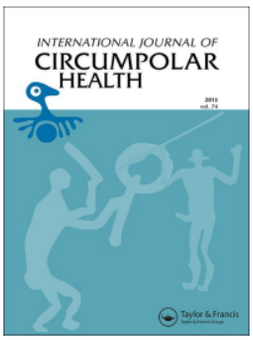

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A population-based study on health and living conditions among Sámi in Sweden: the SámiHET study

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ABSTRACT

The aim of this paper was to describe the study design, data collection procedure and participation of the population-based study "Sámi Health on Equal Terms" (SámiHET) conducted among the Sámi in Sweden in 2021. A Sámi sample was constructed, drawing from three pre-existing-registers: the Sámi electoral roll, the reindeer mark register and the "Labour statistics based on administrative sources" register to identify reindeer herding businesses. All identified persons aged 18–84 were invited to participate during February–May 2021. Among the 9,249 invitations, 3,779 answered the survey (participation rate of 40.9%). More women than men participated, and the age group 45–64 was the most common in both sexes. Around 10% of participants were in the youngest group. A majority of participants were residents of Norrbotten (48%), while almost one fourth were living outside Sápmi (22%). SámiHET has been demonstrated to be a feasible and cost-effective way of investigating health and living conditions among the Sámi in Sweden, providing information easy to compare with Swedish data. The knowledge to be produced may be used to inform policy to guide and improve Sámi health, thus contributing to realising the equal health rights of the Indigenous Sámi in Sweden.

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Sámi; indigenous; epidemiology; ethnicity; health; arctic

Introduction

Sámi people live in the northern parts of Norway, Sweden, Finland and north-western Russia. Sámi have inhabited their homelands (*Sápmi*) since time immemorial and are a distinct people with their own culture(s) and language(s). Sámi have historically been subjected to policies of assimilation and segregation and experienced persecution for their culture, language and religion. Even during the 20th century, the Swedish state has been responsible for forced relocations of Sámi reindeer herders, boarding school systems where the Sámi language was forbidden and racial biological investigations to prove Sámi racial inferiority. Also, Sámi has lost control of their traditionally used lands and water, which is today owned by the Swedish state and private land owners. However, a Sámi resurgence has gradually taken place since the second half of the 20th century, and the new generations are increasingly proud of their ethnicity, culture and language [1,2]. While a common assumption estimates that some 20–40,000 Sámi live in Sweden [3], the precise number and demographic composition of the Sámi people in Sweden remains unknown.

Population-based health studies among Sámi in Sweden are scarce and outdated. The last quantitative studies on Sámi health utilised datasets collected in 2007 and 2008 [4–7], and register-based health information is available only until the year 2000 [8]. One of the greatest challenges has been the difficulty in identifying the Sámi population due to the prohibition by law to register ethnicity in national population registers.

Researchers have tried to overcome this problem, mainly through utilising the electoral roll of the Sámi parliament. For example, several mortality and patient-based studies were conducted in the beginning of 2000s using this approach [8,9]. Similarly, cross-sectional studies conducted in the first decade of 2000s used this approach to explore the health of young people (18–28 years) [4] or adults (18–84 years, 5). Other strategies have been to cooperate with Sámi civil society organisations such as *Sámiid Riikkasearvi* (which organises local Sámi associations and Sámi reindeer herding communities) to explore particular topics among reindeer herders, including mental and behavioural health [10–12], quality of life and access to health care [13,14]. Yet another approach has been to use geographic proxy-methods using municipalities where about 10% of the adult population are enrolled

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to vote in the Sámi parliament elections, which is a very crude strategy to capture Sámi health status [15].

On the Norwegian side of Sápmi, where epidemiological studies on Sámi health have been conducted since the 2000s, another main approach has been used: inviting the total population of geographical areas where many Sámi live to partake in clinical and questionnaire studies [16,17] or in school settings where Sámi children attend [18]. In these studies, Sámi are encouraged to self-identify and report the ethnicity and language competence of previous generations. Quantitative health studies among Sámi in Finland and Russia are very rare in the literature, with a systematic review on somatic health among Sámi identifying only two studies from Finland, and no studies from Russia, 2000–2017 [19].

