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## **Oral health among the indigenous Sámi population**

A population-based study on periodontal health, dental caries, and oral health-related quality of life

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## Abbreviations

AAP	American Academy of Periodontology
CAL	Clinical attachment level
CEJ	Cemento-enamel-junction
CI	Confidence interval
CPI	Community Periodontal Index
DMFS	Decayed, missed, filled surfaces
DMFT	Decayed, missed, filled teeth
DT	Decayed teeth
DS	Decayed surfaces
EFP	European Federation of Periodontology
FI	Furcation involvements
GOHAI	Geriatric/General Oral Health Assessment Index
ILO	International Labour Organization
MT	Missing teeth
NOK	Norwegian Krone
NSP	Non-severe periodontitis
OHIP	Oral Health Impact Profile
OHIP-14	Short version of Oral Health Impact Profile
OHRQoL	Oral health related quality of life
OIDP	Oral impact on daily performance
OR	Odds ratio
PDS	Public dental services
PPD	Periodontal probing dept
PROM	Patient-reported outcome measures
RBL	Radiographic bone loss
SD	Standard deviation
SSHf	Center for Sámi Health Research
WHO	World Health Organization

## **List of papers**

This thesis is based on the following papers, which will be referred to by their Roman numerals:

### **Paper I**

Brustad M, Bongo AKS, Hansen KL, Trovik T, Oscarson N, Jönsson B. Oral health in the indigenous Sami population in Norway - the dental health in the North study. *Acta Odontol Scand.* 2020 Feb;78(2):98-108.

### **Paper II**

Bongo AKS, Brustad M, Oscarson N, Jönsson B. Periodontal health in an indigenous Sámi population in Northern Norway: a cross-sectional study. *BMC Oral Health.*2020;20:104

### **Paper III**

Bongo AKS, Brustad M, Jönsson B. Caries experience among adults in core Sámi areas of Northern Norway. *Community Dent Oral Epidemiol.* 2020;00:1-9

### **Paper IV**

Bongo AKS, Brustad M, Jönsson B. Oral health-related quality of life in an indigenous Sámi population in Northern Norway. Manuscript submitted.

## Abstract

**Background/Aim:** The lack of scientific knowledge on oral health in Sámi populations and the regional differences in caries experience among children in Northern Norway has raised the question of whether the high prevalence of oral disease in that geographic area differs by ethnicity. Evidence-based knowledge on oral health conditions in adults in these areas is scarce. The overall objective of the thesis was to assess oral health in an adult population in core Sámi areas in Northern Norway, with a focus on periodontal disease, dental caries, and oral health-related quality of life (OHRQoL), and their associated risk factors, in Sámi and non-Sámi populations.

**Methods:** The thesis is based on a cross-sectional study of adults aged 18 to 75 years in core Sámi areas in Northern Norway, the Dental Health in The North Study. Data collection was incorporated into daily clinical procedures at six Public Dental Health Services clinics in 2013-2014; it included both clinical and radiographic examination, and a questionnaire. Periodontal probing depth (PPD) was assessed at six sites per tooth for all teeth, except the third molar, and post-clinical measurement of radiographic bone loss was conducted. A five-grade diagnostic scale was used to register caries severity on approximal, buccal, lingual/palatinal, and occlusal surfaces. OHRQoL was assessed with Oral Health Impact Profile-14 (OHIP-14).

**Results:** Altogether, 2235 adults participated in the study, giving a crude response rate of 88.7%. In total, 2078 were included in the study, and of them, 66.5% reported Sámi affiliation and 57% were women. Three ethnic groups were constructed (Sámi, mixed Sámi/Norwegian, and Norwegian), and in most analyses, ethnicity was dichotomized into Sámi and non-Sámi.

According to the modified version of the new American Academy of Periodontology and the European Federation of Periodontology classification system of periodontitis, 49.7% of participants had periodontitis, with 20.1% having stage III/IV, i.e. severe periodontitis. No differences in the prevalence of periodontitis between Sámi and non-Sámi participants were found; however a higher proportion of Sámi had PPD  $\geq$ 6 mm and a higher probability of severe periodontitis.

The overall caries experience among adults in core Sámi areas was high, but differed by region of residence. The mean number of decayed (D), missing (M), and filled (F) teeth (T),



which make up the DMFT score, was 16.2 (standard deviation [SD]=6.7), with a significant difference between Sámi (15.7, SD=6.7) and non-Sámi (17.0, SD=6.7) ( $p<0.05$ ). The mean DT was 1.0 (SD=1.7) in the overall study sample, and 1.0 (SD=1.6) among participants with Sámi affiliation. Sámi from the coastal region had a significantly higher mean DT (1.3, SD=1.8) than inland Sámi (0.8, SD=1.5) ( $p<0.05$ ), but no ethnic differences in the prevalence of caries were observed within these regions. Factors associated with the prevalence of caries were frequent consumption of sugary soft drinks, toothbrushing less than daily, and irregular dental visits.

Both Sámi and non-Sámi participants experienced oral health-related problems that impacted their daily lives. Eighty percent experienced problems related to oral conditions, and around 10% experienced problems fairly often or often (frequent problems). The mean OHIP-14 score among Sámi participants was 5.4 (SD=6.0), significantly higher than among non-Sámi (4.4, SD=5.2). Sámi women experienced problems more often than Sámi men, and Sámi from younger age groups reported problems more often than those from older age groups. Other factors associated with experiencing problems fairly often or often were irregular dental visits, number of teeth, periodontitis and caries.

**Conclusion:** Periodontitis and caries were common among adults in core Sámi areas in Northern Norway, regardless of ethnicity. Caries was more prevalent in the coastal region than in the inland region, but no ethnic differences in the prevalence of caries within these regions was found. Four of five adults in these areas experienced problems related to oral conditions or oral diseases that impacted their daily life.

## Čoahkkáigeassu

**Duogáš dutkamii / Váldomihttu:** Almmolaš bálnedearvvašvuoda dieđut čájehit ahte leat báikkálaš erohusat bálnedearvvašvuodas mánáin ja nuorain Davvi-Norggas, muhto eai gávdno dieđut leat go čearddalaš erohusat. Dutkojuvvon máhttu Norgga álbmoga bálnedearvvašvuodas lea hui vánis, ja sápmelaččaid bálnedearvvašvuodas ii leat vuđolaččat dutkojuvvon. Dán dutkamuša váldomihttu lea leamaš kártet bálnedearvvašvuodadiliid, oktan gullevaš sivaiguin, sápmelaččain Davvi Norggas. Mihttu lei iskat bálnebeassandávdda ja karies leavvama rávisolbmuiin sámi álbmogis ja álbmogis geat eai leat sápmelaččat, ja maid dai iskat movt bálnedearvvašvuodaguoski eallinárvu lea dán čearddalaš joavkkuiin.

**Metoda:** Dutkosis leat geavahan dieđuid Tannhelse i Nord proševttas, mas rávisolbmot gaskal 18 ja 75 jagi oassálaste. Guorahallan čađahuvvui guđa almmolaš bálnedearvvašvuoda klinihkas sámegeiela hálddašanguovlluin Finnmárkkus 2013-2014is. Bálnedoaktárat/ bálnedivššárat iske ja govvejedje röntgengovaid buot bániin, earret agibániin, ja oasseváldit devde jearaldatskovi. Klinihkalaš iskkadeamis vižže dieđuid juohke báni ektui, gos juohke bánis mihtiduvvui guđa sajis man čieŋal bálneoazžegaska lea ja galle millimehtera dákti lea nohkan. Karies mihtiduvvui approssimala, bukkala, linguala/palatinala, ja okklusala duolbadasain, skálas 1 gitta 5. Bálnedearvvašvuodaguoski eallinárvu lea mihtiduvvon Oral Health Impact Profile-14iin (OHIP-14).

**Bohtosat:** Dán dutkamii serve oktiibuot 2235 rávisolbmo, mii lea 88.7 % jerron oasseváldiin. Ledje 2078 olbmo geat čađahedje sihke klinihkalaš iskosa ja devde ollislaččat jearaldatskovi. Dán ledje 66.5 % sámi čearddalačča ja 57 % nissonolbmo. Oassálastit juohkásedje golmma čearddalaš jovkui (sámi, sihke sámi/norgalaš čearddalašvuodas ja norgalaččat), muhto analiissain bohtet ovdan guoktin joavkun; sámit ja eai-sámit.

Dán dutkamis geavahuvvo muddejuvvon veršuvdna ođđa American Academy of Periodontology and the European Federation of Periodontology klassifiseren vuogádagas go árvvoštallá dási bálnebeassandávddas (Dássi I-IV). Obbalaččat duodášuvvui bálnebeassandávda 49.7 % sin gaskkas geat serve dutkamii, ja daid gaskkas lei 20.1 % duodálaš bálnebeassandávda (dássi III/IV). Čearddalaš erohusat eai gávdnon bálnebeassandávdda leavvamis, muhto eanet sámiin ledje gurat  $\geq 6$  mm ja sis lei stuorat várra sámiin leat duodálaš bálnebeassandávda.

Dán dutkama logut čájehit ahte rávisolbmot leat vásihan ráigebániid, muhto loguin leat báikkálaš erohusat. Dat obbalaš gaskamearalaš lohku ráigánan (decayed=D), beassan (missing=M), ja devdon (filled=F) bániin (teeth=T); DMFT lohku, lei 16.2 (standard erohus [SE]=6.7), dat lohku lei unnit sápmelaččaid gaskkas (15.7, SD=6.7) go eai-sámiin (17.0, SD=6.7) ( $p<0.05$ ). Gaskamearalaš lohku ráigánan bániin lei obbalaččat 1.0 (SE=1.7), ja 1.0 (SD=1.6) sámiid gaskkas. Sámiin riddosuohkaniin lei dát lohku stuorat (1.3, SE=1.8) go siseatnan sámiin (0.8, SE=1.5) ( $p<0.05$ ), muhto eai lean čearddalaš erohusat guovllu siskkobealde. Čuohcci fáktorat ráigebániide ledje jus dávjá juhká sohkarjuhkosiid, jus ii geala bániid beaivválaččat dahje jus hárve fitná bátnedivššohagas divššus.

Sihke sámit ja eai-sámit vásihedje ahte bátneearvvašvuoda váttut čuhce árgabeaivái. Gávccilot proseantta sis geat serve dán dutkamii ledje oktii dahje dávjjit vásihan váttuid (dahje givssiid) bátneearvvašvuoda ektui, ja sullii 10 % ledje vásihan dan oalle dávjá dahje dávjá. Gaskamearalaš OHIP-14 lohku sámiid gaskkas lei 5.4 (SE=6.0) ja eai-sámiid gaskkas fas 4.4 (SE=5.2) ( $p<0.05$ ). Sámi nissonat vásihedje bátneearvvašvuodaaguoski váttuid/givssiid dávjjibu go sámi dievddut, ja nuorat fas dávjjibu go vuorraset olbmot. Muđui gávnnavuvvui ahte sii geat hárve ohcalit bátnedivššu, sis geain váilot bánít dahje lea bátnebeassandávda dahje karies, vásihit bátneearvvašvuodaaguoski váttuid dávjjibu go earát.

**Konklusuvdna:** Bátnebeassandávda ja karies leat dábálaččat rávisolbmuin sámi guovlluin Finnmárkkus Davvi Norggas, beroškeahttá čearddalašvuodas. Rávisolbmuin riddosuohkaniin leavvá karies eambo go siseatnan suohkaniin, muhto eai leat čearddalaš erohusat siskkobealde guovlluid. Njealjjs viđa olbmos vásihit bátneearvvašvuodaaguoski váttuid mat váikkuhit beaivválaš doaimmaide.

# 1 INTRODUCTION

Oral health in the indigenous Sámi population is a neglected area within indigenous oral health research. Most of the information we have about oral health among indigenous peoples comes from studies conducted in Australia, New Zealand, Canada, the United States, and Brazil. These studies indicate that indigenous people have poorer oral health, poorer access to dental care, and that they simply have a different conception of oral health than non-indigenous people [1,2].

The Norwegian Government White Paper from 2006/2007 [3], entitled *Tilgjengelighet, kompetanse og sosial utjevning - Framtidas tannhelsetjenester* [Access, competence, and removing social gradients - The future of dental health services], raised concerns about the poorer oral health of Sámi populations in Northern Norway and about the lack of scientific knowledge on oral health in adult Sámi populations in general. Due to these concerns, the Dental Health in The North Study was initiated, and data from that project were used in this thesis to investigate oral health in an indigenous Sámi population in Northern Norway.

## 1.1 Sámi - the indigenous people

The Sámi people are the indigenous people of Sápmi, a territory that includes the northern part of Norway, Sweden, Finland, and the Kola Peninsula in Russia [4]. In Norway, the Sámi have been recognized as indigenous people since the end of the 1980s, when Norway ratified the International Labor Organization convention that ensured the development of Sámi culture, language, and way of life [5], as well as the creation of the Sámi Parliament in 1989. The Sámi Parliament is a complement to the national political system; it is democratically elected by and among the Sámi and deals with all matters concerning the Sámi people [6].

The Sámi in Northern Norway live in mixed communities, with both Sámi and Norwegian inhabitants, and many have mixed, i.e., Sámi and Norwegian, ethnic identity. Mixed ethnicity is common and has existed for generations in areas with a high proportion of Sámi due to mixed marriages. Most Sámi have no problem with their dual ethnic identity [7], i.e. feeling both Sámi and Norwegian. Sámi ethnic identity has been closely linked to the home language and the context of being Sámi, meaning that those who speak the Sámi language may feel a stronger Sámi affiliation and ethnic identity [8].

There are legal restrictions on the registration of ethnicity in Norway. These are outlined in the Discrimination Act (Ot.prp. No. 33, 2004-2005), which is intended to prevent discrimination between people and promote equal opportunities and rights regardless of ethnicity, religion, gender, etc. However, although there is no official register of ethnicity in Norway, The Sámi Act of 1987 established a register for individuals who meet the criteria for voting in Sámi parliamentary elections [6]. These criteria are that the person must consider themselves to be Sámi and have Sámi as their, their parents', or their grandparents' home language. This register is politically motivated, and does not capture all Sámi people. Due to the aforementioned legal restrictions, the registration of Sámi ethnicity in epidemiological research is not straightforward, which presents challenges when attempting to classify a study sample into ethnic groups.

In studies that use ethnicity as a variable, the inclusion criteria must be well defined to make clear who is included in the different ethnic groups. Ethnicity in a multi-ethnic setting is a complex phenomenon that encompasses aspects of social life (e.g. culture) and personal identity, often described by objective and subjective dimensions [9,10]. Objective dimensions are those that can be observed as facts, including kinship, descent, and spoken language, while subjective dimensions are attitudes, values, and feeling of belonging at the individual level. A person may choose not to identify as Sámi, but they will still be entitled to do so if the objective criteria are met. Personal identity is essentially a matter of how individuals conceive themselves, including their relationship to other people and places. Ethnic identity, also described as ethnic self-identification, has been found to be related to ancestry, cultural heritage, values, traditions, rituals, language, and/or religion [11]. Among Sámi adolescents, ethnic identity was found to be closely related to contextual factors, like ethnicity of the parents, language, region of residence, and traditional clothing [12]. Finally, cultural identity refers to how individuals define themselves in relation to the cultural groups to which they belong [13].

### **1.1.1 Core Sámi areas and the administrative areas for Sámi language**

'Core Sámi areas' is an established term describing the areas where the density of Sámi people is high, and the official status of the Sámi and Norwegian languages are equal. Based on this term, various descriptions of the areas where the Sámi are established have been developed. Two such terms are 'The administrative area for Sámi language' and 'Sámi

language administrative district'. These terms were first introduced by the Sámi Act, and are defined as an area where the Sámi and Norwegian languages are equal or have equal status administratively [6]. Within the administrative area for Sámi language, everyone has the right to use the Sámi language when they contact municipal administration and other public services.

Although the Sámi are in a unique position compared to other minorities in Norway today with regards to legal protections and rights, they have a long history of discrimination. From the middle of the 19th century until the middle of the 20th century, the Norwegian government carried out a policy against the Sámi people called Norwegianization, the goal of which was to form an ethnically and culturally uniform Norwegian population. During this time, the Sámi language was not accepted as an official language, and people were not allowed to practice Sámi traditions and culture [14]. These historical efforts to assimilate the Sámi people by forcing them to adopt the Norwegian language and culture caused many lose their Sámi identity, language, and culture, especially in areas where the Sámi people were in the minority. In the inland region of Northern Norway, where the Sámi were in the majority, the Sámi people managed to preserve their language and culture, and this region is still the one with the highest density of Sámi people. Reindeer herding is still a common industry in the inland region, and it is one of the most important parts of the Sámi culture and way of life. Reindeer husbandry is a small industry on a national scale, but in the Sámi context it has great economic importance and plays an important role in preserving Sámi traditions [15]. In core Sámi areas, women have higher education than men; in 2013 22.1% of women had a university or college education compared to 11.5% of men [16]. Norwegian studies have shown an association between indicators of socioeconomic status, like education level and income, and oral health, reporting that those with low education level and/or low income are more likely to have poorer oral health [17,18]. Previous studies on general health conducted in core Sámi areas have shown only minor differences between Sámi and non-Sámi populations, and within ethnic groups only minor gender differences in somatic health have been reported [19,20].

## **1.2 Dental health services**

In Norway, dental health services are offered by both the public and private sectors. Public Dental Health Services (PDS) serve the population in accordance with the Dental Health Services Act [21]; the private sector serves the rest of the population. PDS mainly provide services for patients between the ages of 0 and 18, for mentally disabled persons living in institutions and at home, and for elderly and long-term care patients both at institutions or living at home. Other priority groups in the PDS are vulnerable groups, such as refugees, asylum seekers, prison inmates, drug addicts, and those with odontophobia. These groups may be entitled to dental treatment under the social welfare system. Because the PDS is publicly funded, young people between the ages of 19 and 20 pay 25% of the total cost for examination and treatment, compared to the private sector, where all treatment must be paid in full by the patient. Moreover, all residents of Norway are included in the public social security system, called the Norwegian National Insurance Scheme [22], which partially covers the costs of selected dental treatments for those over 18 years through a reimbursement system [23], i.e. treatment due to accident or injury or if the person has medical conditions that can lead to reduced dental health. People with no or low income can apply to the Norwegian Welfare System for support for dental treatment in accordance with Social Services Act.

