the Sami is yet to be empirically studied.
The future?

In an international perspective, the health situation of the Sami population of Sweden appears to be good. However, the health condition has not been thoroughly investigated yet, largely reflecting a lack of national initiatives for such activities from the Swedish authorities. The research that has been done is mainly the result of the interest and the initiatives of individual scientists (for review see Hassler & Sjölander 2005). There are also few of the authors that are of Sami origin, which probably have contributed to the poor relevance of some of the studies and to an uncertainty whether the right conclusions has been drawn.

In the spring of 1999 the University of Tromsø was delegated by the National Board of Health in Norway to investigate the need and prerequisites for Sami health research. This investigation presented its suggestions in 1999 and two years later the Center for Sami Health Research ('Senter for Samisk Helseforskning') was established in Karasjok. The main task for the centre is to conduct interdisciplinary research and education on Sami health issues.

Corresponding national initiatives is not found in Sweden and Finland. In Sweden the Sami are not mentioned at all in the national policy documents for the Swedish health care system and there is no separate reporting of the health situation of the Sami in the regular reports of the national Board of Health and Welfare (see Introduction).

In many other countries, public health initiatives directed towards the native populations has been part of the agenda in the health care system for many years. In USA, the establishment of the Indian Health in the mid 1950th aimed at finding ways to shape a health care system adapted to the needs of the Natives (Murphy et al. 2004). Since 1968 the Alaska Native Health Board works with planning of research on the health situation of the natives of Alaska (Blum et al. 1992). Similar efforts have been done in Canada where special health organisations, with the aim of fulfilling the health needs of the Natives were founded already in the beginning of the 20th century. In the The Federal Indian Health Policy from 1979 the responsibility of the Canadian state towards the health situation of the native populations was formulated, and some years ago The Institute of Aboriginal People’s Health was established to coordinate and to develop the health research on the indigenous peoples of Canada (Young 2003).

Evaluation of health care programmes directed towards native populations in other parts of the arctic region have brought forward valuable knowledge of gender specific ethnocultural differences in the attitudes and handling of sickness, pain, health and health care (e.g. Inuits in Canada and Greenland; Elsass et al. 1994). Equivalent knowledge from the Sami is scarce.

In the Budget Bill of 2005 regarding the research policy that just recently was presented by the Swedish government, the Sami are mentioned on two occasions (Regeringens proposition 2004/05:80). First, regarding research on Human Rights for certain groups of the population, the Sami are mentioned as an example of a group that could be covered by such studies. Second, in
order to create sustainable conditions for the reindeer herding industry, the Bill also suggests certain research contributions. Thus, again the health and living conditions of the Sami people has been left unrecognised.

Even if it earlier on was motivated with directed health efforts towards the Sami it is not something that would be justified today, considering the relatively good health situation that seems to be the case of the Sami. But there might still be regional or specific needs that could motivate special efforts. One such example is the need to reduce the number of musculoskeletal symptoms, fatal accidents and psychosocial risk factors among reindeer herders. The establishment of occupational health measures in order not only to improve the health situation of the reindeer herders but also to help create conditions for a sustainable industry, has also been suggested (Daerga et al. 2004; Regeringens proposition 2004/05:80).

One important experience that has been made in Canada is that improvements of the health situation of the indigenous peoples will not come from just improved access to health care services alone, but through increasing control over the determinants of health (Newbold 1998). Allocating resources to programs aimed at meeting the health problems identified by Aboriginals themselves, such as education programs and community control over resources and health management, might be a better choice in order to improve the health situation. Similar efforts in the Nordic countries could improve the prerequisites for research on the Sami health situation, significantly. Efforts where the Sami themselves have a real influence over what and how research is being done. This would promote investigations of relevant health issues and that the results are analysed and interpreted in an initiated way.

Mötet med den västerländska livstilen har för många ursprungsbefolkningar fört med sig dramatiska hälsokonsekvenser. De första kontakterna förde med sig infektionssjukdomar såsom smittkoppor och tuberkulos, medan det fortsatta västerländska inflytandet påverkat livsstilen på ett mer omfattande sätt och orsakat en dramatisk ökning av livsstilsrelaterade sjukdomar som cancer, diabetes, stroke, övervikt och högt blodtryck. Den psykiska hälsan har också påverkats negativt hos många ursprungsbefolkningar till följd av det västerländska inflytandet, och bl.a. gett upphov till en dramatiskt ökad självmordsfrekvens och ökat droganvändande.

Sambandet mellan ackulturation och hälsa har länge diskuterats när hälsoläget hos ursprungsbefolkningar studerats. Ackulturation definierat som kulturförändring orsakad av kontinuerlig kontakt mellan två skilda kulturer, kan ge upphov till olika former av psykisk och fysisk ohälsa. Hos de circumpolära ursprungsbefolkningarna har ackulturationsprocessen ofta inneburit en ofördelaktig förändring av hälsoläget. Även om samernas roll och status genom historien beskrivits i mer generella termer, har dessa processer ännu inte utförligt värderats i förhållande till deras hälsosituation.