Both a United Nations special rapporteur on the right to health and the Sámi parliament in Sweden have defined the production of updated and accurate health information on the Sámi a key priority for the realisation of equal Sámi health rights in Sweden [20,21]. Supporting this goal, the Sámi parliament and the Public Health Agency in Sweden (PHAS) in 2020 contracted the Department of Epidemiology and Global Health (EpiGH) at Umeå University, Sweden, to conduct studies to update the knowledge regarding the health status of the Sámi population using both self-reported and register-based approaches.

The aim of this paper is to describe the study design, data collection procedure and participation of the population-based study "Sámi Health on Equal Terms" (SámiHET) conducted among Sámi in Sweden in 2021.

Methods

Design, sample selection and data collection

The Swedish HET survey

The PHAS has been conducting a national public health survey, the "Health on Equal Terms" (HET) (*Hälsa på lika villkor*, in Swedish) annually since 2004 and every 2 years since 2016. In 2021, an extra data collection was carried out due to the COVID-19 pandemic. The survey is voluntary and done with the purpose to investigate the health in the population and to show changes in the population's health over time as a follow-up of the national health politics.

The sample is randomly drawn from Statistics Sweden's population register including around 20,000 people aged 16–84 years in the first surveys and increasing to 40,000 from 2018. Response rates have spanned from 60.8% in 2004, decreasing constantly to 42.3% in 2020 [22]. Using the unique personal identification number assigned to all Swedish citizens, the sample data are linked to national registers administered by Statistics Sweden to obtain demographic and socioeconomic information. For instance, data regarding education is collected from the education register, and data on income, economic support, sickness benefits and pensions are collected from the income and taxation register.

The 2021 HET questionnaire included 66 questions, 10 of them related to COVID-19. The questions covered physical and mental health, consumption of pharmaceuticals, contact with healthcare services, dental health, living habits, financial conditions, work and occupation, work environment, safety and social relationships.

This national sample will constitute the comparison group of the Sámi health population-based study.

The SámiHET study

Inspired by the previous studies, three registers were used to identify Sámi and construct a sample population in Sweden: the Sámi electoral roll (SER), the reindeer mark register (RMR) and the "Labour statistics based on administrative sources" register to identify reindeer herding businesses, as defined through the Swedish Standard Industrial Classification.

For a person to be registered in the SER, that person must apply and ensure that they self-identify as a Sámi and either have grown up in a family where Sámi was spoken at home or have a parent or grandparent fulfilling that criterion or have a parent who is or has been enrolled in the SER. A specific board within the Sámi parliament accepts or declines the applications for enrolment.

Theoretically, reindeer herding is a Sámi-specific livelihood in Sweden, as per the Reindeer Herding Act (1971:437). However, most reindeer owners in the concession Sámi communities are non-Sámi (although the active reindeer herders should be Sámi), and non-Sámi reindeer owners are also common in some Sámi communities in the northernmost region of Norrbotten. Because of this, consultations about the most reasonable inclusion and exclusion criteria were held with the Sámi parliament, responsible for managing the RMR, before they were decided upon. As a result, all owners of reindeer marks in forest or mountain Sámi communities, as well as the Muonio Sámi concession reindeer herding community, were included from the RMR. Furthermore, to include Sámi in the concession Sámi communities (who are likely to be actively engaged in the reindeer husbandry industry), all individuals with reindeer herding as a registered source of income in

the taxation registry were included, regardless of what type of reindeer community they belonged to. The resulting Sámi index was cross-referenced with the Swedish population register and all individuals not registered as deceased, with a valid postal address, currently residing in Sweden, in the age span 18–84 years old, were invited to participate.

The SámiHET questionnaire was based on the same questions as the HET survey. However, Sámi-specific sections were added with support from mandated members of the Sámi parliament board, including questions on access to health care, exposure to violence, discrimination and racism, as well as Sámi identity and language. In total, 81 questions were included. Key stakeholders, including both individuals (including Sámi health researchers) and organisations (including the *Sámiid Riikkasearvi* and the Knowledge Network for Sámi Health) actively contributed to the construction of the questionnaire. The SámiHET was piloted among a sample of volunteers in November 2020. Thereafter, mandated members of the Sámi parliament board approved the final version.