The Sámi people in Norway have the same access to dental health services as the general population [21,24], and in core Sámi areas, they have the statutory right to speak Sámi when contacting health services [6]. Being able to use one's preferred language in a health context contributes to better communication between the patient and the provider. This is especially important when describing a health condition, but also for understanding the information given in the consultation, as it may enhance mutual understanding, lead to a good therapeutic experience, and may improve the quality of treatment [25-27]. How individuals understand and receive oral health information is tied to the complexity of the information presented, the cultural overlay of health beliefs, and the quality of health communication [28]. Cultural norms, ethnic historical background, and personal experiences may influence the communication style of Sámi when speaking about their health [29,30]. Indeed, the Sámi way of speaking is often characterized by indirect descriptions of disease, using body language in communication, and not talking about emotions and illness. It has been shown that cultural differences and the opportunity to use the Sámi language can improve satisfaction with health services among Sámi patients [26,27,30-32].

### **1.2.1 Public Dental Health Services clinics as a research arena**

The use of PDS clinics and private dental health services among adults in Northern Norway varies by geographic area. For example, the rural areas of Northern Norway are somewhat unique in that the majority of their adult population receives regular dental care from PDS, as there are few private dental health services in these areas [33].

The use of PDS clinics during data collection in oral health surveys is common, but the varying response rate that accompanies this approach presents a challenge [34]. In a pilot study [35] on oral health among adults in Northern Norway, randomly selected individuals received a postal invitation from the academic institution, and were offered a free oral examination at the local PDS clinic, but the response rate was low (27%). This experience made it obvious that the recruiting procedure needed to be improved in future studies, and it was suggested that the responsibility for recruitment should be shifted from the academic institution to the local PDS clinics.

## **1.3 Oral diseases**

### **1.3.1 Periodontitis**

Periodontitis is a chronic inflammatory disease and the result of a complex interplay between specific bacteria, the host response, and environmental factors [36]. The infection is initiated by a bacterium, which activates the host's immune response and the inflammatory systems that affect tooth-supporting structures, such as periodontal ligaments and alveolar bones. The determination of the severity of periodontitis depends on the criteria applied. Over the years, there have been various criteria for defining periodontitis [37], but in the last 2 decades, the 1999 Classification System for Periodontal Disease and Conditions [38] has been used in population-based studies. At the World Workshop on the Classification of Periodontal and Peri-Implant Diseases held in 2017, a new framework for the case definition of periodontitis was developed by the American Academy of Periodontology (AAP) and the European Federation of Periodontology (EFP). This new AAP/EFP classification scheme defines periodontitis by staging and grading [39]. Staging classifies periodontitis by severity and complexity [40]. Severity is determined based on interdental clinical attachment level (CAL), radiographic bone loss (RBL), and/or tooth loss, while complexity is based on the need for



treatment to eliminate local factors such as periodontal probing depth (PPD), horizontal or vertical bone loss, furcation involvement (FI), tooth hypermobility, and/or loss of masticatory function. In this new AAP/EFP case definition, anyone with an interdental CAL on two or more non-adjacent teeth or a buccal or oral CAL  $\geq 3$  mm with PPD  $> 3$  mm in two or more teeth is defined as a periodontitis case. In cases where CAL is not available, RBL should be used. Using these criteria, periodontitis can be classified into four stages, with stages III and IV generally referred to severe periodontitis (Table 1).

Table 1. Periodontitis stages by severity and complexity [40]

Periodontitis stages		Stage I <i>Initial periodontitis</i>	Stage II <i>Moderate periodontitis</i>	Stage III <i>Severe periodontitis with potential for additional tooth loss</i>	Stage IV <i>Advanced periodontitis with extensive tooth loss and potential for loss of dentition</i>
Severity	Interdental CAL at site of greatest loss: $\geq 2$ teeth	1-2 mm	3-4 mm	$\geq 5$ mm	$\geq 5$ mm
	RBL: $\geq 2$ teeth	Coronal third (<15%)	Coronal third (15-33%)	Extending to middle or apical third of the root	Extending to middle or apical third of the root
	Tooth Loss	No tooth loss due to periodontitis		Tooth loss due to periodontitis of $\leq 4$ teeth	Tooth loss due to periodontitis of $\leq 5$ teeth
Complexity	Local	Maximum PPD $\leq 4$ mm  Mostly horizontal bone loss	Maximum PPD $\leq 5$ mm  Mostly horizontal bone loss	In addition to stage II complexity:  PPD $\geq 6$ mm Vertical bone loss $\geq 3$ mm FI: class II or III Moderate ridge defect	In addition to stage III complexity:  Need for complex rehabilitation due to: Masticatory dysfunction Secondary occlusal trauma (Tooth mobility degree $\geq 2$ ) Severe ridge defect Bite collapse, drifting, flaring Less than 20 remaining teeth (10 opposing pairs)
Extend and distribution	Add to stages as descriptor	For each stage, describe extent as localized (<30% of teeth involved), generalized, or molar/incisor pattern.			

CAL: clinical attachment level; RBL: Radiographic bone loss; PPD: periodontal probing depth; FI: furcation involvement

The prevalence of periodontitis varies between and within countries and populations, and these differences are not straightforward to compare, due to changes in the classification of periodontitis in the last decades and to which periodontal data are collected [37,38,41]. In Norway, some epidemiological studies have estimated the prevalence of periodontitis in the general adult population to be around 50% [17], with around 8-12% having severe periodontitis [17,42,43]. However, periodontal health among the Sámi in Norway was

unknown due to a scarcity of information. Indeed, studies on periodontitis conducted in Norway either have not defined their populations in relation to ethnicity, or the proportion of Sámi participating was too small [17]. However, the overall prevalence of severe periodontitis has decreased in recent decades in Norway [42]; the proportion of individuals with PPD  $\geq$ 6 mm decreased from 21.8% in 1984 to 8.1% in 2003. The same trend had been reported in Sweden and Finland, where the prevalence of severe periodontitis was reported to be 11% in Swedish adults in 2013 [44], and 21% in Finnish men and 14% in Finnish women in 2011 [45]. These findings are comparable with data from the 2010 Global Burden of Disease Study, which found that around 11% of the global population suffered from severe periodontitis [46].

### **1.3.2 Dental caries**

Dental caries is a multi-factorial disease that develops through the interaction of host factors (tooth surface), substrates (sugars), oral bacteria (plaque), and time; it is affected by dietary patterns, behavioral factors, socioeconomic factors, and environmental factors. Dental caries is a major oral health problem among people all over the world, affecting 60-90% of children and most of the adult population [47]. Untreated caries in permanent teeth is common and represents a major public health challenge in most countries [48]. During the last decades, there has been a remarkable decrease in the prevalence of dental caries [49,50]. This decline has led to changes in the diagnostic criteria of caries. It is no longer sufficient to score caries according to the World Health Organization (WHO) criteria, at the cavitation level [51]. Due to the slower progression of caries and a reduction in the number of cavities, classification criteria at non-cavitation level is necessary, i.e. using the International Caries Detection and Assessment System, a visual classification [52], and/or radiographic five-grade scale classification [53,54].

Caries diagnosis and its application in epidemiological surveys differs, depending on how the prevalence of caries is reported in different countries, and the criteria used for caries diagnosis. A review reporting caries experience among European adults [49] showed that data on coronal caries experience are traditionally reported as the number of decayed (D), missing (M), and filled (F) teeth (T), which are then summed to make the DMFT score. Mean DMFT scores in European adults aged 35-44 years varied between 6.6 and 17.6 [49]. Among 35-year-olds in Oslo, Norway, the mean DMFT score was 11.7 [55], and among elderly Norwegians it was 25.4 [56]. A study from Northern Norway reported a mean DMFT of 15.1

(including caries grade 1-5) in a general adult population [57]. In Norway, PDS report prevalence of caries (DT) and caries experience (DMFT score) among children aged 5, 12, and 18 years to Statistics Norway every year. According to this data, children and adolescents from Finnmark County in Northern Norway have a higher mean DMFT than Norwegian children and adolescents in general (Figure 1) [58]. Since individual-based statistics in Norway are not given by ethnicity or indigenous status, it is not possible to draw conclusions about ethnic differences in caries experience in this geographic area.

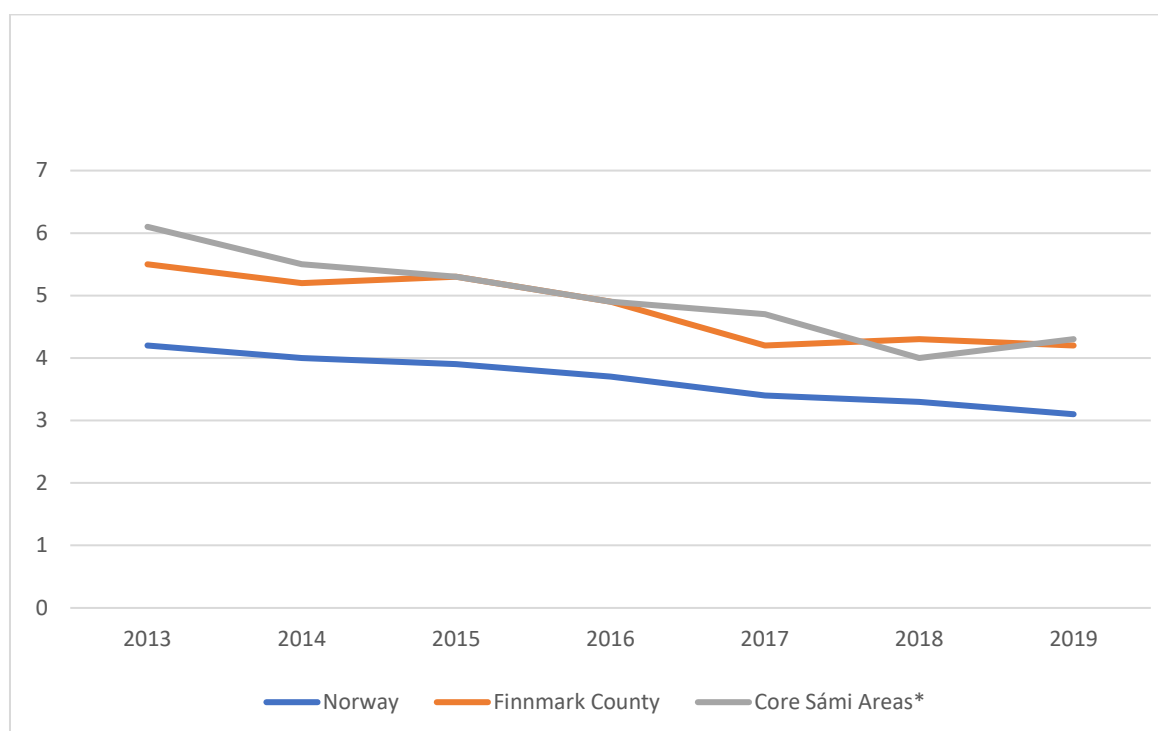


Figure 1. Average number of decayed (D), missing (M), and filled (F) teeth (T) (DMFT score) among 18-year-olds in Norway, Finnmark County, and core Sámi areas in Finnmark County

\*Core Sámi areas include the municipalities of Kautokeino, Karasjok, Porsanger, Tana, and Nesseby in Finnmark County. Data for Norway and Finnmark County are from Statistics Norway [58]. Data on core Sámi areas are from a computerized protocol (Opus Dental) in Public Dental Health Services (unpublished data).

### 1.3.3 Oral health-related quality of life and the Oral Health Impact Profile

Oral health-related quality of life (OHRQoL) is a commonly used term to describe how oral disease and disorders affect overall quality of life, which is defined by the WHO as “an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” [59].

The perception of quality of life has a subjective component, and thus varies across individuals, cultures, physical and psychological aspects, social relationships, environmental factors, and personal/religion beliefs [59]. OHRQoL is a multidimensional concept that captures people’s perceptions about oral health-related factors that are important in their daily life, like functional factors, psychological factors, social factors, and experience of pain or discomfort [60] (Figure 2).

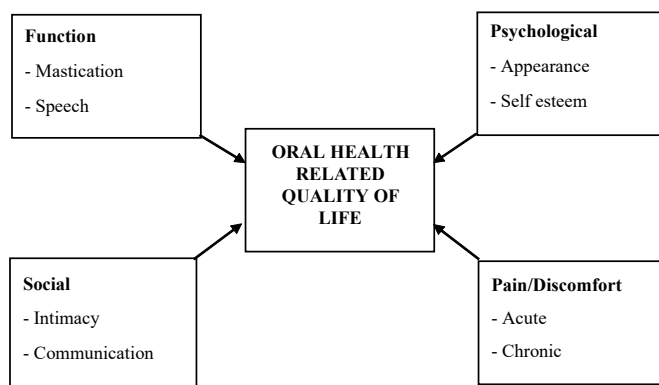


Figure 2. Factors associated with oral health-related quality of life (Inglehart and Bagramian, 2002)

David Locker’s conceptual model for oral health was developed to explain the pathways by which oral diseases and conditions affect quality of life [61]. This model did not consider individual (e.g. oral health beliefs, dental behaviors, subjective socioeconomic status) or environmental factors (e.g. social network), which are likely to have an integral role on how individuals perceive oral health [62,63], but it did inspire the creation of new measuring tools for OHRQoL.

Fundamentally, three categories are used to measure OHRQoL: sociodental indicators, global self-ratings of oral health, and multiple-item questionnaires [62]. Sociodental indicators are used to assess the effect of oral conditions at the community level, and global self-ratings are single ratings, asking individuals a general question about their oral health status or about their quality of life at that particular period, but multiple-item questionnaires are the most widely used method. These questionnaires assess the functional, psychological, and social impacts of oral conditions on quality of life, and include instruments like the Oral Health Impact Profile (OHIP), the Geriatric/General Oral Health Assessment Index, and the Oral

Impact on Daily Performance. All these instruments are similar in that they address the functional and psychosocial outcomes of oral disorders, but they provide different information about the person's OHRQoL [64]. Information on health status that comes directly from patients is referred to as a patient-reported outcome measure, and may include reports of disease symptoms, pre-post treatment comparisons, functional status, or wellbeing [62].

The OHIP measures people's perception of the social impact of oral disorders on their wellbeing [65]. The original OHIP questionnaire consists of 49 questions, but the OHIP-14 is a shortened version [66] in which respondents are asked to indicate on a five-grade Likert scale how frequently they experience problems, ranging from 'never' to 'very often' with scores from 0 to 4. These items are grouped into seven conceptual dimensions: functional limitations, physical pain, psychological discomfort, physical disability, psychological disability, social disability, and handicap (Appendix 2) [66].

In Scandinavia, the OHIP-14 has been used in some studies to describe OHRQoL in general adult populations [18,67,68], expressed as mean OHIP-14 score and/or proportion of individuals having problems. Comparing study findings among Norwegian, Swedish, and Finnish adults shows comparable mean OHIP-14 scores in this three countries: around 4 in Norway [18] and Finland [68], and about 6 in Sweden [67]). The OHIP-14 has also been used to describe OHRQoL in target populations, for example in indigenous people [69] and in studies investigating the associations between OHRQoL and things like oral diseases (e.g. periodontitis and caries) [70,71].

#### **1.4 Oral health among indigenous people**

In order to identify previous studies that used periodontitis, dental caries, and oral health-related quality of life as outcomes, we searched PubMed and the Web of Science, using the search terms 'Indigenous', 'Aboriginals', 'Torres strait Islanders', 'Native', 'Maori', 'Sami', in association with 'oral health', 'oral disease', 'dental caries', 'periodontal disease', and 'OHIP-14'. The results showed that few studies employed these clinical outcomes (Table 2).

*Table 2. Studies reporting periodontitis, dental caries, and/or oral health-related of life based on the Oral Health Impact Profile (OHIP)-14 in indigenous people*

Author	Year	Country	n	Indigenous		Non-Indigenous		
				Age	Outcomes	N	Age	Outcomes
Williams et al [69]	2010	Australia	468	38.0	OHIP-14=15.0			
Kapellas et al [72]	2014	Australia	312	39.5	DT=3.0	4967	45.5	Mean DT=0.6
Amarasena et al [73]	2015	Australia	312		DT>0=77.9% DT=3.0			
Miranda et al [74]	2016	Brazil	71	35-44	DT=2.6	9493	35-44	DT=2.3
			71	65-74	DMFT=17.1 DT=0.9 DMFT=25.3	7437	65-74	DMFT=16.9 DT=0.8 DMFT=27.0
Jamieson et al [75]	2016	Australia	64	46.4	DT>0=48.6	5300	46.4	DT>0=22.6
		New Zealand	100	44.7	DT>0=49.7	3615	44.7	DT>0=34.4
		Canada	386	44.6	DT>0=35.0	3089	44.6	DT>0=18.7
Such et al [76]	2017	Brazil	144	35-74	DT>0=65.3 PPD≥6mm=11.8	17254	35-74	DT>0=56.7 PPD≥6mm=5.0
		New Zealand	270	35-74	DT>0=16.4 PPD≥6mm=10.2	510	35-74	DT>0=12.9 PPD≥6mm=3.7
		Australia	107	35-44	PPD≥6mm=31.8	120	35-44	PPD≥6mm=7.5
Parker et al [77]	2018	Australia	424	18-82	OHIP-14=19.5	4130	18-82	OHIP-14=7.6
Arantes et al [78]	2018	Brazil	1337	≥5	DMFS=17.2			
Soares et al [79]	2019	Brazil	107	35-44	DT=4.3 DMFT=14.5 DT>0=91.6			
Arantes et al [80]	2020	Brazil	266	35-44	DT>0=96.1 DMFT=17.1	1492	35-44	DT>0=99.0 DMFT=12.5
DeSilva et al [81] (review)	1978-2014	Australia			DT>0=88.4% Caries Periodontitis	29395	15-44	DT>0=89.9%

To be included, the study must have reported the prevalence or severity of periodontitis, dental caries, or oral health-related quality of life in an indigenous adult population, and the data must have been collected during clinical examination (not self-reported dental experience or self-reported dental health). DT; decayed teeth, DMFT: decayed, missing, filled teeth; PPD: periodontal probing depth, DMFS: decayed, missing, filled surfaces

As previously mentioned, most of the existing epidemiological information on indigenous oral health is based on studies conducted in Australia, New Zealand, Canada, the United States, and Brazil. Data from these countries are often collected from national surveys, and comparisons are done between indigenous people and the general population. Irrespective of country, indigenous people experience significant disparities in oral health, with poorer oral health [1,82] and a higher prevalence of both periodontitis and caries [72,81,83] than their

non-indigenous counterparts. Studies have generally focused on specific populations from small geographic areas or remote communities, and have small sample sizes [81], making it difficult to present a valid nationwide or worldwide understanding of indigenous oral health. In recent decades, there has been an increasing focus on measuring and addressing the impact of oral conditions on general wellbeing and quality of life among indigenous people, and although information on this impact is still limited, previous studies have indicated that oral conditions have an impact on OHRQoL among indigenous populations [69,84].