Det övergripande syftet med denna avhandling är att undersöka och beskriva samernas hälsoläge, via hälsoindikatorer som dödsorsaker och förekomst av cancer och hjärt- och kärlsjukdomar, och att diskutera hälsoläget i förhållande till olika demografiska och ackulturella förhållningssätt som assimilation, integration, separation och marginalisering.

För att kunna genomföra registerepidemiologiska studier på samer i Sverige har en databas skapats. Databasen innehåller bl.a. information om demografiska förhållanden hämtade från Statistiska Centralbyråns (SCB) befolkningsregister samt utdrag ur Socialstyrelsens olika hälsoregister (dödsorsaksregistret, cancerregistret och patientregistret).

Då information om etnisk tillhörighet inte förekommer i svenska myndighetsregister har skapandet av databasen skett genom ett försök rekonstruerar den samiska befolkningen i Sverige. Rekonstruktionen utgick från de två definitioner av samisk identitet som förekommer i svensk lagstiftning, nämligen de som reglerar rätten att rösta i Sametinget samt rätten att bedriva renskötsel. Med utgångspunkt från dessa definitioner, och de register (Sametingets rösträtt och Jordbruksverkets register över rennäringen) där dess samer kunnat identifieras, har en grupp index-samer identifieras. Genom att ta fram släktingar till dessa index-samer via befintliga
släktskapsregister har en samisk population sedan kunnat rekonstrueras. Totalt består samekohorten av 41 721 individer (7 482 rensköttande samer och 34 239 icke rensköttande samer). Delar av denna studiepopulation har sedan använts till de olika studierna i avhandlingen. En fyra gånger så stor demografiskt matchad kontrollpopulation av icke-samer har också tagits fram på liknande sätt.


De biomedicinska och psykosociala riskfaktorerna för hjärt- och kärlsjukdomar bland svenska samer studerades i en kontrollerad kohort studie (Artikel IV). Studien visade att samer och icke-
samer hade ett liknande riskfaktormönster. Bland renskötare däremot, noterades vissa köns skillnader beträffande vissa beteendelaterade, biomedicinska och psykosociala riskfaktorer. Renskötande män hade lägre blodtryck och beslutsutrymme på jobbet, medan kvinnorna uppvisade lägre intellektuell stimulans, mindre kontroll och socialt stöd i arbetet.


De skillnader i inkomst och utbildningsnivå som noterades gällde främst renskötande samiska män som hade signifikant lägre inkomst och utbildningsnivå än såväl icke-samer som icke renskötande samer. Inkomstnivån för renskötande kvinnor är i stort sett lika med icke-samer medan de uppvisar större andel högutbildade. Inkomst- och utbildningsnivå för icke renskötande samer och icke-samer var i stort sett lika. Sammantaget pekar resultaten på att det är rimligt att anta att skillnaden i incidens av stroke beror på psykosociala riskfaktorer snarare än de traditionellt socioekonomiska.

Som visats i studierna så är skillnaderna i hälsa mellan samer och icke-samer relativt små, vilket kontrasterar starkt till förhållanden för många andra ursprungsbefolkningar som uppvisar sämre hälsa jämfört med den övriga befolkningen.

Utifrån svensk samepolitik kan två huvudprocesser identifieras gällande förhållandet samer och det svenska samhället. En av separation eller segregation som gällt renskötande samer och en andra av assimilation som gällt den övriga samiska befolkningen. Av resultaten i studierna att döma så verkar den förra ha varit mer hälsobefrämjande då den förmodligen fått till följd att vissa positiva hälsoeffekter i den traditionella livsstilen bevarats. Men de huvudsakliga likheterna i hälsa mellan samer och icke-samer antas ändå bero på samernas relativt långtgående integration och assimilation med det övriga svenska samhället. Processer som till skillnad från många andra ursprungsbefolkningar pågår under mycket lång tid i de Nordiska länderna. Faktorer som spelar in för likheterna i hälsa är bland annat graden av blanddäktenskap, likheter i kultur och livsstil samt lika tillgång till sjukvård och sociala trygghetssystem.
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This thesis is dedicated to the Sami of Sweden and if it in any little way could contribute to the improvement of the health or the living conditions of the Sami of Sweden, it certainly has served its purpose. My humble wishes for the good of this dissertation are therefore that it could serve as a tool, however little, for the work of the best of the Sami.

In accomplishing this thesis, there are many that I owe gratitude to and I would like to start with the Sami people. Without the support and participation of the Sami Parliament (‘Sametinget’), the Sami organisations like SSR (‘Svenska Samernas Riksförbund’) and the Sami communities (‘Samebyarna’) of which I most of all would like to mention Vilhelmina Södra and Vilhelmina Norra, this thesis would not have been written. Health studies on an ethnical minority is a delicate matter which we from the very start of this project was very well aware of. And it should of course be a delicate matter! Historical wrongdoings in the name of science (measurements of sculls in the 1930s) have given us an answer to why. So without the support from the Sami in the initial stage of the project (1998), we would most certainly have backed off from the project. But I’m glad that we didn’t have to.

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