The researchers contracted Statistics Sweden to construct the sample and carry out the data collection. The first invitation was sent out on 22 February 2021, containing a letter of invitation and instructions for participating through a secure web-survey format. The physical version of the questionnaire was sent to those who had not participated within 2 weeks' time after the initial letter should have reached their destinations, followed by two additional reminders. The final date of data collection was the 17th of May 2021. The SámiHET data collection procedures mimicked those of the HET. The 2021 HET data collection was also conducted by Statistics Sweden, but starting 1 week in advance of the SámiHET.

The survey was only made available in Swedish, but the invitations to participate, information about the study and letters of reminder were sent out in Northern-, Lule- and Southern-Sámi (the researchers failed to identify available translators into Ume- and Pite-Sámi) as well as Swedish. All of this material, along with a video recording of a webinar explaining the study in Swedish, was made publicly available at the Umeå University website. The study was advertised in Sámi media and on social media platforms.

The collected dataset was pseudo-anonymised (personal identity number exchanged for serial numbers) by Statistics Sweden and thereafter stored at a secure server at Umeå University, with restricted access.

Ethics

The Swedish Ethical Review Authority approved this study (DNR 2020–04803 and Ö 70–2020/3.1). The researchers were contracted by the Sámi parliament in Sweden to conduct this study and continuously consulted with the mandated members of the board of the Sámi parliament throughout the process.

Historically, the Swedish government authorities and past generations of researchers have supported and conducted highly unethical research among Sámi, including racial biology studies aiming to "prove" Sámi racial inferiority. Naturally, among Sámi this has created ambiguity towards academic institutions and a lack of confidence in scientific research. However, this sort of conduct and its consequences are not unique to the Swedish/Sámi context, as many other Indigenous peoples have had similar experiences. In many of those contexts, states have opted to create Indigenous-specific systems and/or ethical guidelines to remedy past injustices and ensure good ethical health research practices moving ahead [23]. Sweden has not. Therefore, the ethical permissions obtained for this study from the Ethical Review Authority cannot be regarded as meeting the current ethical standards in Indigenous health research internationally, for example, including the "collective consent" that is the basis for the Sámi Norwegian Ethical Guidelines for Sámi Health Research [24].

Results

Ten thousand three hundred and eighty potential participants were identified through cross-reference between the Sámi electoral roll, the reindeer mark register, the RAMS register (SNI 01491) and the Swedish population register. Seventy-six of these were excluded from being invited due to them being scheduled to participate in the Swedish national HET survey. Another 1,055 persons were excluded due to being deceased (n = 30), having migrated from Sweden (n = 280), not being identifiable by Statistics Sweden (n = 50) or not being Sámi (reported by phone, n = 15; reported in the questionnaire, n = 680). The sampled population thus included 9,249 individuals.

Participation

Among the 9,249 invitations, 3,779 answered the survey and were included in the study, corresponding to a participation rate of 40.9%. However, of these, 121 persons did not unequivocally self-identify as Sámi; that is, when answering the first survey question: "how do you define yourself?" They did not tick the box for having a Sámi identity. Because of these circumstances, they were excluded from further analysis. A flow chart of the construction and participation in SámiHET is included in Figure 1.

In total, 3,658 individuals constituted the analytical sample. Most of the participants (92.92%) were in the SER, 40.05% in the RMR and 6.45% were registered as receiving income from reindeer husbandry. A total of 2,067 (54.5%) participants chose the web-based questionnaire. Table 1 presents the distribution of participants by sex and age and in total. More women than men participated, and the age group 45–64 years old was the most common in both sexes.

Around 10% of participants were in the youngest group. Most of the participants lived in the three northernmost counties of Norrbotten (48%), Västerbotten (23%) and Jämtland Härjedalen (7%), while almost one-fourth lived outside these counties (22%) (Table 2).

Table 3 presents the analysis of potential sources of selection bias in the survey. Overall, there was a similar representation regarding the selected demographic and socioeconomic variables in both groups. However, an overrepresentation of women and highly educated participants was found.