To the best of our knowledge, there are only a few peer-reviewed studies on oral health conditions among Sámi populations in Norway, Sweden, Finland, and Russia. In Norway, Holst et al [85] conducted a study on adults (25-60 years) in Northern Norway back in the 1980s, which included municipalities with a high density of Sámi people. They found that periodontitis and caries were common diseases in this region, regardless of ethnicity, but ethnic background was defined on the basis of geographic affiliation, and not on an individual level. In Sweden, Mienna et al found that Sámi women are commonly affected by temporomandibular disorders [86], which also can have a negative impact on their daily life [87]. However, their study included Sámi women selected from the Swedish Sámi Parliament's electoral register or from reindeer owners and herders with the Swedish Board of Agriculture. To the best of our knowledge, no studies on oral health in the Sámi population in Finland and Russia have been published.

## **1.5 Justification for the study**

Regional differences in caries experience among children in Norway, and knowledge about inequalities in oral health among indigenous people worldwide, raise the question of whether the high prevalence of caries in the northernmost part of Norway differs by ethnicity.

Statistics for the prevalence of caries in children from municipalities in core Sámi areas [58] and the Norwegian Government White Paper from 2006/2007 [3] indicate that there may be a higher risk of poor oral health among indigenous Sámi than among the non-Sámi population from the same geographical areas in Norway.

Clinically assessed oral health outcomes, such as periodontitis and caries, affect OHRQoL, thus assessing the prevalence, the distribution, and the associated risk factors of these conditions in the indigenous Sámi population can provide a more comprehensive

understanding of oral health in this population. This knowledge will be of benefit when planning tailored oral health interventions among the Sámi.

## **2 AIMS OF THE STUDY**

The overall objective of the thesis was to assess oral health in an adult population in core Sámi areas in Northern Norway. Focuses were on studying periodontitis, dental caries, and OHRQoL in a Sámi population compared to a non-Sámi population, as well as exploring risk factors associated with periodontitis, dental caries, and OHRQoL.

The specific objectives were:

Paper I. Oral health in the indigenous Sámi population in Norway - the dental health in the North study

- To present and describe the methods, data collection, and participation in the Dental Health in the North Study.
- To categorize the study population into different ethnic groups using Sámi inclusion criteria.
- To illuminate the methodological strengths and weaknesses of using PDS clinics in Sámi communities as an arena for data collection for epidemiological oral health research.

Paper II. Periodontal health in an indigenous Sámi population in Northern Norway: a cross-sectional study

- To describe the prevalence, severity, and distribution of periodontitis in an indigenous Sámi population in Northern Norway.
- To assess the association between periodontitis and risk factors, and to investigate differences between indigenous Sámi and the non-Sámi population.

Paper III. Caries experience among adults in core Sámi areas of Northern Norway

- To describe dental caries experience in an adult population in core Sámi areas in Northern Norway.



- To assess the corresponding associations with sociodemographic, socioeconomic, and oral health-related behavioral factors.

Paper IV. Oral health-related quality of life in an indigenous Sámi population

- To describe OHRQoL, measured by the OHIP-14, in an indigenous Sámi population and a non-Sámi population from the same area.
- To explore associations between OHRQoL and clinically assessed dental health, sociodemographic, socioeconomic, and behavioral factors in the Sámi population.

### **3 MATERIAL AND METHODS**

This thesis is based on data from the Dental Health in the North Study, which was performed in Finnmark County in Northern Norway.

#### **3.1 Study area and population**

The municipalities included in the study were Kautokeino, Karasjok, Porsanger, Tana, and Nesseby. These are all municipalities of the administrative area for Sámi language in Finnmark County (Figure 3), and are rural communities with a multi-ethnic population, including Sámi, Kven, and Norwegian inhabitants.

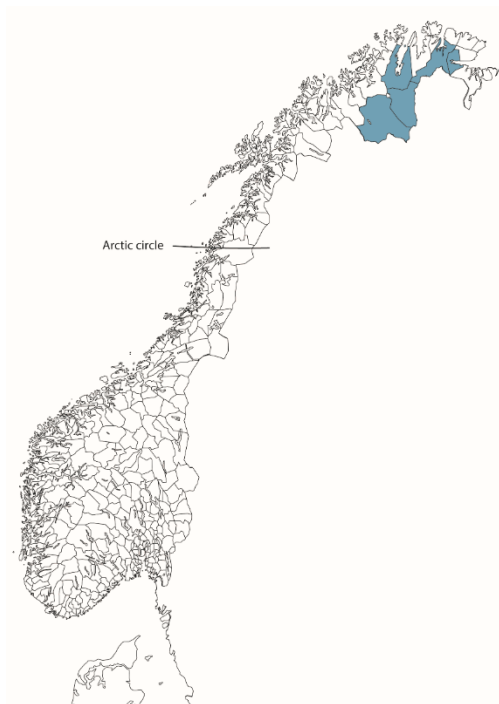


Figure 3. Map of Norway. The municipalities included in the survey are marked in blue (Kautokeino, Karasjok, Porsanger, Tana, and Nesseby)[88]

Because Norway does not have an ethnicity register, the ethnic composition in these municipalities is unknown. However, the 2013 Sámi parliamentary election register [89] indicated that the inland region (Kautokeino and Karasjok) has a higher density of people reporting Sámi affiliation than the coastal region (Porsanger, Tana, and Nesseby). To get the best knowledge about ethnic groups in these municipalities, information on ethnicity in the present study was self-reported by questionnaire. The distribution of Sámi according to the 2013 Sámi parliamentary election register and that in the present study are given in Table 3.

Table 3. The distribution of adults in communities in core Sámi areas in relation to population size, number of adults in the 2013 Sámi parliamentary election register, and participants in the present study

Municipalities	Population size on 1 January 2014 <sup>a</sup> N	N adults on 1 January 2014 <sup>a</sup> N	2013 Sámi parliamentary election register n (% of adults)	N participants in this study	
				In total	Sámi (%)
Kautokeino	2931	1909	1572 (82.4)	509	455 (89.4)
Karasjok	2698	1957	1318 (67.4)	492	414 (84.2)
Porsanger	3963	2934	734 (25.0)	411	121 (29.4)
Tana	2883	2112	859 (40.7)	581	324 (55.8)
Nesseby	919	667	371 (55.6)	86	67 (77.9)
<b>Total</b>	<b>13,394</b>	<b>9579</b>	<b>4854 (50.7)</b>	<b>2078</b>	<b>1381 (66.5)</b>

## 3.2 Study design

This was a cross-sectional study of adults aged 18-75 years. All data was collected between February 2013 and May 2014 at PDS clinics in the selected municipalities. The project was announced in the media (radio, newspaper). Patients who had an appointment scheduled or were on the re-call list during the data collection period were sent an invitation to participate in the study by mail or were invited to participate directly at the PDS clinic during their appointment. Information about the study, the questionnaire, and the consent form were either sent out together with the invitation or given upon arrival at the appointment. The clinical examination was free of charge. In total, 2,520 individuals were invited to participate; of these, 285 declined or did not respond to the invitation, giving a crude response rate of 88.7%. The preliminary study sample comprised 2,078 individuals, but after excluding participants with ethnic backgrounds other than Norwegian, Sámi, or Kven<sup>1</sup> the final sample was 2,034 (Figure 4).

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<sup>1</sup> Kven is an ethnic minority group in Norway, descendants of immigrants from Northern Finland.

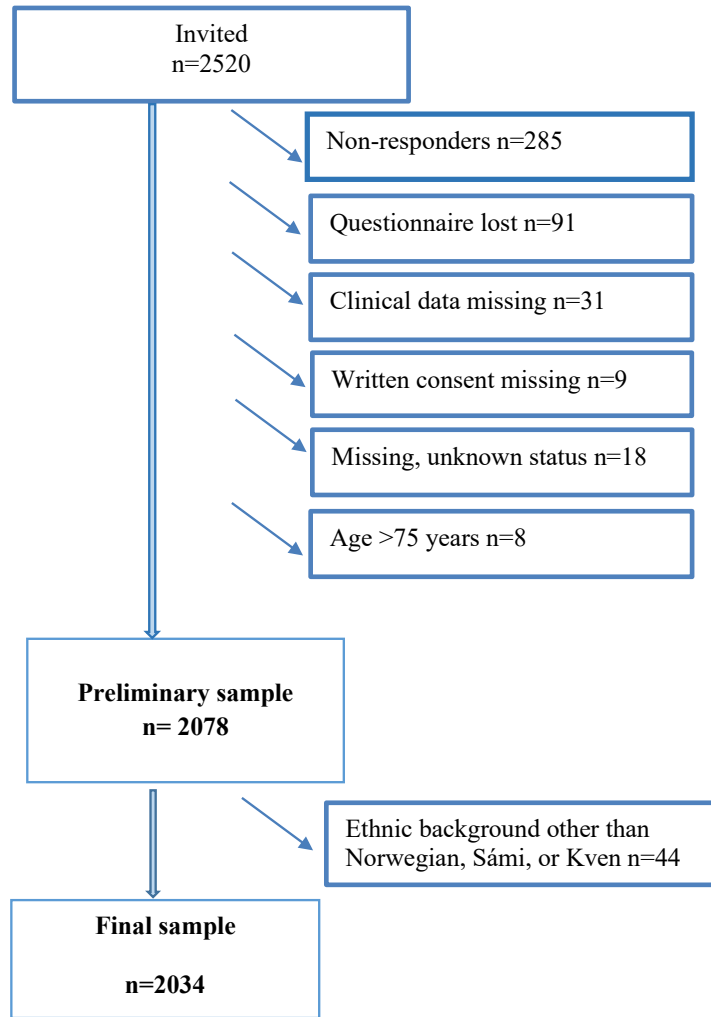


Figure 4. Flowchart of the study sample and participation (Paper I)

### 3.3 Questionnaire

The four-page questionnaire was developed based on questions from previous studies, and covered information about ethnicity, demographic characteristics, socioeconomic factors, oral health-related behavioral factors, use of dental health services and self-reported oral health outcomes.

#### 3.3.1 Ethnicity

Questions on ethnicity in the questionnaire were developed and used previously in The Population-based Study on Health and Living Conditions, SÁMINOR 1 and SÁMINOR 2, which were conducted in areas with multi-ethnic populations [90,91]. Ethnicity was defined by three questions: 1) “Which language do/did you/your parents/grandparents speak at home?”; 2) “What is your/your parents’ background?”; and 3) “What ethnicity do you consider yourself to be?”. The response options to all these questions were ‘Norwegian’, ‘Sámi’, ‘Kven’, or ‘other’.

### **3.3.2 Background characteristics**

Sex was categorized as male and female. Information about participants’ age was not included in the questionnaire; instead it was obtained from the computerized protocol (OPUS dental 7.1.107), and then categorized as 18-34, 35-49, 50-64, and 65-75 years. Region of residence was categorized as inland region (Kautokeino and Karasjok) and coastal region (Porsanger, Tana, and Nesseby) in Paper II. This categorization was based on population structure in relation to ethnicity and regarding the difference in the historical background of Sámi in majority and minority societies i.e. the Norwegianization policy.

### **3.3.3 Socioeconomic factors**

Annual gross household income was assessed in one question with seven response options and grouped into four categories ( $\leq 300,000$  Norwegian kroner [NOK], 300,001-600,000 NOK, 600,001-900,000 NOK,  $>900,000$  NOK). Duration of education was assessed with the question, “How many years have you been studying?”, with responses categorized into three groups (1-9, 10-13, and  $\geq 14$  years) in Papers II and III, and into two groups (1-13 and  $\geq 14$  years) in Paper IV.

### **3.3.4 Oral health-related behavioral factors**

Toothbrushing frequency was assessed with one question, “How often do you brush your teeth?”, with six response options from ‘less than once a week’ to ‘twice daily or more’.

Toothbrushing frequency was grouped into three categories (<1 time a day, 1 time a day,  $\geq 2$  times a day) in Papers II and III.

Consumption of sugary soft drinks was reported in seven categories and divided into two groups (seldom or never, several times a week or daily). This variable was used in Paper III.

Smoking habits were assessed with the question, “Do you smoke daily?”, with response options ‘yes’ or ‘no’, and was used in Paper II.

### **3.3.5 Use of dental health services**

Dental attendance was assessed with the question, “When was the last time you went to the dentist or dental hygienist?”, reported in four categories from ‘less than a year ago’ to ‘more than 5 years ago’, and grouped into three categories (yearly, every other year, and seldom) (Paper II). Frequency of dental visits was assessed with the question, “How do you attend dental health services?” with response options ‘regularly convened’, ‘regularly booked dental appointment’, ‘irregular use of dental health services’, and ‘attending only when having problems’. During analysis, the response options were divided into two groups (regular, irregular) (Papers III and IV).

### **3.3.6 Self-reported oral health outcomes**

Global self-rated oral health was assessed with one question, “How do you perceive your oral health?”, reported in four categories: ‘poor’, ‘not good’, ‘good’, and ‘very good’. Data were dichotomized into poor and good in Paper IV.

OHRQoL was measured using the OHIP-14 [66]. The response options were ‘never’ (score 0), ‘seldom’ (score 1), ‘occasionally’ (score 2), ‘fairly often’ (score 3), and ‘often’ (score 4). The overall OHIP-14 score was calculated by adding the scores for the 14 items to give a total score ranging from 0 to 56, where a low score indicates better OHRQoL. Participants who reported experiencing problems fairly often and/or often as the highest rank in at least one of the 14 items were categorized as participants with frequent problems.

### 3.4 Clinical and radiographic examination

Clinical examination was performed by nine dentists and six dental hygienists with assisting dental nurses, at six PDS clinics in the selected municipalities in Finnmark County. All clinical data were registered in a computerized protocol (OPUS dental 7.1.107) on a secured server.

#### 3.4.1 Periodontitis

Case definition of periodontitis was based on a modified version of the new AAP/EFP classification system [39,92,93] (Table 4), using RBL and PPD. In relation to the original classification (previously described in Table 1), MT, FI, number of teeth, and other complexity factors related to stage IV periodontitis were not taken into account. Instead, severity was determined by RBL, and complexity factors could increase the disease stage.

*Table 4. Definition of periodontitis stages by severity and complexity measured by radiographic bone loss (RBL) and periodontal probing depth (PPD)*

<b>Periodontitis stages</b>		<b>NSP</b>	<b>Stage II</b>	<b>Stages III and IV</b>
<b>Severity</b>	RBL $\geq 2$ teeth	Coronal third (<15%)	Coronal third (15-33%)	Extending to middle or apical third of the root
<b>Complexity</b>	Local	Maximum PPD $\leq 3$ mm	Maximum PPD 4-5 mm	PPD $\geq 6$ mm

NSP: non-severe periodontitis

PPD was measured to the nearest millimeter using a WHO-probe LM555B and assessed at six sites per tooth for all teeth except the third molar. Before the RBL measurements were carried out, the following test was performed on x-ray machines in four of five PDS clinics (not performed in Nesseby): First, an orthodontic metal string of exactly 10 mm was attached vertically to first molar in the mandibula before a bitewing was taken. In total, 10 bitewings were taken from each clinic. Secondly, bitewings were calibrated, and the length of the metal string was measured with the measuring tool in the Soredex Digora Optime Intraoral X-ray reader. The difference between the original 10 mm length and the measured length of the

metal string was calculated on each bitewing. Mean differences per clinic were calculated for Kautokeino, Karasjok, Porsanger, and Tana, showing a discrepancy of +0.84 mm (8.4%), +0.27 mm (2.7%), +0.48 mm (4.8%), and +1.1 mm (11%), respectively (Table 5). These enlargements were found to be too small to affect the RBL measurements. Based on this, we accepted Digora as a measuring tool.

Table 5. Estimated differences in mean length (mm) in relation to a length on 2,3,4,5, and 6 mm, stratified by Public Dental Health Services clinic

	<b>Kautokeino</b>	<b>Karasjok</b>	<b>Porsanger</b>	<b>Tana</b>
Mean difference , %	8.4	2.7	4.8	11
	mm	mm	mm	mm
2 mm	+0.2	+0.1	+0.1	+0.2
3 mm	+0.3	+0.1	+0.1	+0.3
4 mm	+0.3	+0.1	+0.2	+0.4
5 mm	+0.4	+0.1	+0.2	+0.5
6 mm	+0.5	+0.2	+0.3	+0.6

RBL was measured on bitewings. Two to four bitewings were taken on all participants and calibrated in Digora. The marginal bone level of both the mesial and distal surfaces of all teeth were measured. Reference points for RBL were taken from the cemento-enamel junction to the alveolar crest, or to the bottom of the bony defect. As only bitewings were available, alveolar bone loss was measured in relation to mean root length values, as described by Bath-Balough and Fehrenbach [94] (Table 6).

Table 6. Classification of periodontitis by radiographic bone loss (RBL) per tooth

<b>Tooth</b>	<b>17/27</b>	<b>16/26</b>	<b>15/25</b>	<b>14/24</b>	<b>37/47</b>	<b>36/46</b>	<b>35/45</b>	<b>34/44</b>
Mean root length, mm*	12		14					
RBL, mm								
Stage I	≤2		≤2					
Stage II	>2 to 4.5		>2 to 3.4					
Stage III/IV	>4.5		≥ 3.5					

\*Data from Bath-Balough and Fehrenbach [94]

### 3.4.2 Dental caries

Dental caries was examined clinically and radiographically. A five-grade diagnostic scale [52,54] was used to register caries severity on approximal, buccal, lingual/palatinal, and occlusal surfaces. Caries was classified as grade 1 if the surface had a white or brown visual



caries lesion in the enamel and/or radiolucency in the outer half of the enamel; grade 2 if the surface had a small cavitation in the enamel and/or radiolucency in the inner half of the enamel; grade 3 if there was a cavitation of moderate size and/or radiolucency in the outer third of the dentin; grade 4 if there was a big cavitation and/or radiolucency in the middle third of the dentin; and grade 5 if the surface had a big cavitation and/or radiolucency in the inner third of the dentin. Caries grade 1-2 were denoted as enamel caries and grade 3-5 as dentine caries. In the present study, the outcomes DT and decayed surfaces (DS) include caries grade 3-5. Root caries and secondary caries were included in caries outcomes. Third molars were excluded.

### **3.5 Examiner reliability**

Prior to data collection, a workshop was conducted for all examiners and assisting dental nurses to introduce the Dental Health in the North Study. Examination procedures, diagnostic criteria, and the questionnaire were presented. The questionnaire was discussed, revised, and adapted for Sámi participants. After the workshop, an experienced periodontist visited all participating clinics to train and calibrate the examiners. This calibration included radiographic examination of caries from two cases and periodontal pocket probing on one patient each. The experienced periodontist was used as a gold standard. Kappa values were not calculated.

One examiner was trained and calibrated by the experienced periodontist, and performed all RBL measurements on bitewings. Measurements were assessed in two sets, including 10-20 bitewings from five randomly chosen participants. Interproximal bone loss was measured on premolars and molars. Inter-examiner agreement was conducted, with an intraclass correlation coefficient of 0.97. To conduct intra-examiner reliability for the measurements, the examiner performed the measurements twice, which rendered an intraclass correlation coefficient of 0.95.

Post-clinical inter-examiner agreement was estimated to ensure the reliability of caries registration. In order to estimate Kappa values, one examiner was calibrated with a specially designed software (DIL version 1.21, University of Bergen, Bergen, Norway). The calibration was based on a judgement of 51 occlusal and approximal surfaces on radiographs of extracted teeth. Two different exercises were performed (different sets of teeth). The agreements with

an expert group, expressed by weighted kappa, were 0.67 and 0.70, respectively. Secondly, caries registration was performed by the calibrated examiner for all participants. This registration was based on bitewings, using the five-grade diagnostic scale [53,54]. These registrations were used as the gold standard for the inter-examiner agreement analysis. Finally, three randomly chosen registrations (participants) from each examiner (dental health workers) were used to calculate the mean kappa value for each examiner ( $\kappa=0.55-1.00$ ) and for all examiners ( $\kappa=0.84$ ) (Table 7).

Table 7. Kappa values and mean kappa value from three patients from each examiner

Examiner	Kappa value			Mean
	Patient 1	Patient 2	Patient 3	
1	0.379	1	0.484	0.62
2	0.284	1	0.379	0.55
3	0.763	1	0.657	0.88
4	1	0.333	1	0.78
5	1	1	1	1.00
6	1	0.733	0.657	0.80
7	0.727	1	1	0.86
8	1	1	0.657	0.89
9	1	1	0.647	0.88
10	1	1	1	1.00
11	1	0.657	1	0.89
12	1	1	0.948	0.98
13	0.833	1	1	0.94
14	0.484	1	1	0.83
15	0.846	0.309	0.954	0.70
<b>Mean</b>				<b>0.84</b>

### 3.6 Data analysis and statistical methods

Data were analyzed using STATA/MP for Windows (StataCorp LLC) (Paper I) and IBM® SPSS®, version 25 (Paper II) and version 26 (Papers III and IV). A summary of statistical methods is presented in Table 8.

Table 8. Summary of statistical methods used in Papers I-IV

Statistical test used	Paper I	Paper II	Paper III	Paper IV
Intraclass Correlation Coefficient	+		+	
Cohen's Kappa	+		+	
Pearson's $\chi^2$ test		+	+	+
One-way ANOVA		+		
Independent sample t-test		+		
Logistic regression		+	+	+
Mann-Whitney U test			+	+
Kruskal-Wallis test			+	+
Chronbach's $\alpha$				+

Descriptive statistics for the Dental Health in the North Study are presented in Paper I, with no further statistical analysis of data.

In Paper II, the characteristics of study participants were stratified by ethnicity and presented as numbers (proportions). Differences between ethnic groups were assessed with Pearson's  $\chi^2$  test. Distribution of periodontitis in relation to ethnicity, demographic, socioeconomic, and oral health-related behavioral factors were presented as proportions (numbers and percentages) in the total study sample and in the Sámi group. Case definition of periodontitis was grouped in three categories based on severity and complexity (non-severe periodontitis (NSP), stage II, stage III/IV). Differences between groups were assessed with Pearson's  $\chi^2$  test. Significance levels were set at 0.05. Prevalence and extent of RBL and PPD, stratified by ethnicity and age, were presented as numbers of individuals (proportions) and/or means and standard deviations (SD). Comparisons between Sámi and non-Sámi within age groups were done using Pearson's  $\chi^2$  test and the independent sample t-test. Univariate and multinomial logistic regression was performed to determine the relationship between stages of periodontitis in relation to ethnicity, sex, age, duration of education, smoking habits, and dental attendance. NSP was used as the reference group and compared with stage II and stage III/IV periodontitis. Analyses were performed in the total study sample and in the Sámi group. Results were reported as odds ratios (ORs) and 95% confidence intervals (CIs). The significance level was set at 0.05.

In Paper III, demographic and socioeconomic characteristics were presented as numbers (proportions), stratified by ethnicity and region of residence. Comparisons between Sámi and non-Sámi or between the inland and coastal regions were assessed with Pearson's  $\chi^2$  test.

Number of teeth, intact teeth, and caries experience in relation to ethnicity, sex, and age were presented as means and SD. Mean number of DT was also presented in relation to demographic, socioeconomic, and oral health-related behavioral factors stratified by ethnicity. The Mann-Whitney U test and the Kruskal-Wallis test were used for comparisons between/within ethnic groups and within variables. Binary logistic regression was used to analyze the association between having untreated caries ( $DT \geq 1$ ) or not having caries ( $DT = 0$ ) in relation to sex, age, region of residence, education, and oral health-related behavioral factors. Findings were reported as ORs and 95% CIs.

In Paper IV, OHIP-14 scores were presented as means and SDs, and as numbers of individuals having problems, stratified by ethnicity. OHIP-14  $> 0$  was presented as proportions in relation to dimensions, stratified by ethnicity. Differences in mean OHIP-14 scores between Sámi and non-Sámi were assessed with the Mann-Whitney U-test or the Kruskal-Wallis test. Binary logistic regression analysis (ORs and 95% CIs) was used to assess the adjusted association between frequent problems and demographic factors, oral health-related behavioral factors, and clinically assessed factors. Three models were performed. In model 1 ethnicity, sex, and age were included. In model 2, frequency of dental visits was included in addition to all the variables in model 1. In model 3, number of teeth, periodontitis, and caries were included in addition to the variables in model 2.

### **3.7 Ethics**

The study was approved by the Regional Committee for Medical and Health Research Ethics of the University of Tromsø, Norway (2012/1902/REK Nord). All invited participants were given a detailed description of the study and were informed that they could withdraw at any time without reason. In addition, they provided written informed consent before inclusion in the study. Planning and data collection were carried out in close collaboration with representatives from the administrative unit of the PDS in the region and with the examiners at the different PDS clinics.

Health research on an ethnic group requires permission at the group level (collective consent), in addition to individual permission (written informed consent) and ethical permission given by the Regional Committee for Medical and Health Research Ethics. Health research has been performed in the Sámi population since the early 1900s [95], but Sámi research ethics were

first illuminated and discussed in 2002, during a seminar entitled *Samisk forskning og forskningsetikk* [Sámi research and research ethics] [96]. At the same time, in 2001, the Center for Sámi Health Research was established at UiT The Arctic University of Norway, with the purpose of gaining knowledge on Sámi health and living conditions. Research on the health of the Sámi population has expanded substantially since the establishment of the Center for Sámi Health Research, as has the need for ethical guidelines [97]. To develop ethical guidelines for Sámi health research, a commission was established by the Sámi Parliament of Norway, which proposed the Ethical Guidelines for Sámi Health Research and Research on Sámi Human Biological Material [98]. These guidelines have been accepted by the Sámi Parliament of Norway and provide guidance to individual researchers, research institutions, Sámi communities, and private individuals about which principles of research ethics should be applied as the basis for Sámi health research to ensure Sámi self-determination. Sámi self-determination must be documented in a collective consent, and Sámi ethnicity as a variable must be used in a balanced, responsible manner so that research contributes to knowledge, not stigmatization. In Norway, this consent must be approved by an expert group, which is to be appointed by the Sámi Parliamentary Council. Collective consent is required for all Sámi health research projects as from 2016; however, the data collection for the present study was conducted ahead of the implementation of these guidelines.

## **4 RESULTS**

In total, 2078 adults completed the questionnaire and the clinical examination (57.0% women). The mean age was 47.5 years (SD=14.3) in the overall sample, 46.7 (SD=14.7) in participants with Sámi affiliation, and 48.9 (SD=13.4) in non-Sámi ( $p<0.001$ ). The mean number of teeth was 25.1 (SD=3.8), with no significant difference between Sámi and non-Sámi. A majority of participants brushed their teeth at least twice daily (56% of Sámi and 71% of non-Sámi;  $p<0.05$ ), while around 10% of Sámi participants and 5% of non-Sámi participants brushed their teeth less than once daily ( $p<0.05$ ). A majority of the participants attended dental health services regularly, but 21% of Sámi and 17% of non-Sámi reported an irregular use of dental health services or attended only when having problems or pain ( $p<0.05$ ).

### **4.1 Paper I**

In total, 157 participants were excluded due to missing data (Figure 4). In the analysis of Paper I, participants from abroad (n=44) were excluded, giving a final analytical sample of 2034. In total, 1381 (76%) reported Sámi affiliation, based on questions about home language, ethnic background, or self-perceived ethnicity. Of these, 981 reported all three of these criteria, and were categorized as Sámi. Four hundred participants reported only one or two of these criteria (Sámi as home language only, n=14; Sámi home language and ethnic background, n=18; Sámi ethnic background only, n=53; Sámi ethnic background and self-perceived Sámi, n=236; self-perceived Sámi only, n=48; or self-perceived Sámi and Sámi as home language, n=18) and were categorized as mixed-Sámi (Figure 5). All other participants were classified as Norwegian (n=653).

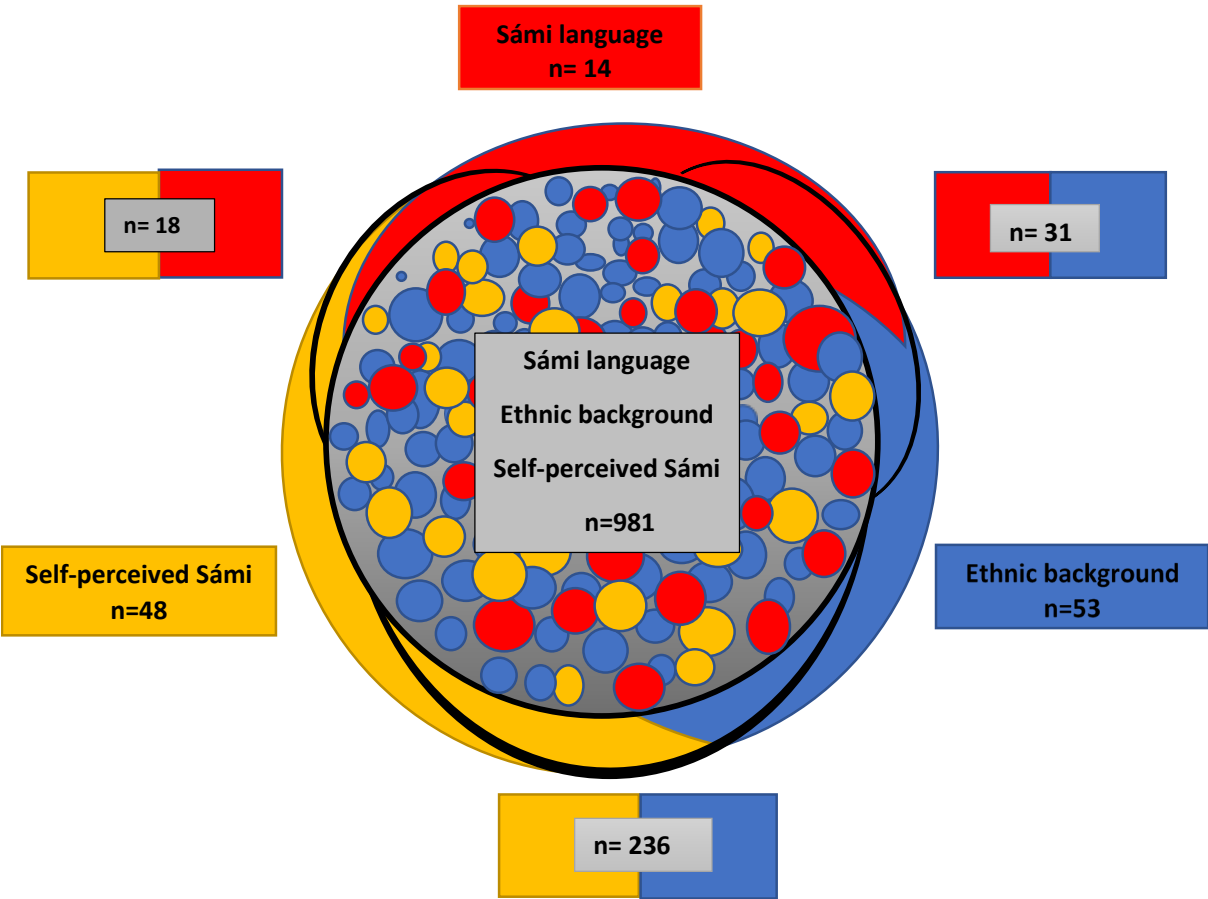


Figure 5. Distribution of individuals in relation to Sámi language, ethnic background, and self-perceived ethnicity

## 4.2 Paper II

There were 2078 participants included in Paper II, categorized as Sámi and non-Sámi. Participants included in Sámi category were those who considered themselves to be Sámi or responded Sámi on at least one of the questions about home language or ethnic background. All others were classified as non-Sámi, mainly consisting of Norwegians, Kven (without Sámi affiliations, n=99), and Sámi who did not report any subjective appraisal criteria (n=165). Of the total study population 66.5% reported Sámi affiliation.

In total, 49.7% of the study sample had stage II-IV periodontitis, and 20.1% had stage III/IV periodontitis, with no significant ethnic differences ( $p=0.630$ ). The prevalence of RBL and PPD were higher in older age groups in both ethnic groups. A higher proportion of Sámi than non-Sámi had one or more PPD  $\geq 6$  mm (19.4% and 15.6%, respectively;  $p<0.05$ ).

Sámi participants were more likely to have stage III/IV periodontitis than non-Sámi (adjusted OR=1.6, 95% CI: 1.1-2.2). Risk factors associated with having stage III/IV periodontitis were female sex, increasing age, shorter duration of education, smoking, and regular dental visits.

### **4.3 Paper III**

The analytical sample in Paper III consisted of 2033 participants (excluding participants from abroad, n=44). Participants were categorized as Sámi and non-Sámi, as in Paper II. Of the total study sample, 67.9% reported Sámi affiliation, and of those 63% were from the inland region.

The overall mean DMFT and mean DT were 16.2 (SD=6.7) and 1.0 (SD=1.7), respectively. The mean DMFT among Sámi was 15.7 (SD=6.7), and among non-Sámi it was 17.0 (SD=6.6). Mean DT was 1.0 (SD=1.6) among Sámi and 1.2 (SD=1.8) among non-Sámi. Non-Sámi had a significantly higher mean DMFT ( $p<0.05$ ) and mean DT ( $p<0.05$ ) than Sámi participants.

Participants from the coastal region had a higher mean DT than those from the inland region, regardless of ethnicity (coastal: 1.3, SD=1.8, inland: 0.8, SD=1.5;  $p<0.05$ ).

The prevalence of individuals with one or more DT was 46.7% in the total study sample, 44.3% in Sámi, and 51.9% in non-Sámi ( $p<0.05$  between ethnic groups). Having untreated dental caries (DT $\geq 1$ ), compared to not having caries (DT=0), was associated with living in the

coastal region, consumption of sugary soft drinks several times a week, toothbrushing less than daily, and irregular dental visits in both ethnic groups.

#### **4.4 Paper IV**

Paper IV included 1913 participants (excluding participants from abroad,  $n=44$  and participants missing  $>2$  OHIP values,  $n=121$ ). Participants were categorized as Sámi and non-Sámi. Of the total study sample, 67.8% reported Sámi affiliation. The mean OHIP-14 score was 5.1 ( $SD=5.8$ ) in the entire study sample, with a significantly higher mean OHIP-14 in Sámi (5.4,  $SD=6.0$ ) compared with non-Sámi (4.4,  $SD=5.2$ ) ( $p<0.001$ ). Around 80% of the respondents reported having problems during the last year (OHIP-14  $>0$ ). The proportion of subjects who experienced one or more items fairly often or very often was 11.6% for Sámi and 8.6% for non-Sámi ( $p<0.05$ ). The most frequently reported OHIP-14 dimension in both ethnic groups was physical pain.

In the adjusted logistic regression analysis, ethnicity was not associated with reporting frequent problems ( $OR=1.3$ , 95% CI: 0.9-1.8). When adjusted for all variables in model 3, the odds of reporting frequent problems was significantly higher among women, younger participants, those with irregular dental visits, with less than 20 teeth, and those with periodontitis or caries. The odds of reporting frequent problems among those with  $PPD \geq 6$  mm or  $DT >0$  were 2.2 (95% CI: 1.5-3.1) and 1.4 (95% CI: 1.0-1.8), respectively.

## **5 DISCUSSION**

### **5.1 Methodological discussion**

To increase knowledge on oral health among populations in rural regions in circumpolar areas, a good epidemiological study design is required. In addition to high methodological quality in health research, on the indigenous Sámi people require that the team have documented knowledge on Sámi culture and Sámi health and living conditions [98]. Thus, for this study, it was important to find a study design that was suitable in this area, in line with the requirements on indigenous research.