Discussion

This study described the study design, data collection procedure and participation in a self-reported population-based public health study among the Sámi people in Sweden. In the following, we will discuss some of the

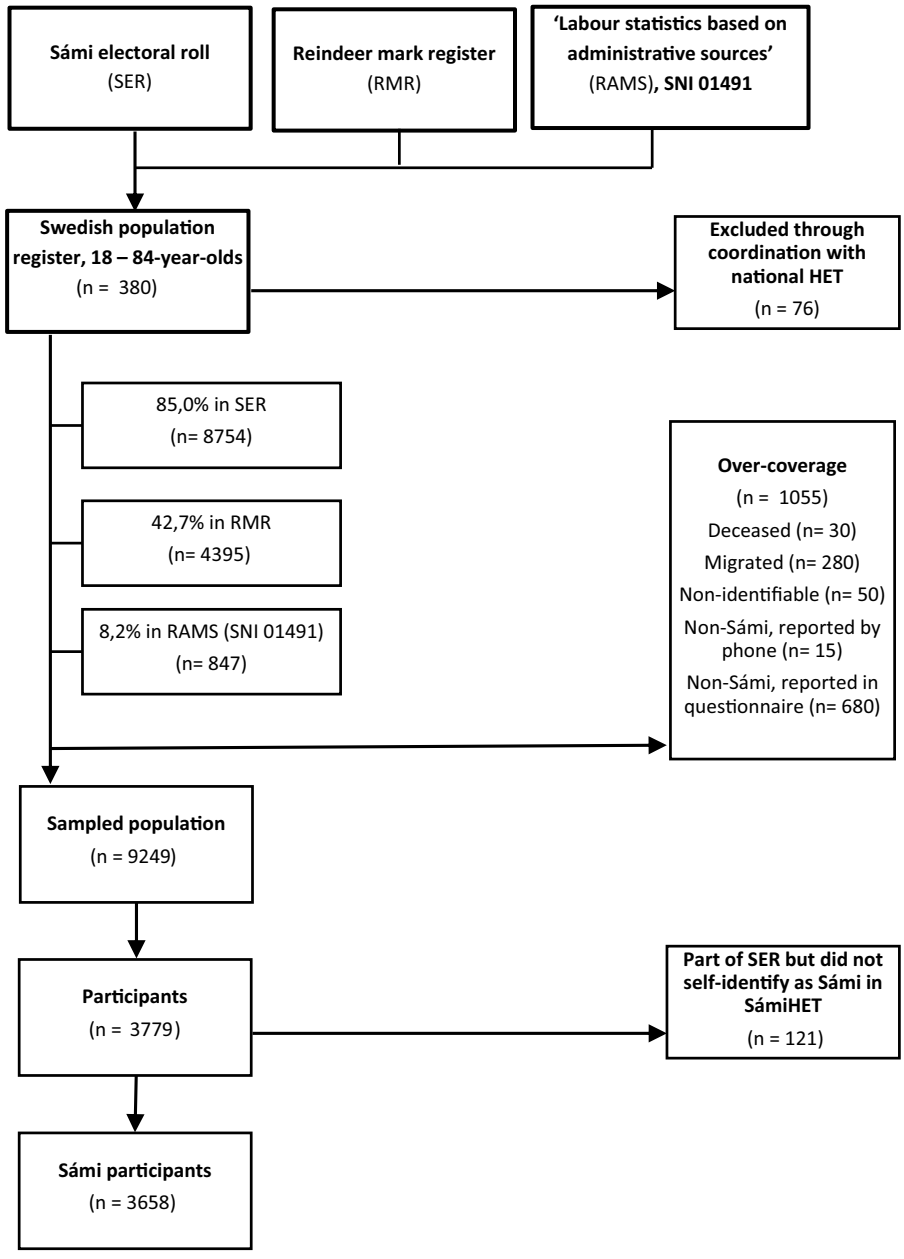

Figure 1. Flow chart of the sample construction and participants in the SámiHET study.

Table 1. Participation of self-identified Sámi, by age and sex, in SámiHET 2021 (percentages in brackets).

	Men	Women	Total
18–29	137 (8.62)	227 (10.98)	364 (9.95)
30–44	287 (18.05)	481 (23.26)	768 (21.00)
45–64	611 (38.43)	791 (38.25)	1402 (38.33)
65–84	555 (34.91)	569 (27.51)	1124 (30.73)
Total	1590 (100)	2068 (100)	3658

Table 2. Participation of self-identified Sámi, by region and sex, in SámiHET 2021 (percentages in brackets).