### **5.1.1 The use of Public Dental Health Services clinics as a study arena**

In the present study, PDS clinics were used as recruitment arena; all patients in contact with the clinics during the data collection period were invited to participate. To recruit from as broad a spectrum as possible in the population, local dental health workers advertised the project in the media (radio, newspaper) and encouraged the population to participate. The participation rate was high, but because the participants were not randomly selected, the question remains as to whether the study sample reflects the general population. If not, this may affect the study's external validity. We chose to use PDS clinics as the arena for recruiting participants because a high proportion of adults in rural areas of Northern Norway use them for dental examination and treatment. Although this assured good accessibility for participants, it came with the challenge that most of those who participated were already PDS users. This selection of participants is likely to result in a study sample that is more interested in their oral health than individuals who do not seek dental health services, and a risk that individuals with poorer oral health are underrepresented. Although a report from Statistics Norway showed that those with good oral health go to the dentist more often than those with poorer oral health [99], the main findings of the present study show a high prevalence of oral diseases in these areas, consistent with findings in rural areas of Troms County, where the study sample was chosen randomly [17,57].

The participation rate in the present study was much higher than that in the pilot study conducted in rural areas in Northern Norway as a part of the methodological preparation and planning for the Dental Health in the North Study. The recruitment procedure was changed following the pilot study, in which postal invitations were sent from the academic institution. In the present study, the invitation was sent from the local PDS clinic, or given to potential participants directly at the clinic during their appointment. The commitment around the research project before and throughout the data collection period, as well as the proximity to the research arena and the use of local dental health workers may be the reason for the high participation in this project.

Local involvement was a focus throughout all stages of research planning and data collection. Local dental health workers had the opportunity to cooperate in the planning process and were in contact with participants while they completed the questionnaire and during the dental examination. As more than half of the dental health workers were Sámi (16 out of 29), the PDS clinics had close ties to the local communities and knowledge about the Sámi population.

Relationships between Sámi communities and researchers should be characterized by respect, reciprocity, equality, and accountability [98] in order to contribute new knowledge, not stigmatize an ethnic group. Many Sámi have a strained relationship with the research community, because of the history of research in the Sámi population, which includes skull measurements, disturbance of Sámi graves, and removal of Sámi skeletal material [100]. Based on skull measurements from different ethnic groups in Northern Norway [95], Sámi were considered an underdeveloped race and a low-status group. The fact that many of the employees were Sámi may have contributed to more people wanting to participate in the study.

The use of PDS as a research arena may be more cost-effective, because data collection can be incorporated into daily clinical routines, and the setting is close to participants, so they do not need to travel far away to participate. A limitation may be the use of many examiners who collected data in different clinics, instead of a specialized team that is calibrated and trained to conduct the registrations.

### **5.1.2 Validity and reliability**

The validity of a research study refers to how well the results represent true findings for those participating in the study [101]; it is often expressed as external and internal validity. As mentioned previously, external validity depends on the methods used to select the study sample, while internal validity depends on the methods used to collect the relevant information and conduct analyses [102]. One potential source of bias that can threaten internal validity is information bias.

Information bias can be introduced in a study through the misclassification of exposure variables from questionnaires or clinical examinations [101]. In situations where the participant gives inaccurate answers or selectively responds to sensitive information, recall bias occurs, which is one of the most common biases that produces misclassification. This can lead to overestimation or underestimation of the actual situation, which may affect the association between the exposure and outcome variables. Examples in the present study may be information on the consumption of sugary soft drinks and toothbrushing frequency. As sugar is a well-known risk factor for the development of caries [103,104], and toothbrushing twice daily is recommended, respondents might have understated the frequency of sugar

intake or overreported toothbrushing frequency, because they know that frequent consumption of sugar may cause caries and toothbrushing prevents caries. In the present study, around 18% of respondents reported that they consumed sugary soft drinks more than once a week, while 9% drank sugary soft drinks four times a week. This is a bit lower than national estimates on the daily consumption of sugary soft drinks in 2015, which was 15% [105].

Another variable that may cause recall bias is ethnicity. Participants affected by Norwegianization or who are insecure in their ethnic background may not have responded to the question on ethnicity, or they may have tended to choose 'Norwegian' as the response option, leading to a misclassification of ethnicity. This may affect the association between ethnicity and oral health outcomes. However, the distribution of Sámi in this study was comparable to the number of people registered in the 2013 Sámi parliamentary election register in the selected municipalities, which makes the ethnic distribution in this study reliable.

Another factor that may affect the validity of the study is the high number of examiners, which may lead to observer bias. Periodontal diagnosis was based on RBL and PPD and classified by staging and grading. Staging was based on the measurable extent of destroyed periodontium, expressed by % of RBL. Precautions were taken to classify periodontitis as correctly as possible. We performed a test on the x-ray machines from the different clinics to ensure the accuracy of the measurements and found a minor enlargement of the mean measurements (2.7-11.0%). These enlargements were found to be too small to affect the RBL measurements. Based on this, we accepted Digora as a measuring tool. However, studies have demonstrated that orthoradial projection may influence the accuracy of measurements of intraoral radiographics [106,107] and lead to an underestimation or overestimation of measurements, even if the image quality is high. This must also be taken into account in this study, but the differences in the x-ray tests showed both larger and smaller values, which could lead to overestimation in some measurements and underestimation in others. To further improve and secure RBL measurements, all registrations were performed by one examiner, who was calibrated twice prior to the registrations. The calibration of PPD measurements was done on one patient, and the examiner's measurements were calibrated against an experienced periodontist (gold standard). However, inter-examiner kappa values were not calculated, thus inter-examiner reliability of the PPD measurements was not assessed. Another factor that may affect the diagnosis of periodontitis is the use of mean root length instead of the exact length of the tooth to calculate the percentage of loss of RBL. This could underestimate or

overestimate the prevalence of periodontitis. Because of that, stage I periodontitis was classified as NSP. RBL was measured on premolars and molars, which may underestimate the prevalence of periodontitis, as canines and incisors were not included in the RBL.

To ensure the reliability of caries registration, post-clinical radiographic caries registration was performed by one calibrated examiner. Although there was large variation in the average kappa values, no systematic pattern was observed in the distribution of kappa values. Thus, we can consider this to be a random variation in caries registration and that the measurements from examiners are acceptable.

The original OHIP questionnaire is in English, but it has been translated and validated in many languages [108-110]. The OHIP-14 has not been validated in the Norwegian or Sámi language, which may affect the validity, reliability, and responsiveness of the instrument. However, the translated Norwegian version of the OHIP-14 has been used in several Norwegian studies [18,111-113], and was translated into the Sámi language for use in Sámi populations in the present study.

### **5.1.3 Classification of Sámi ethnicity**

We focused on oral health conditions in the indigenous Sámi population, using ethnicity as an independent variable. Previous studies on the Sámi population used various inclusion criteria and categorizations to define Sámi ethnicity, with region of residence and individual-based information being the most common criteria [114]. Region of residence as a Sámi ethnicity marker is based on former census-based demographic knowledge of density of Sámi inhabitants [90], administrative units defined by Sámi Parliament subsidy schemes for business development [115], or the administrative areas for Sámi language [6,116]. When using region of residence as an ethnicity marker, no individual-level information is obtained, and researchers cannot look at differences between different ethnic groups or groups within an ethnic group in the same area. In the present study, region of residence was used as an indirect inclusion criterion, as the study was conducted in administrative areas for Sámi language. However, the classification of ethnicity at the individual level was based on self-identification.

Information on ethnicity was collected via questionnaire, using both subjective (self-perceived Sámi) and objective (Sámi kinship, descent, and spoken Sámi language) criteria of ethnic

identity at the individual level. Ethnic identity and ethnic classification are place-, time-, and context-specific [10]. The formation of ethnic identity is a developmental process; it may differ throughout life in relation to individual experiences or vary across contexts. For example, Sámi who do not speak the Sámi language may self-identify as Sámi in areas where the Sámi is a minority group (the Sámi language is not the main language) and Norwegian in areas where the Sámi are the majority [8]. Self-identification, and especially self-perceptions, are a measure of ethnicity which must be handled with respect, due to the fact that many Sámi gave up the Sámi language and identity during the policy of Norwegianization [14]. This was one of the main reasons for placing Sámi who did not consider themselves as Sámi into the non-Sámi group.

In Paper I, ethnicity was classified into three groups, with a subcategorization of participants with Sámi affiliation, while in Papers II-IV, ethnicity was constructed as a dichotomous variable. As ethnicity is an objective, socially constructed, complex phenomenon, with imprecise boundaries [9,117,118], it is necessary to define and classify ethnicity in line with the research question or purpose of the study. As the purpose of Paper I was to assess the distribution of ethnicity among the participants, including the different measures of ethnicity, the distribution was made as accurate as possible in relation to the information obtained.

Around 25% of the respondents reported being Sámi without speaking the Sámi language indicating that the legacy of historical assimilation is still ongoing, and is something that should be considered when categorizing ethnicity in research on Sámi, especially when language affiliation is used. Subcategorization of Sámi can be perceived as ranking instead of a nuance of ethnicity, and such ranking should be carefully considered by the researcher, as it can give participants the impression that they were placed in a lower-ranked subgroup when the results are communicated to the public.

However, it is important not to avoid subcategorization of ethnic groups, as this is how we glean knowledge about similarities and differences within an ethnic group [9]. In Paper III, we found a significant difference in caries experience between Sámi and non-Sámi, but when stratifying caries experience by ethnic group first and then by region of residence, the ethnic difference was no longer significant. This type of change in results shows that comparisons between ethnic groups must be made with caution, and published results must be thoroughly tested in order to provide the most accurate knowledge possible. Future studies should strive to gain knowledge that covers a broader spectrum of relevant factors dealing with ethnicity; for example, regional factors and group-level factors, in addition to individual factors

included in the social construction of ethnic categories [10]. Regional forces that shape ethnicity may include Sámi settlement patterns, which lead to regional differences in population compositions, meaning that those who live in areas with a high density of Sámi differ from those in low-concentration areas. On the other hand, it is important to include the cultural aspects and traditions that characterize an ethnic group, as they influence personal identity and shape group members' knowledge, attitudes, and behavior. Groups perceived as very different from the majority group may experience higher rates of oral disease or limited access to care, as reported in many indigenous oral health studies [75,76,119].

## **5.2 Discussion of main findings**

### **5.2.1 Oral health conditions among Sámi and non-Sámi**

#### **5.2.1.1 Periodontitis (Paper II)**

Findings from Paper II showed that periodontitis is a common oral disease among adults in Northern Norway; around half of the study sample had periodontitis, and one of five had stage III/IV periodontitis. No significant difference in the prevalence of periodontitis between ethnic groups was found, but a higher proportion of Sámi had PPD  $\geq 6$  mm than non-Sámi.

As periodontitis was defined according to a modified version of the new AAP/EFP classification system [39,93], the factors that may have affected the classification of periodontitis should be highlighted. Firstly, age was not considered when classifying periodontitis. The influence of age on periodontitis is complex. While the likelihood of developing periodontitis increases with age, suggesting that age is a risk factor for this disease [120], age may also be an underlying characteristic that influences the variance of the disease. Indeed, there may be a “normal” age related-increase in the distance from the cemento-enamel junction to the alveolar bone crest that is not calculated in the present study. This distance is approximately 0.4 mm/year in those younger than 45-50 years and 0.02-0.03/year in older people [121]. This may affect the severity of disease in relation to age in the study population. Secondly, the number of MT was not included in the case definition, meaning that RBL and PPD measurements were based on remaining teeth; teeth that may have been extracted due to severe periodontitis were not included in the classification, and may thus have affected the severity of disease. The last factor I want to highlight is RBL measurements

in relation to fillings and extractions of third molars, as fillings with cervical closure close to the bone, as well as extractions, may affect RBL without being a periodontal case.

Prevalence and severity of periodontitis were found to be associated with sex, age, duration of education, and smoking. A higher likelihood of having stage III/IV periodontitis was found in Sámi men, which supports previous studies among indigenous people [72,122]. Also consistent with previous studies [17,44,123], the prevalence of periodontitis was highest in the older age groups, with a significantly higher proportion of those in the oldest age groups having periodontitis compared with the youngest age group. Adults aged 50 years or older also had a higher prevalence of PPD  $\geq 6$  mm compared with young adults. Lower education was associated with increased probability of severe periodontitis, supporting the findings from a study of adults in the population in Troms County, Northern Norway [17], but contradictory to findings from in a study of Norwegian old-aged pensioners [43], which did not reveal any association between education and periodontitis. Finally, smoking is strongly associated with periodontitis [17,120], and this association was confirmed by our finding that smokers had higher odds of severe periodontitis than non-smokers (Paper III).

The prevalence of periodontitis in the present study sample is comparable, but somewhat higher, than estimates in previous Norwegian studies. Among adults (20-79 years) in Troms County [17,124], the estimate of stage III/IV periodontitis was quite similar (20.8%) to that in the present study, while the prevalence of stage II periodontitis was lower (19.2%), indicating that the overall prevalence of periodontitis is higher in Finnmark than Troms County. In a cohort study of 35-year-olds in Oslo [42], the prevalence of PPD  $\geq 6$  mm was reported to be 8.1%, which is in line with the prevalence in a comparable age group in the present study (Paper II). The Oslo study [42] showed that periodontal health among young adults in Norway has improved from 1973 to 2003. The proportion of people with PPD  $\geq 6$  mm reduced from 21.8% in 1984 to 8.1% in 2003, and the proportion of people with RBL reduced from 54% to 24%, respectively. In a nationwide study of a random sample of elderly individuals ( $\geq 67$  years of age), 33% had periodontitis, and of those, 12% had severe periodontitis ( $\geq 3$  periodontal pockets  $\geq 6$  mm). However, comparisons must be done with caution, as different classification criteria were used in the different studies.

#### **5.2.1.2 Prevalence of caries and caries experience (Paper III)**

The prevalence of caries and caries experience, expressed with mean DT and mean DMFT was found to be high in this study sample. Around half of the participants had one or more DT, while the mean DT and mean DMFT was found to be higher than those in adults in Troms County, Northern Norway [57]. Contradictory to findings in Paper II, where we did not observe any ethnic differences in the prevalence of periodontitis, we found significant differences between Sámi and non-Sámi regarding the prevalence of caries and caries experience. A larger proportion of non-Sámi had a higher mean DT and mean DMFT compared to Sámi. The differences in mean DT were no longer significant when comparing ethnic groups within the inland and coastal regions, but participants from the coastal region had a higher mean DT and mean DMFT compared to those from the inland region. When comparing characteristics in populations from inland and coastal regions, we found that Sámi are in the majority in the inland region, while they are in the minority on the coast. Moreover, in the inland region there was a higher proportion of young people who participated in the study, and respondents from this region had a higher mean duration of education than those from the coastal region. The differences between the inland and coastal regions in relation to caries is an interesting finding, and should be investigated further in future studies. As Sámi in these areas live in mixed Sámi and Norwegian settlements, with minority and majority ethnic groups, the community is influenced by both Sámi and Norwegian culture and traditions. It would be interesting to find out if or how sociocultural factors affect oral health in different communities using both quantitative (socioeconomic, cultural, and ethnic information) and qualitative methodology (subjective perspective). This may expand our knowledge on indigenous perspectives on oral health.

Oral health-related behavioral factors, like consumption of sugary soft drinks, toothbrushing frequency, and dental attendance were found to be associated with DT. In relation to the frequency of consumption of sugary soft drinks, we did not find any differences between ethnic groups, but we observed frequent consumption of sugary soft drinks in one of five of the participants, regardless of ethnicity. Frequency and amount of sugar intake has been associated with caries development [103,104], but the association was found to be strongest in those who reported frequent sugar consumption in addition to brushing their teeth less than daily with fluoride toothpaste [103]. Therefore, reducing sugar consumption and increasing toothbrushing frequency seem to be important preventive measures to reduce the prevalence of caries among adults in core Sámi areas regardless of ethnicity. Participants who brushed their teeth less than daily, and those who consumed sugary soft drinks frequently, had a higher



risk of DT. Toothbrushing daily is an effective preventive measure against caries [125], and the effect is more pronounced when brushing teeth twice daily with fluoride toothpaste [126]. In the present study, we found a significant difference in toothbrushing habits between Sámi and non-Sámi. Among Sámi, only half of the participants brushed their teeth twice daily, while 10% were infrequent brushers. The prevalence of caries was significantly higher among infrequent brushers compared with those with regular brushing habits.

The prevalence of caries and caries experience in Norwegian adult populations has been discussed in several studies. Most of these are cross-sectional and were conducted in the general adult population [57], age cohorts [55,127], or elderly populations [56,128], using prevalence of caries (DT or DS) or caries experience (DMFT) as the outcome measure. In Paper III, we used DT<sub>3-5</sub> as the outcome measure, giving an indication of the mean number of teeth with cavitation and treatment needed, but the inclusion of enamel caries on the surface level revealed the total caries status in the examined population, with less risk of underestimating the prevalence of caries in the population. We found that the mean values of DMFS, DFS, and DS were markedly higher when including enamel caries compared with the findings in Paper III (Table 9). This finding may indicate the need for preventive measures and interventions that may stimulate a non-operative (preventing) approach in favor of restorative care [129].

Table 9. Dental caries experience by ethnicity, sex, and age group

Characteristics	N	D <sub>1-5</sub> MFS	D <sub>1-5</sub> FS	D <sub>1-5</sub> S
		Mean (SD)	Mean (SD)	Mean (SD)
Total	2033	48.9 (25.6)	35.1 (18.1)	5.2 (5.4)
Ethnicity				
Sámi	1380	47.3 (25.5) <sup>a</sup>	33.4 (17.5) <sup>a</sup>	5.0 (5.2) <sup>a</sup>
Non-Sámi	653	52.3 (25.6)	38.8 (18.7)	5.7 (5.7)
Sex				
Men	875	49.2 (25.8)	35.2 (18.2)	5.6 (5.7)
Women	1158	48.7 (25.6)	48.7 (18.0)	4.9 (5.1) <sup>a</sup>
Age (years)				
18-34	413	26.6 (16.9) <sup>b</sup>	22.6 (14.6) <sup>c</sup>	9.1 (7.3) <sup>c</sup>
35-49	668	38.3 (19.4)	30.7 (15.1)	5.5 (4.8)
50-64	694	61.2 (19.6)	44.5 (16.4)	3.5 (3.8)
65-75	258	78.8 (18.5)	41.3 (18.7)	2.9 (3.2)

<sup>a</sup>P<0.05; Mann-Whitney U test.

<sup>b</sup>P>0.05; Kruskal-Wallis test. Significant differences between all age groups.

<sup>c</sup>P<0.05; Kruskal-Wallis test. Significant differences between all age groups, except of age group 50-64 and 65-75 years. DMFS: decayed, missing, filled surfaces, DFS: decayed, filled surfaces, DS: decayed surfaces, SD: standard deviation

Comparing the findings in Paper III with other study populations, we found that our reported prevalence of caries was higher than that in the general population in the TOHNN-study carried out in Troms County [57]. In the TOHNN-study, both enamel and dentin caries were reported on the surface level, showing that the prevalence of enamel caries (D<sub>1-5</sub>S) was lower among adults in Troms than in our study sample. The prevalence of caries among young adults was also somewhat higher in the present study compared to 35-year-olds in Oslo [55]. This was not surprising, as the average number of DT is higher among 18-year-olds in core Sámi areas compared to the average in Finnmark County and in Norway in general (Figure 1). Also, data from statistics Norway reported that only 18.8% of 18-year-olds in Finnmark County had no caries experience (DMFT=0), which is significantly lower than the proportion in Hedmark County in the south of Norway, where 42.7% had no caries experience. Among the elderly population in Norway, the mean DT is reported to be 0.3 [56], which is consistent with findings from a study among the elderly in Troms County [128], but lower than what we found in the present study. The observed differences across studies could be due to the use of different outcome measures, or to regional and sampling variations. Nevertheless, the high prevalence of caries experience in the present study calls for health promotion and caries prevention measures targeted at adults in these areas.

#### **5.2.1.3 Oral health-related quality of life (Paper IV)**

The present study is the first to assess OHRQoL in an adult Sámi population in Northern Norway. A majority of the respondents experienced oral health-related problems that impacted their daily lives during the last year, and around 10% of the study sample experienced frequent problems. There were no differences in the proportion of Sámi and non-Sámi reporting frequent problems, but Sámi had a higher mean OHIP-14 score than non-Sámi. This may indicate that Sámi experienced oral health-related problems that impacted their daily life more often than non-Sámi, but the effect size was low (<0.17), indicating that the clinical importance of the mean difference may not be meaningful for patients [130].

The OHIP-14 score in the present study was higher than that among adults (20-80 years) in a nationwide study in Norway (4.1, SD=6.2) [18] and Finland (4.0, 95% CI: 3.8-4.2) [68], lower than among Swedish adults (6.4, SD=7.1) [67], and markedly lower than among a convenience sample of indigenous Australians (15.0) [69]. The OHIP-14 is meant to assess the 'social impact' of oral disorders, expressed by prevalence (frequency of problems) and/or

severity of functional and psychosocial impacts associated with oral disorders [64]. As OHIP-14 score is one of the most commonly used patient-reported outcome measures, it has been described thoroughly [62,65,66], but questions have been raised about the interpretation of OHRQoL using the OHIP-14 [130]. Mean OHIP-14 score is the most common way to present OHRQoL, calculated by adding the scores for the 14 items to a overall score ranging from 0-56. This overall score can be derived from different sets of responses, making it impossible to provide 'one' profile for a specific score. This makes it difficult to interpret what the mean OHIP score really says about OHRQoL.

The association observed between clinically assessed outcomes and OHRQoL in Paper IV suggests that DT and PPD  $\geq 6$  mm had a negative impact on OHRQoL. Dental caries has been reported to have a negative impact on OHRQoL among children and adolescents [71,131], but studies on adults are scarce. In Norway, studies on the association between caries and OHRQoL in adult populations [111,132] have reported contradictory results. A study among Norwegian young adults (35-47 years) showed that those with several DT experienced worse OHRQoL [132], which is consistent with the present study, while another study conducted on adults in the general population in Troms County, Northern Norway, found that number of DT was not associated with poorer OHRQoL [111].

The association between periodontitis and OHRQoL in adults has been better documented than the association between caries and OHRQoL [70,133-136]. In the present study, we used PPD  $\geq 6$  mm as the clinical parameter and found that individuals with one or more PPD  $\geq 6$  mm had a higher mean OHIP-14 score, reported frequent problems more often, and had higher odds of reporting frequent problems compared with those without PPD  $\geq 6$  mm. These findings are consistent with a previous study conducted on Norwegian adults [112], in which a positive association was reported between periodontitis and OHRQoL; they are also in line with findings from a Swedish study, where they found that participants with severe marginal bone loss experienced worse quality of life than participants with no or minor bone loss [134]. However, an important clinical implication of the present study is that oral health promotion and disease preventive measures aimed at reducing caries and periodontitis among Sámi adults have the potential to improve OHRQoL.

#### ***5.2.1.4 Oral health in rural areas of Northern Norway***

Available data on oral health in Norway shows an improvement in oral health among children and adolescents in recent decades, a trend that also applies in the rural areas of Northern Norway [137]. As shown in Figure 1, the average DMFT among 18-year-olds in Norway and in Finnmark County decreased from 4.2 and 5.5 in 2013 to 3.1 and 4.2 in 2019, respectively [58], while in core Sámi areas the mean DMFT was 6.1 in 2013 and 4.3 in 2019 (unpublished data from a computerized protocol, Opus dental, in PDS). This indicates that the geographic differences in oral health among adolescents and young adults in Norway have become smaller. The prevalence of periodontitis and caries among adults are reported to be higher in rural areas of Northern Norway compared with urban areas [17,57]. Accessibility to dentists and dental hygienists varies according to geographic area, and Finnmark County has a history of irregular access to dental health workers [137]. The situation has improved since the establishment of a dental education program at the University of Tromsø in 2002, which helped increase the number of dentists who speak Sámi [137].

Periodontitis is a chronic inflammatory disease that is triggered by bacterial microorganisms. It involves severe chronic inflammation that causes the destruction of the tooth-supporting apparatus and can lead to tooth loss if not treated. This disease requires routine follow-up and care. The new case definition of periodontitis is classified by staging and grading [93], and designated a need for clinical guidelines for treatment. These guidelines have been developed [138], and they recommend that patients with stage II periodontitis be given non-surgical periodontal treatment, including oral health education, individual oral hygiene instruction, and sub- and supragingival instrumentation to remove calculus and reduce the dental biofilm. Stage III/IV periodontitis implies significant damage to the periodontal support tissue, with RBL extending to the middle or apical third of the root and PPD  $\geq 6$  mm. In this stage, more advanced treatment may, in addition to the above, include periodontal surgery, with a possible need for specialist care [138]. No matter the stage of disease, more frequent treatment and clinical visits are warranted.

Dental health services are organized differently in different parts of Norway. In core Sámi areas in Northern Norway, there is no specialist care for the treatment of periodontitis, indicating that patients must travel far to receive recommended treatment. Studies have reported that a higher availability of dentists decreased the likelihood of periodontitis among indigenous people [75,76]. However, in the present study, those attending PDS clinics yearly or every other year did not have less periodontitis, but more severe periodontitis, than those who seldom attended PDS clinics. This could be a result of the recruitment procedure, as we

invited all people who had an appointment scheduled, including those undergoing periodontal treatment, or it may be the result of neglected prevention or treatment of disease among those who regularly attend PDS clinics. These findings support those from a study among adults attending PDS in Troms County [17].

All five municipalities included in the present study are defined as rural areas, thus we are not able to compare the prevalence of disease between urban and rural areas. However, the prevalence of primary caries ( $DS_{1-5}$ , Table 6), is comparable with the findings among adults in rural areas ( $DS_{1-5}=5.0$ ), but higher than among those from urban areas ( $DS_{1-5}=2.5$ ) in Troms County [57]. The high prevalence of oral health diseases in rural areas may be related to the availability of dental health services [17]. In rural areas of Northern Norway, the use of PDS is reported to be more common than the use of private services, with the explanation that private dental health services are lacking in these areas [33]. Indeed, in the five municipalities where the study was conducted, there is only one private dental health clinic. Furthermore, a majority of the participants attended PDS clinics regularly, yearly, or every other year, a finding which is consistent with previous studies reporting the use of dental health services in Norway. In Paper II, 83% of the participants from core Sámi areas in the SAMINOR 2 study used PDS clinics regularly, while another study from Troms County reported that around 70% of adults had dental visits at least every other year [17].

### **5.2.2 Oral health in an indigenous perspective**

Comparing the prevalence of periodontitis in the present study with findings from other studies of indigenous peoples is not straightforward, due to the use of different case definitions. The most commonly used definitions in indigenous studies is the Community Periodontal Index (CPI) [51] and PPD [76,81]. A review study [81] showed that periodontitis is common among indigenous Australians in rural areas, with 87.5% to 100% of the target population affected (CPI 1-4), and up to 50% having severe periodontitis (CPI 4,  $PPD \geq 6$ mm). The prevalence of severe periodontitis seems to be higher in indigenous populations in Australia, compared with those in New Zealand and Brazil, where around 10% and 12%, respectively, of the study populations had one or more pockets with  $PPD \geq 6$ mm [76]. Comparing these findings with findings in Paper II, the prevalence of stage III/IV periodontitis among the Sámi people seems to be in range with the findings among indigenous people in New Zealand and Brazil, but lower than among indigenous Australians. Although it

is difficult to compare findings from different studies or between different populations, previous studies have found that periodontitis is common among indigenous people worldwide, which was confirmed in the findings of the present study.

In the present study, DT was defined as caries grade 3-5. This definition was chosen so that we could compare the findings with previous studies on caries in indigenous populations. Caries experience in indigenous studies is often defined according to WHO guidelines [51] and expressed as DMFT or DT. The prevalence of DT (DT >0) in our Sámi population was similar to that in indigenous adults in Brazil (47%) [76], New Zealand (49%) [75,76], and Canada (35%) [75]. Caries experience has been documented more often among indigenous Australians, but this information has not been obtained systematically. Therefore, reported results often represent a selected population and cannot be generalized to the entire indigenous population of Australia [81], resulting in a wide range of prevalence of caries (26% to 81%) [73,75,76,139]. Although the prevalence of DT is comparable between Sámi and other indigenous peoples, our findings show that, compared with other indigenous groups, mean DT is lower among Sámi in core Sámi areas, where the mean DT is reported to be 1.8-4.4 [72-74,122,140,141], indicating that Sámi with caries experience have less DT.

Some issues must be highlighted in relation to research on oral health among indigenous peoples. One is whether the sample size of the indigenous group represents the indigenous people in that area/country. In many studies, indigenous groups are very small. The definition of 'small' depends on the main study objective. For example, when describing the prevalence of caries in a group, the representativeness of the data depends on the participation rate in the study: the larger the sample size, the more reliable the results. The main problem with small studies is the external validity, with large 95% CIs, while a strength of a small sample size is that it makes the study being quicker and cheaper to conduct [142]. A review study on oral diseases in indigenous adults in Australia [81] found that one of the difficulties of research on indigenous people was achieving a representative sample. They registered a big difference in the number of participants across studies (n=21 to 981) and identified inconsistencies in data capture and reporting. For example, different age groups and regions of residence were used in the studies, which limited the possibility for meaningful comparisons. Indeed, the comparison of findings is another factor that needs to be discussed when reporting oral health among indigenous people. In countries where data on ethnicity is collected through self-identification for use in statistics, i.e. Australia and New Zealand, oral health conditions are reported through national surveys, like the National Surveys of Adult Oral Health in

Australia, where 2.3% of respondents reported indigenous identity in 2017-2018 [143]. Findings from these surveys are compared to the results from ethnic groups in other studies. A study by Miranda et al [72] compared findings from a convenience sample of indigenous Australians (n=312) with findings from a national survey (n=4967; 1.2% indigenous) [144] and found that participants from the convenience sample had three times the prevalence of periodontitis and five times the prevalence of untreated caries, compared with national estimates. This raises the question of whether these differences would still be significant if the comparison were made in ethnic groups with equal sample sizes, from the same region, and with comparable background characteristics. In Paper III, the research context, like region of residence, may affect the findings, as mentioned previously.

### **5.3 Ethical considerations**

In medical health research, there are certain ethical recommendations, guidelines, and declarations that must be followed. Ethical approval was obtained from the Regional Committee for Medical and Health Research Ethics of the University of Tromsø, and all participants provided written informed consent in accordance with the guidelines of the Declaration of Helsinki [145]. This declaration is a policy statement outlining the ethical guidelines for medical research to protect research participants, including the principle of informed, voluntary consent. All participants signed an informed consent form before inclusion in the study, and they were informed that they could withdraw at any time without any reason.

In the context of research, ethnicity is challenging to measure, especially in quantitative research methods [9]. The use of ethnicity data and the classification of ethnic groups were thoroughly discussed by the research team and in a workshop for employees, during which local dental health workers were invited to give input on how ethnic classification should be handled in the analysis. Indeed, we included local dental health workers in all stages of this project, with seminars and workshops arranged before, during, and after data collection. This approach is in line with the proposed ethical guidelines for Sámi health research [98].

Research on Sámi people requires that the researcher or the research team have knowledge about the Sámi people, their culture and their traditions [98]. In the present project (the Dental Health in the North Study), Principal Investigator Magritt Brustad both extended knowledge

of, and experience with conducting epidemiological studies in the Sámi population. In the present study, those who performed the data collection had a strong affiliation to the Sámi community, as 16 of 29 of the local dental health workers were Sámi, including myself. Being a part of the data collection and being a Sámi researcher in a Sámi community has benefits, but also ethical challenges. Knowledge of the study population and the Sámi language has been a resource in this research project, especially when communicating information about the study to participants, and during examinations and analyses. Mutual understanding and respect between researcher and participants is essential for developing research that is useful to society and in line with aforementioned guidelines [98]. On the other hand, a researcher's Sámi affiliation, experience, and knowledge of the culture may affect their objectivity during data analysis. For example, close affiliation to the study population may make one feel personally involved in the study, or give a preconception of what the results can or should be in relation to one's own experiences. Therefore, it is especially important that researchers not allow themselves to be influenced by their own preconceived notions when analyzing the data material; they must follow the data and accept the results.

## **6 Conclusion**

The findings in this thesis contributed to knowledge about oral health and OHRQoL among adults in the Sámi population in core Sámi areas in Northern Norway. Periodontitis and caries were found to be common in these areas, and had a marked impact on people's functional, psychological, and social wellbeing. Information on oral health in the Sámi people also provides new information on indigenous oral health. Findings from our study are in accordance with studies from other indigenous peoples, and thus support statements that oral diseases are common among indigenous people. The difference with our study was that we found only minor differences in oral health between indigenous and non-indigenous peoples, in contrast to findings from others.

The specific conclusions drawn from this thesis were as follows:

- Recruitment through PDS clinics provides a high willingness to participate in epidemiological studies. Incorporation of data collection into daily work routines at local PDS clinics was feasible and yielded clinical data with a satisfactory level of validity.



- Classification of ethnicity by self-identification in relation to objective and subjective dimensions provides the opportunity to classify ethnic groups into different subgroups, but also the possibility of multi-ethnic identification. It is recommended that the creation of ethnic groups be based on the research question in each population-based study, whether it should be a Sámi/non-Sámi ‘dichotomy perspective’ or a Sámi internal gradient grouping.
- The prevalence of periodontitis was high in core Sámi areas in Northern Norway, regardless of ethnicity. Sámi people had more PPD  $\geq 6$  mm and an increased likelihood of having severe stages of periodontitis. Severe periodontitis was found to be associated with increasing age, lower education level, and smoking.
- Sámi men had a higher prevalence of severe periodontitis than Sámi women.
- Caries experience among adults in core Sámi areas was high, with variation by region of residence. Adults from the coastal region had a higher burden of caries than those from the inland region. Caries was associated with frequent consumption of sugary soft drinks, less frequent toothbrushing, and irregular dental visits.
- Impaired OHRQoL was found to be common among Sámi and non-Sámi populations in core Sámi areas in Northern Norway. A substantial proportion of adults experienced frequent oral health-related problems that impacted their daily life.
- Overall perceptions of OHRQoL were influenced by aspects related to sex, age, and dental attendance, along with number of teeth, periodontitis, and caries.

## 7 Future perspectives

Based on the findings from this thesis, which showed that oral diseases are common among Sámi in Northern Norway, with regional differences, there is a need for further studies to gain more knowledge on oral health in the general Sámi population. One way to do this could be to include oral health as one of the research areas within already existing research centers such as the Center for Sámi Health Research [146]. This center has good knowledge on research within Sámi communities, and its main aim is to enhance knowledge on the health and life of the Sámi population in Norway. As Sámi today live all over Norway, from north to south, in

rural and urban communities, it would be interesting to find out if there are similarities and/or differences in oral health between Sámi populations in Norway and those across national borders within Sápmi, i.e. in Sweden, Finland, and Russia. To achieve this, collaboration with research teams in all these countries would be needed.

As the present study found regional differences in oral health, longitudinal cohort studies with a focus on the cause of these differences would be of interest. We do recommend the use of PDS as an arena for recruitment in epidemiological studies in other communities, as the internal validity of our clinical data was satisfactory based on the comprehensive calibration, reliability assessments, and quality procedures we described.

Studies on indigenous people need to deal with ethnicity as a variable and with the creation of ethnic categories. In order to compare findings between different epidemiological studies and study populations, it will be an advantage if the ethnic variable is created with the same inclusion criteria. In the present study, we described one way of creating ethnic categories, which may be used in future studies on oral health in Sámi populations.

The high prevalence of periodontitis and caries among adults in Northern Norway indicates a need for prevention strategies in this region to improve oral health in the whole population. Information about the burden of disease in this area needs to be reported to both Sámi and non-Sámi populations in their respective languages, and could be integrated into other public health strategies. All Norwegian municipalities have a statutory obligation to the virtue of Folkehelseoven § 5, implemented in 2012 to systematically monitor and analyze public health conditions and their predictors. Oral health is rarely integrated in community-based strategies, but its inclusion could have a measurable effect on public health.