	Men	Women	Total
Norrbotten	785 (49.37)	963 (46.57)	1748 (47.79)
Västerbotten	404 (25.41)	430 (20.79)	834 (22.80)
Jämtland	106 (6.67)	149 (7.21)	255 (6.97)
Elsewhere in Sweden	295 (18.55)	526 (25.44)	821 (22.44)
Total	1590	2068	3658

Table 3. Differences between participants and non-participants according to selected demographic and socioeconomic variables, SámiHET 2021 (percentages in brackets).

	Participants (n = 3779)	Non-participants (n = 5458)
Sex		
Men	1644 (43.50)	3013 (55.19)
Women	2135 (56.50)	2445 (44.81)
Age		
18–24	182 (4.82)	335 (6.14)
25–34	423 (11.19)	851 (15.61)
35–44	541 (14.32)	875(16.05)
45–54	648 (17.15)	1043 (19.14)
55–64	794 (21.01)	990 (18.15)
65–74	748 (19.79)	751 (13.77)
75–84	443 (11.72)	607 (11.13)
Residence		
Stockholm	313 (8.28)	384 (7.05)
Jämtland	264 (6.99)	329 (6.04)
Västerbotten	861 (22.78)	1118 (20.52)
Norrbotten	1796 (47.53)	2893 (53.08)
Other	545 (14.42)	725 (13.31)
Education		
Primary	453 (12.01)	891 (15.64)
Secondary	1897 (50.29)	3461 (60.76)
Tertiary	1422 (37.70)	1344 (23.60)

challenges in implementing the study, and what impact this new data may have both on the knowledge about Sámi health and priorities for the future.

The moderate participation rate (40.9%) was slightly below the results of a similar study conducted by the PHAS in the Swedish population during the same period, 44.3% [25]. Among those included in this study because of being enrolled in the SER, the response rate was 43.6%. Because SER differs from the other inclusion criteria through all individuals in it being Sámi (by definition), this suggests that a substantial amount of the lower response rate among non-SER participants (22.6%) might be explained by a larger proportion among them not being Sámi (but not having returned the questionnaire and opted out of the study, thus decreasing the response rate). While it is not possible to prove that this was the case, another hypothesis might be related to selection bias, where the Sámi in the SER were more prone to respond to the questionnaire. Regardless, the response rate in the SámiHET was substantially higher than in the SAMINOR 2 questionnaire study conducted in Sámi areas in Norway (response rate 27%) in 2012 [17].

Several considerations were taken into account to fit the Sámi context such as the study being conducted on behalf of the Sámi parliament (increasing the legitimacy of the study), including information in Sámi languages and incorporating Sámi-specific themes and questions. Other issues that may have contributed to increase participation included that all questionnaires were pseudo-anonymised, that the survey was advertised in Sámi media and that the first author is a well-known Sámi health researcher in the Swedish Sápmi. However, assessing which, if any, of these activities had a positive impact on the response rate is difficult to judge. For example, the first author was contacted both by Sámi who expressed their positive views of the study and some who did not want to take part in the study because of fear of not being anonymous to the research group because of including a fellow Sámi. Also, the inclusion of Sámi-specific questions may not have been unequivocally positive. For example, some participants reported feeling unease when answering the items regarding (Sámi) identity and language competency, perhaps being frightened by the potential of misuse of ethnic registries. Indeed, isolated examples from the free-text self-definitions may also be interpreted as indicative of discontent with the focus on ethnicity, i.e.: "I define myself as a human." However, although this may have had some effect, the availability of the questionnaire only in Swedish might have been a more relevant issue.