There is also a need for more knowledge about the periodontal prevention and treatment strategies given in PDS in this region, and the effectiveness of treatment. Findings from Paper II show that regular dental visits did not reduce the likelihood of periodontitis. This may indicate that a change in prevention and treatment strategies is needed in Sámi communities. Experimental studies that identify which evidence-based periodontal treatment implementation strategies are most effective in different ethnic populations are important to gain more knowledge and improve periodontal health in this part of Norway.

Findings from Paper IV show that oral diseases affect quality of life in individuals in core Sámi areas. This shows the need for further investigation on how periodontitis, caries, or other oral disabilities (temporomandibular disorder, tooth loss, etc.) affect quality of life.

Assessing experiences, beliefs, attitudes, and social norms among patients in relation to oral disease, and especially a chronic disease like periodontitis, through mixed-methods research (quantitative and qualitative) could give another perspective on how people live with oral disease and on the communication between Sámi patients and dental personnel. Traditionally, patients with periodontal disease receive information about the disease and individualized oral hygiene instructions from the view of dental professionals, i.e. what dentists/dental hygienists think is best regardless of what might actually be best for the patients in order to be able to use the suggested tooth cleaning devices in their daily life. Therefore, it would be interesting to investigate whether more patient-centered educational approaches affect the incidence and prevalence of disease, especially when these approaches are introduced in early disease stages. Involving patients in the planning, goal setting, and treatment process could improve communication between patients and dental hygienists/dentists, and might also have a positive impact on oral hygiene-related behavior [147]. Intervention studies could be conducted to investigate the effect of more patient-centered care in PDS in core Sámi areas.

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## Paper I

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## Oral health in the indigenous Sámi population in Norway – the dental health in the North study

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### ABSTRACT

**Objective:** This study aims at presenting the feasibility of using the public oral health clinics in indigenous Sámi communities, as arena for a comprehensive data collection for population-based epidemiological oral health research among adults (age, 18–75 years) in a multi-ethnic setting.

**Material and methods:** The study design was cross-sectional. The data collection was incorporated into the clinical procedure at six public dental clinics situated in the Administrative Area for the Sámi Language in Finnmark County, Northern Norway, during 2013–2014. Both clinical- and questionnaire-data were collected. The quality of clinical data was thoroughly calibrated and validated.

**Results:** Altogether, 2235 people participated in the study gave a crude response rate at 88.7%. In the final data sample ( $n = 2034$ ), 56.9% were female. We constructed three ethnic groups (Sámi, Mixed Sámi/Norwegian and Norwegian). Altogether, 67.7% reported Sámi or mixed Sámi ethnicity. The internal validity of the clinical data was found to be satisfactory when assessed by comprehensive quality procedure, calibration and reliability assessments.

**Conclusion:** This study design and method assessments provide solid documentation that public dental clinics are suitable as arenas for data collection in epidemiological oral health studies in the Sámi population in this region.

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### Introduction


The Sámi people are an indigenous people primarily living in the northern part of Norway, Sweden, Finland and the Kola Peninsula in Russia. There is no direct means to estimate the number of Sámi in Norway due to the lack of ethnicity registries [1] although it is assumed that Norway has the largest proportion of the total Sámi population [2]. Sámi resides all over Norway, but the highest Sámi density is found in the areas north of the Arctic Circle and in the northern most county Finnmark in particular.

The research project *The Dental Health in the North Study* was initiated based on the Norwegian Government White Paper from 2006/2007 [3] *Tilgjengelighet, kompetanse og sosial utjevning – Framtidas tannhelsetjenester* [Access, Competence and removing Social Gradients – The Future's Dental Services], where concern was raised due to the lack of scientific knowledge on oral health in the adult Sámi indigenous population. Concern was also related to some indications, however not scientific based, on poorer oral health for the Sámi population in Northern Norway.

In general, there have only been conducted a few population-based studies on adults describing oral and dental

health using epidemiological research methodology in Norway [4–10]. Apart from a small study published as a report in 1988, where dental health data from 300 patients were collected in collaboration with public health clinics in Finnmark [9], to the best of our knowledge, no epidemiological research focusing on oral health status in Sámi population has been conducted in Norway. However, studies among indigenous people worldwide have shown substantial oral health inequalities between these populations compared to reference populations [11]. Challenges related to oral health among northern indigenous people have been actualized as well as the need for evidence as basis in oral health policy decisions in order to improve oral health for these populations [12].

The concern raised in the mentioned *White Paper* [3] was based on register-data on children (<18 years) from the Public Dental Services in Norway. These data showed clearly that dental health in Norway had improved; however, still large regional differences were revealed. The incidence of caries in children in the northernmost part of Norway i.e. the county of Finnmark has for long been the highest in the nation [13]. There has also formerly been registered a higher

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prevalence of edentulousness among adults in this region (23 vs. 10% nation average), compared to the south of Norway [14,15]; however, recent data on the current situation among adults in the region have been lacking. Registry-based analysis on oral health among children in Finnmark county and one of the main Sámi core areas [13] has shown that oral health in this region has improved remarkably during a 10-year period (2004–2014). This improvement was found in 5-, 12- and 18 years old. The proportion of children with no caries experience in this region is now close to the nation-average [13].

In Norway, children and adolescents (up to 19 years) have access to free dental and oral health services. In addition, some prioritized groups (young adults up to 20–21 years; cognitive impairment, or persons with mental disorders; elderly; disabled or chronically ill; addicted to drugs, or imprisoned persons) are under given conditions, fully or partly covered under the social welfare systems. Nationally, the public dental clinics provide services to adults, only to a minor extent. This is mainly due to capacity limitations. Thus, private clinics are the main provider for oral health services to the Norwegian adult population; the service is paid out of pocket and relatively costly. However, in rural Finnmark county, private clinics are more or less absent. The public dental clinics in Finnmark were former known for being understaffed and affected by instability with high turnover of dentists, but the establishment of a new dentist school in 2004 at the Arctic University of Norway has started to contribute to the recruiting and stability of dentist with both local cultural and language competence at all dental clinics in Finnmark [13].

In recent years, a few population-based surveys on oral health, with both questionnaire and clinical oral examination data, have been conducted in the region of Northern Norway like the THONN study (Tromstannen-Oral Health in Northern Norway) [16] and The Tromsø Study [17], where oral health was included as one of the several research topics in the data collection entitled Tromsø 7 conducted in 2015–2016. In the SAMINOR 2 study [18], some questionnaire data on oral health were collected and have been published as two Master Theses in Public Health [19,20]. However, as mentioned no oral health study using clinical data has, to our knowledge, been conducted with the adult Sámi indigenous people in Norway as a target group.

As part of the methodological preparation and planning for the *The Dental Health in the North Study*, a pilot study was carried out in Finnmark in 2010, to test both questionnaires and the population's willingness to take part in an epidemiological study focusing on oral health. The pilot study has been described elsewhere [21]. People were recruited by postal invitation sent from UIT The Arctic University of Norway. Altogether, 34% answered and returned the questionnaires, and only 27% actually showed up for the clinical examination. Based on this experience, a need for improvement in the recruiting procedure was obvious, in order to improve participation by changing the arena for recruiting from an academic to health service institutions.

Using clinics and hospitals as arena for enrolling participants and using patients' journal information as source for clinical data are, in general, common in epidemiological studies. To the best of our knowledge, in Norway there are no published population-based oral health study on adults where the data collection has been an incorporated part of the daily clinical routines at public dental clinics. Such study design can, however, have cost-effective benefits as well as quality improvements spin-off effects in the clinical work. The participation, representativeness as well as validity of clinical and questionnaire data need, however, to be carefully considered in such a study design.

The main purpose with this article has been to present and describe the method, data-collection procedure and participation in The Dental Health in the North Study. Because Sámi ethnicity has been the focus in this project, special attention has been on the ethnicity-data and ways of categorizing the participants into different ethnic groups. Finally, we aimed at illuminating the methodological strengths and weaknesses of using the Public Dental Services in Sámi communities as arena for such a comprehensive data collection for epidemiological oral health research.

## Methods

### *Setting, study participants and ethics*

As the focus for this research was oral health in the Sámi population, the municipalities of the Administrative Area for the Sámi Language within the Finnmark county in Northern Norway were selected as geographical area for the data collection (Figure 1). The municipalities for the study were Tana, Nesseby, Porsanger, Karasjok and Kautokeino. These are all rural communities that are sparsely populated with a population size ranging from around 900 in Nesseby and up to 4000 in Porsanger, whereas the three others have close to 3000 inhabitants each. The Sami culture are strong in these communities and use of Sami language is common. Norway does not have ethnicity registry; however, population-based surveys conducted in these areas have shown that the majority in all these municipalities report Sami affiliation [22].

During 2013–2014, all patients at the Public Dental Services in the selected municipalities between the ages 18–75 years old who were on the re-call list or had booked an appointment at any of the clinics during the data-collection period (dental check-up or treatment), were invited to participate in the 'Tannhelse i nord' study [Dental Health in the North study]. Information about the study and questionnaire were either sent out together with the clinics' regular convene card or distributed upon arrival at the clinics. Information about the study were announced on the local radio station, to increase the awareness of the study and hence facilitate the recruitment of study participants.

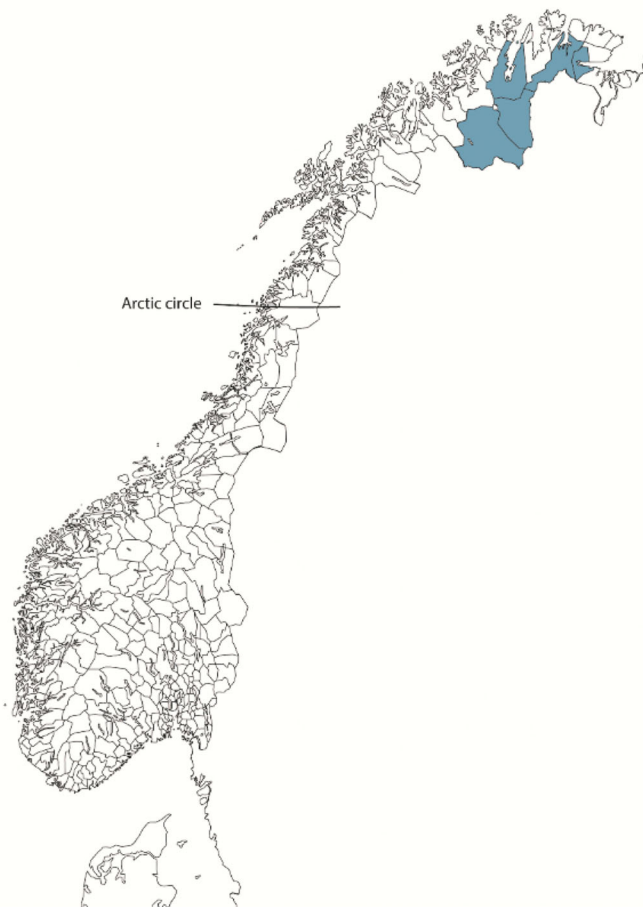
The study was carried out with a cross-sectional epidemiological design. Both questionnaire information and clinical examination data were collected.

The study has been approved by the Regional Committees for Medical and Health Research Ethics (REC) in Norway (2012/1902/REK Nord). All participants gave their

signed informed consent before inclusion in the study and they were informed that they could withdraw at any time without any reasons. The clinical examination was free of charge. Permission has been obtained from REC to store, until 2027, the identification key for follow-up studies or linkage to national registers for further oral health research purposes. However, separate approvals are required to conduct such new research activities.

### Questionnaire

The four-page questionnaire included questions about background characteristics, socioeconomic status, oral health-related behaviours and oral health-related quality of life.



**Figure 1.** Map of Norway. The municipalities included in the survey are marked in blue (Nesseby, Tana, Prosanger, Karasjok and Kautokeino).

Most of the questions included in the questionnaire have been used in population-based surveys. An overview of the themes included in the questionnaire is summarized in [Table 1](#). The participants could choose either a Sámi or a Norwegian language version of the questionnaire. Most participants filled out the questionnaire before the clinical examination. All participants could, if needed, ask for help from the dental health personnel at each clinic on filling out the questionnaire or other questions related to the study.

### Questions on ethnicity

As this study aimed at investigation of oral health in the Sámi population, the self-reported questionnaire instrument on Sámi ethnic affiliation developed and used in the 'Population-based study of health and living conditions in areas with both Sámi and Norwegian populations – the SÁMINOR study' [18,23] was included in the questionnaire. Thus, the following questions were used in the questionnaire to collect data on ethnicity: 'Which language do you/did you use at home?', 'Which language did your parents use at home?', 'Which language did your grandparents use at home?' and 'What do you consider yourself as?'. The response options were as follows: 'Norwegian', 'Sámi' and 'Kven<sup>1</sup>', or 'Other, describe' with the option to tick off more than one answer. Questions on the ethnic background of the respondents and the respondents' parents had the same response options. Respondents were also asked about their self-perceived ethnicity; specifically, 'What do you consider yourself as?'. For each of the above questions, respondents were allowed to provide more than one answer.

### Ethnicity categorization

Based on the responses to these questions, three categories for ethnic affiliation were defined i.e. *Sámi affiliation*, *Mixed Sámi-Norwegian* and *Norwegian*.

The *Sámi* category represented those answering 'Yes' to the three following questions: 'I consider myself Sámi'; 'My ethnic background is Sámi' and 'My home language is Sámi'. Another sub-population termed *Mixed Sámi-Norwegian* represented those answering 'Yes' to either one or two (but not three) of the questions. All other respondents were categorized as Norwegian including respondents who reported use of the Sámi language by, or the Sámi ethnicity of, their grandparents or parents, but did not consider themselves to be Sámi, or reported that they did not have a personal Sámi

**Table 1.** List of self-reported information collected in the questionnaire.

Theme	Description
Background characteristics	Country of birth and childhood [21] and ethnicity [23]
Socioeconomics	Education and employment [23], income [18]
Use of dental health care services	Frequency of dental visits, public or private dental services and influence of costs on dental treatment [21]
General health and health behavior	Self-perceived health and smoking [23]
Diet	Frequency of sugary foods and drinks, including alcohol [24]
Oral hygiene behaviour	Frequency of brushing, oral hygiene aids and fluoride [21]
Subjective norms, normative beliefs and self-efficacy	Questions about brushing behaviour developed from Theory of Planned Behaviour [25,26]
Attitudes towards oral health	Importance of oral hygiene and oral health [21]
Q36 Oral health-related quality of life (OHIP-14)	Perception regarding discomfort and dysfunction caused by oral conditions [27]
Q37 Dental anxiety scale	Dental Anxiety Scale describing imagined dental situations [28]
Other	Use of traditional healer

**Table 2.** Overview of clinical parameters.

Disease/clinical parameters	Description to the parameter in patient-records	Description of parameters in post-clinical measurements
Teeth (max <i>n</i> )	Permanent teeth when third molar excluded [28]	Premolar and molar when third molar excluded [16]
<b>PERIODONTITIS</b>		
Bleeding on probing (BOP)	Bleeding from gingival sulcus on gentle probing. Assessed at six sites per tooth	
Periodontal probing depth (PPD)	Distance from the bottom of a pocket to the gingival margin. Measured in nearest millimetre	
Furcation involvement (FI)	Grade I: Horizontal loss of periodontal support not exceeding one-third of the width of the tooth Grade II: Horizontal loss of periodontal support exceeding one-third of the width of the tooth, but not encompassing the total width of the furcation area. Grade III: Horizontal 'trough-and-trough' destruction of the periodontal tissues in the furcation area	Furcation that was clearly visible on Bitewing radiographs. Radiolucency in between the roots in molars, i.e. grades 2 and 3
Alveolar bone level (ABL)		Distance from CEJ to AR. Measured to the nearest 0.5 mm
<b>CARIES</b>		
Decade Teeth (DT)/surface (DS)	Tooth or surface with caries grades 3–5 included secondary caries	Tooth with caries grades 3–5, included secondary caries
Missed Teeth (MT)/surface (MS)	Missing tooth or surface because of caries or periodontitis, included implants	All missing teeth, included implants
Filled Teeth (FT)/surface (FS)	Tooth or surface with permanent filling, on lay or crown	Tooth or surface with temporary or permanent filling, on lay or crown
Decayed Missed Filled Teeth (DMFT)	Sum of DT, MT, FT	Sum of DT, MT, FT
Decayed Missed Filled Surfaces (DMFS)	Sum of DS, MS, FS	Sum of DS, MS, FS

background/home language. Responders who reported Kven ethnicity were merged with the Norwegian ethnicity due to low numbers.

### **Clinical and radiographic examination**

A total of nine dentists and six dental hygienists with assisting nurses, at six Public Dental Services clinics (one in each municipality), examined all teeth except the third molar, and corresponding teeth surfaces clinically and radiographically. All personnel had long clinical experience, were highly motivated and had participated in workshops on clinical research methodology. Clinical measures collected in the study were previous dental treatment, dental caries and periodontal conditions. An overview of the clinical measures is summarized in Table 2. In addition, intraoral radiographs were taken, 2 or 4 bitewing depending on number of teeth and quality needs for analyses. The images were exported by Soredex Digora Optime intraoral X-ray reader. All clinical data were registered in a computerized protocol (OPUS dental 7.1.107) on a secured server.

### **Caries registered in the clinics**

A five-grade diagnostic scale [29] was used to register caries severity radiographically on proximal tooth and occlusal surfaces not accessible for clinical examination. Caries grades 1–2 were denoted as enamel caries, and grades 3–5 as dentine caries. Caries on root surfaces and secondary caries were included in the registration of caries and all caries were registered at surface level. Missed and filled surfaces were also registered. Dental crowns were registered as filled surfaces. Decayed surface (DS), filled surface (FS), missed surface (MS), decayed and filled surface, decayed-, missed-, filled surface (DMFS), decayed teeth (DT), missed teeth (MT), filled teeth (FT), decayed and filled teeth and decayed-, missed- and filled

teeth (DMFT) were calculated. Grades 3–5 lesions reaching into dentine were included in the DMF-scores, whereas grades 1 and 2 (enamel lesions) were assigned to initial caries and not included in the DMF-scores. The DMF index values were calculated by adding all 'decayed', 'missing' and 'filled' (due to caries) permanent teeth (DMFT)/surfaces (DMFS).