The decision to only make the questionnaire available in Swedish was made due to pragmatic reasons to accommodate data collection within the given time frame and to the limited financial and human resources. This decision was supported in consultations with the Sámi parliament. However, the lack of availability of the questionnaire in any of the five Sámi languages spoken in Sweden is a limitation for this study in several respects. Firstly, not being able to answer the questionnaire in one's own language may have impacted the way participants answered the questions both because of (lack of) language proficiency and because of participants adapting to (Swedish) norms of responding. Secondly, and perhaps most importantly, it is possible that the Sámi-speaking population may have refrained from participating if they experienced this as disrespectful. Indeed, the first author received feedback from people during the data collection, arguing that

they would not take part unless the questionnaire was available in Sámi. Although we cannot estimate to what extent this affected the response rate, it is possible that it skewed the dataset in a way that overrepresented the non-Sámi speaking Sámi.

There was an underrepresentation of men, young people and low education among respondents. If these groups were differently affected by the mentioned issues is unknown, but similar issues of underrepresentation in other Sámi public health questionnaire studies suggest not [17]. However, future studies may want to make available the questionnaire in Sámi languages, as well as ramp up communication strategies, to ensure good participation in the aforementioned groups. On a more positive note, a group that stands out in this study is the Sámi living outside traditional Sámi areas. This understudied group [26] participated to the same extent as those living within Sápmi, thus allowing for investigating the health and well-being of Sámi in urban and southern parts of Sweden.

Interestingly, more than half of our participants chose the web-based questionnaire to answer the survey. This was slightly lower than in the national HET survey (64.6%), but much higher than in the Norwegian SAMINOR 2 study where only approximately 16% of the total submitted questionnaires were digital [17]. The increased digitalisation of Scandinavia within the almost 10 years difference between the studies probably accounts for most of this disparity. This is therefore an encouraging result since digital surveying, in addition to reducing costs, may also increase the feasibility to offer the survey in different Sámi languages.

It is important to note that overall there were very few missing data in the variables, even for the questions that could be considered particularly sensitive. For instance, in the section related to experiencing violence the missing pattern reached only 5%. This finding is encouraging since it indicates that the Sámi want to participate in studies even if they include sensitive and possibly taboo issues.

The findings from SámiHET may now be used for improving public health work among the Sámi in Sweden, as well as to create a research infrastructure. In both cases, SámiHET offers unique possibilities as it includes a large enough sample size to allow for subgroup analyses as well as a dataset that may be compared with the Swedish HET data. Furthermore, this feasible and pragmatic approach has already been recognised, as the Swedish government recently ordered the PHAS to bring forth a plan for a system centred around the HET to continue monitoring health among Sámi in Sweden. The fact that the sample in the SámiHET was identified through registries opens many new research possibilities through the creation of follow-up studies, cohort studies and register-based studies investigating Sámi health outcomes linked to the Swedish patient and mortality registers. It is our assessment that knowledge generated from such approaches would greatly strengthen the field of Sámi health in Sweden, and we suggest these as suitable approaches to employ in future research efforts.

Finally, it should be noted that the successful implementation of the SámiHET study adds an important piece into the puzzle about what methods are usable when investigating Sámi health. To be specific, utilising the SER as the basis for constructing a Sámi sample to be surveyed, and then inviting all SER members to take part, is not uncontroversial. Although arguments have been made in favour of utilising the SER as a tool in constructing Sámi statistics [,27,28] some have warned that this method may not be acceptable from a Sámi perspective [29] or should be used with great caution as to not risk people resigning from the SER due to experiencing the SER as unsafe or not being used for intended purposes [30]. With regard to this, the acceptable response rate for SámiHET and the fact that we did not encounter any pushback for utilising the SER among the Sámi population during implementation of the study may be interpreted as most Sámi view this particular design as safe to participate in.

Conclusion

We have described the implementation and reflected on the challenges of a population-based survey conducted among the Sámi in Sweden. SámiHET has shown that it is feasible approach to conduct health studies among the Sámi population, cost-effective and easy to compare with Swedish health data. As in the case of Norway, SámiHET provides an enormous amount of health and living conditions information that can guide policy-makers in the implementation of targeted health interventions. It also offers to the Sámi population accurate health data, fulfiling their right to know their own health status. Future studies should focus on increasing the participation of specific sub-populations and expand the survey offer into Sámi languages. It is our hope that the SámiHET could be part of a monitoring health system, funded by the Swedish government and in coordination with the Sámi parliament, to guarantee its legitimacy and sustainability.

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Disclosure statement

No potential conflict of interest was reported by the author(s).

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