### **Post-clinic caries registration by X-ray and examiner calibration**

To investigate reliability and consistency of the dental caries registration, an inter-examiner agreement was assessed post-clinically. The inter-examiner agreement for premolar and molar regions was estimated by comparing caries registrations from three examined participants, randomly chosen from the OPUS Journal software, from each examiner (15 in total). A calibrated examiner (A-KSB) was used as a Golden standard. Prior to the inter-examiner assessment, A-KSB was calibrated using a special designated software system for examiner calibration (DIL ver 1.21; University of Bergen, Bergen, Norway) and re-analyzed the radiographs. The DIL-calibration is based on the judgement of 51 occlusal and approximal surfaces on random radiographs. Two different exercises were performed on different tooth surfaces.

For the inter-examiner agreement analysis, the caries registration was categorized as 'no caries' (grades 1 and 2) and 'manifest caries' (grades 3–5). The Cohen's Kappa value for each of the 15 examiners compared to the calibrated examiner (A-KSB) was calculated.

### **Periodontal parameters**

Bleeding on probing (BOP) and periodontal probing depth (PPD) were assessed at six sites per tooth for all teeth (except the third molar). Periodontal probing depth was measured to the nearest millimetre with a periodontal probe, WHO-probe



LM555B. Bleeding on probing was measured in conjunction with the periodontal probing. To improve and secure measurements and inter-examiner reliability, different precautions were taken. Prior to study start, all examiners were trained and calibrated towards an experience periodontist who was the gold standard (NO), regarding the diagnostic criteria and examination procedures including radiographic examination technique and periodontal pocket probing on one patient. The measurement with pocket probing was repeated for three teeth (six surfaces). In addition, each examiner received a diagnostic manual in which all measurements and the procedures for diagnostics were described.

### **Post-clinical measurement of bone levels**

To be able to estimate the prevalence and severity of periodontitis, a categoric case definition was necessary. The case definition was based on a method used in a previous cross-sectional study [30]. Hence, alveolar bone level (ABL) was measured on radiographs post-clinically on all participating patients by one experienced examiner (A-KSB). In addition, furcation involvement clearly visible on e-rays was registered (i.e. grades 2 and 3). The cervico-occlusal lengths of the crown, described by Bath-Balogh and Fehrenbach [18] was used as reference marker. The distance from cemento-enamel junction (CEJ) to alveolar crest (AR) was measured to the nearest, 0.5 mm. As only bitewing radiographs were available, mean root length values were used as described by Bath-Balogh and Fehrenbach [31] to make it possible to estimate the relation between the total root length and ABL.

Prior to the measurements of radiographic ABL, the examiner (A-KSB) was trained by an experienced periodontist (NO) and an inter-examiner agreement was conducted. In addition, A-KSB did an intra-examiner agreement. Bitewing-radiographs from 10 study-participants were randomly selected and the distance from the CEJ to the AC was measured. All post-clinical data were registered using Microsoft Excel 2013, and the classification of severity of disease was calculated.

### **Data managing and the final data set**

The questionnaire and informed consents were sent to the study coordinator who consecutively punched the questionnaire data into an excel file as the questionnaires were received. All the punched questionnaire-data as well as the OPUS ID versus questionnaire ID were controlled once.

Each questionnaire had a unique id-number. At the clinics, lists were made with these id numbers and each participant corresponds to the medical record number based on the computerized medical record system, OPUS. The OPUS data and questionnaire data were punched and stored in computers disconnected to the Internet, during the whole data-collection period. Backups and the computer were locked in when they were not in use.

Information on age and gender were manually obtained for each participant from OPUS and registered in the data file after the main data collection was completed and the

questionnaire data and OPUS data were merged. Age was rounded off to the nearest year.

### **Local involvement**

Through all stages in the research project's planning and data collection, representatives from the administrative unit of the Public Dental Services in the region worked closely with the research group. Seminars/workshops were arranged before, during and after the data collection. At these gatherings, the recruiting of participants, data collection procedures and the content of the questionnaire were thoroughly discussed with the employees at the participating clinics, as well as the cost-benefits for the clinics and the workers were involved. Based on the initiative from workers at the dental clinics at such a workshop, questions on use of e.g. traditional healers as pain management were developed and included in the questionnaire. These workshops were also valuable, together with the local dental health workers, to make strategies for recruiting participants to the study. The seminars/workshops also included lectures on general epidemiological research design, and research methodology for oral health studies in particular. In addition, information and process evaluation of the on-going data collection were the focus in these seminars.

After the data collection was completed and validated, preliminary clinic-wise results were presented at a workshop for the employees at the clinics. In this meeting, the use of the ethnicity data was in particular a topic and the local health workers were invited to give input on how ethnic classifications should be handled in the analysis.

### **Statistics**

Stata/MP 15.0 for Windows (StataCorp LLC) was used for the statistics presented in this article. Due to the nature and scope of this article, only descriptive statistics were presented. The agreements were calculated by utilizing Cohen's kappa ( $\kappa$ ) and Intraclass Correlation Coefficients (ICC) values in SPSS.

## **Results**

### **Participation**

In total, out of 2520 invited 2235 of the adult patients (age, 18–75 years) who had an appointment at, or came to any of the six clinics during the data-collecting period, participated in the study, giving a crude response rate at 88.7%.

As shown in [Figure 2](#), 157 participants were not included in the final sample due to questionnaire data, clinical data or both were missing, not within the target age, or missing written content, or could not be accounted for and thus given *missing unknown status*. Participants who reported a foreign ethnicity and who did not report Norwegian, Kven or Sámi ethnicity were excluded. The final sample consisted of 2034 participants.

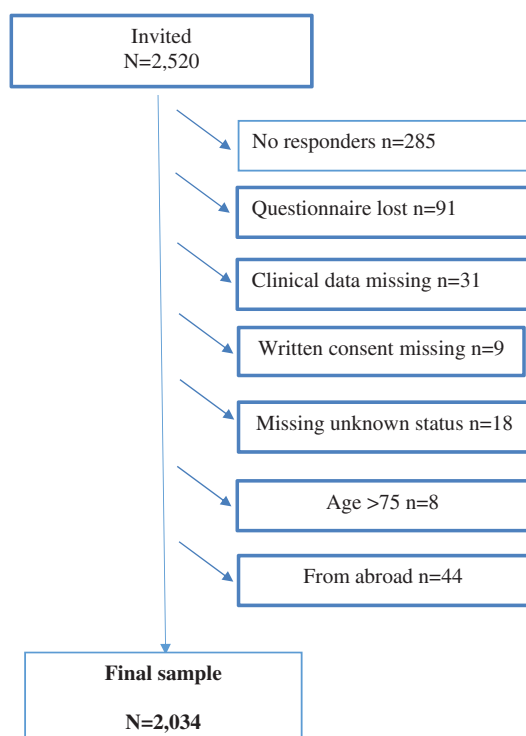


Figure 2. Flowchart of the study sample and participation.

Table 3. Participation by municipality.

Municipality	Filled in questionnaire <i>n</i>	No responders <i>n</i>	Crude response rate % <sup>a</sup>	Final sample <i>n</i> (%)
Kautokeino	515	14	96.8	500 (24.6)
Karasjok	508	26	95.1	485 (23.8)
Porsanger	476	198	70.6	404 (19.9)
Tana/Seida	640	47	93.2	563 (27.7)
Nesseby	96	0	100	82 (4.0)
Totalt	2235	285	88.7	2034 (100)

<sup>a</sup>100 × Invited/filled in questionnaire.

Table 3 summarizes the participation by municipality units. The municipality of Porsanger had a considerably larger portion of no-responders compared to the rest of the clinics. The participants from Nesseby constituted only 4% of the total sample. The contribution from the other municipality ranged from around 20 to 28% of the total sample. The response-rate ranged from 70.6 to 100%.

### Characteristics of the study sample

In Table 4, selected characteristics for the study sample are summarized. One quarter of the sample was below the age of 38 years. More women participated than men. Nearly, 30% of the study sample reported a household gross annual income above NOK 750,000 and about 10% reported gross annual income below NOK 300,000. Slightly above 60% of the sample reported more than 12 years of education. The majority of the study sample (54%) reported to be in fulltime occupation. Around 14% of the study sample reported not living in the County of Finnmark at the age of 10 years.

Table 4. Selected characteristics for the study sample *n* = 2034<sup>b</sup>.

	<i>n</i>	(%)
Age (years)		
18–37	505	24.8
38–56	898	44.2
57–75	631	31.0
Daily smoking		
Yes	434	21.6
No	1572	78.4
Gender		
Females	1158	56.9
Men	876	43.1
Gross income <sup>a</sup>		
<150,000	68	3.5
150,000–300,000	201	10.4
301,000–450,000	443	22.9
451,000–600,000	327	16.9
601,000–750,000	322	16.7
751,000–900,000	283	14.6
>900,000	289	15.0
Education (years)		
<7	23	1.1
7–9	217	10.7
10–12	532	26.2
13–16	734	36.1
>16	528	26.0
Income source status		
Fulltime	1092	53.7
Part time	181	8.9
On welfare	201	9.9
Retired	143	7.0
Student	79	3.9
Other	338	16.6
Last visit to dental clinic (years)		
<1	1127	55.9
1–2	708	35.1
3–5	116	5.8
>5	65	3.2
Childhood residence in Finnmark at 10 years		
Yes	1751	86.1
No	283	13.9
Ethnicity		
Sámi	981	48.2
Mixed Sámi/Norwegian	400	19.7
Norwegian	653	32.1

<sup>a</sup>Norwegian currency, NOK.

<sup>b</sup>Subgroups may not total to 2034 due to missing variables.

Three quarters (76%) of the participants in the study reported Sámi affiliation.

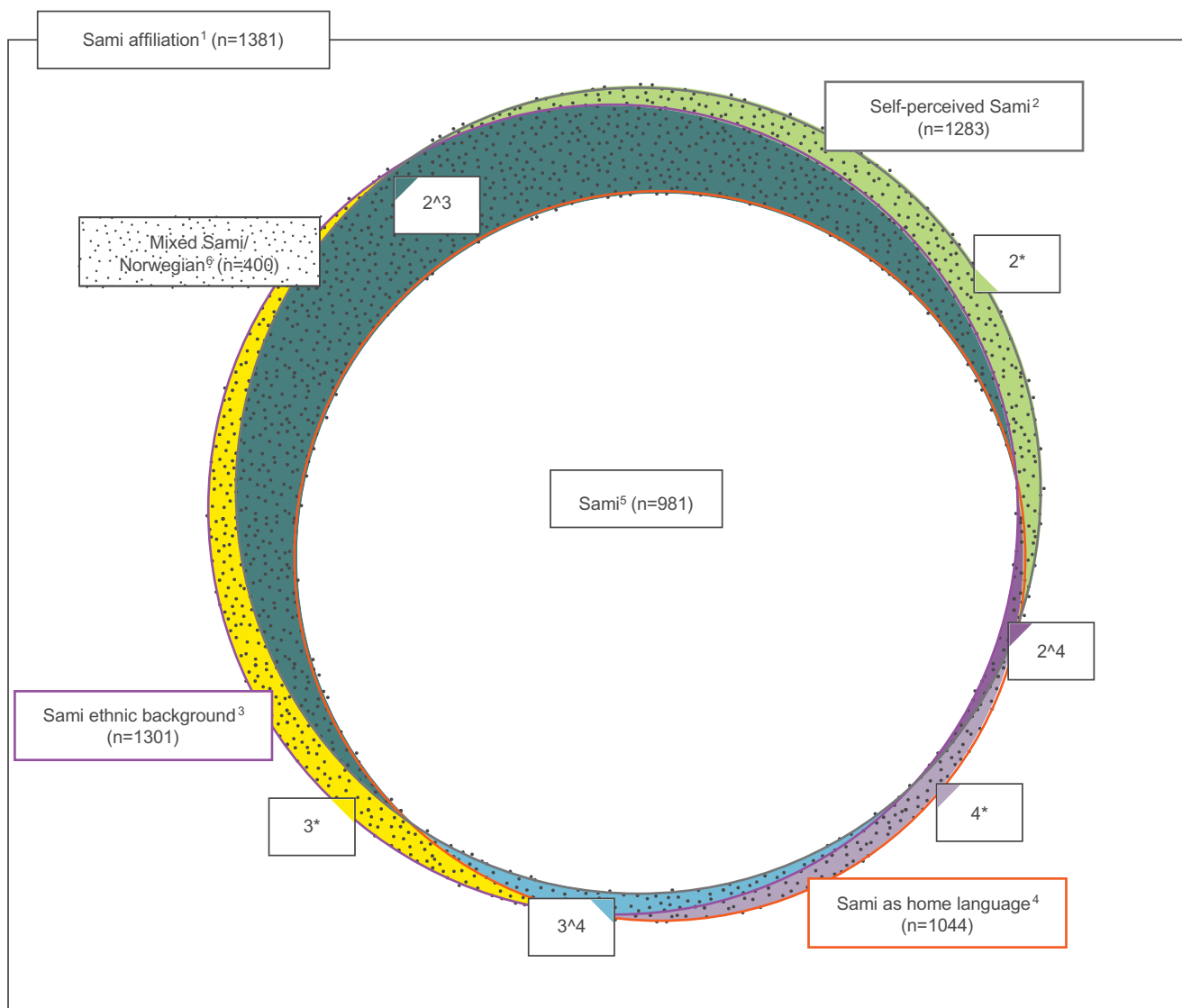
The majority of the sample reported a full-time income (54%), about one-tenth reported being on any kind of welfare-income and the sample consisted of 85 students (4%). Based on the question on occupation altogether 131 participants (6.4%) reported being self-employed within the reindeer herding industry.

Altogether, 91% of the participants reported that time since last visit to the dental clinic was <3 years and slightly more than half of the participants reported <1 year since last visit.

### Inter-examiner agreement

#### Caries registration

Result of the inter-calibration with the software was  $\kappa = 0.67$  for the first data set, and  $\kappa = 0.70$  for the second. The mean  $\kappa$  for all 15 examiners compared to the golden standard (A-KSB) was  $\kappa = 0.84$  (range, 0.55–1.0).



**Figure 3.** Distribution of sub-populations among participants with Sámi affiliation: The Dental Health in the North Study. <sup>1</sup> Sámi affiliation is defined as Sámi language being spoken at home by at least one of the grandparents, parents or the respondent, or Sámi ethnic background reported for respondent or a parent, or that the respondent considers himself/herself as Sámi ( $n = 1381$ ). <sup>2</sup> Self-perceived Sámi is defined as yes to the question: *I consider myself Sámi* ( $n = 1283$ ). <sup>3</sup> Sámi ethnic background is defined as yes to the question: *My ethnic background is Sámi* ( $n = 1301$ ). <sup>4</sup> Sámi as home language is defined as yes to the question: *My home language is Sámi* ( $n = 1044$ ). <sup>5</sup> Answered yes to all three questions in footnote: 2, 3 and 4 ( $n = 981$ ). <sup>6</sup> 'Mixed Sámi/Norwegian' is defined as yes to one or two of the question(s) in footnote 2 or 3 or 4 ( $2^*+3^*+4^*+2\wedge3+2\wedge4+3\wedge4$ ) ( $n = 400$ ).  $2^*$ : Reported only self-perceived Sámi ( $n = 48$ ).  $3^*$ : Reported only Sámi ethnic background ( $n = 53$ ).  $4^*$ : Reported only Sámi as home language ( $n = 14$ ).  $2\wedge3$ : Reported Sámi ethnic background and self-perceived Sámi ( $n = 236$ ).  $2\wedge4$ : Reported self-perceived Sámi and Sámi as home language ( $n = 18$ ).  $3\wedge4$ : Reported Sámi ethnic background and Sámi as home language ( $n = 31$ ).

### Periodontal pocket probing and measurement of distance from CEJ to AC

The inter-examiner agreement on ABL measurement on radiographs was  $\kappa = 0.97$  and the intra-examiner reliability was  $\kappa = 0.95$ .

### Ethnicity

Table 3 summarizes the distribution of answers on the ethnicity-related questions by our defined three ethnic groups *Sámi*, *Mixed Sámi/Norwegian* and *Norwegian*. In total, 1381 (67.9%) of the participants reported some Sámi affiliation, and out of these, 981 participants (71.0%) reported Sámi as home language, considered themselves to be Sámi with Sámi ethnic background and reported Sámi self-perceived belonging. These were defined as belonging to the ethnic

category 'Sámi' ( $n = 981$ ). Altogether, 400 of the participants reported 'Yes' to either one or two (but not three) of the questions 'I consider myself Sámi'; 'My ethnic background is Sámi' or, 'My home language is Sámi' and thus belonging to the ethnic category *Mixed Sámi-Norwegian*. Most participants in this category ( $n = 236$ ; 59%) reported Sámi ethnic background and self-perceived Sámi ethnicity, but not Sámi as home language, shown as the area  $2\wedge3$  in Figure 3; where the distribution of sub-populations among participants with Sámi affiliation and the degree of overlap between these groups are shown.

Table 5 summarizes self-reported ethnicity, self-perceived ethnicity and language at home according to our ethnic definition. All defined as belonging to the *Sámi* group consider themselves as Sámi and of Sámi ethnicity and had Sámi language as home language. The 'Mixed Sámi/Norwegian'

**Table 5.** Self-reported ethnicity, self-perceived ethnicity and language at home according to our ethnic definition.<sup>a</sup>

	Sámi % <sup>b</sup>	Kven % <sup>b</sup>	Norwegian % <sup>b</sup>	Other % <sup>b</sup>
Self-reported ethnicity (Based on the question: 'What is your ethnic background?')				
<i>Sámi</i>	100.0	1.6	9.6	1.0
<i>Mixed Sámi/Norwegian</i>	80.0	14.2	58.0	6.3
Norwegian	—*	6.1	93.9	1.7
Self-perceived ethnicity (Based on the questions: 'I consider myself')				
<i>Sámi</i>	100.0	1.1	13.1	0.6
<i>Mixed Sámi/Norwegian</i>	75.5	8.0	66.3	3.5
Norwegian	—*	6.0	96.5	0.9
Language at home (Based on the questions: 'My home language is')				
<i>Sámi</i>	100.0	0.5	16.3	1.0
<i>Mixed Sámi/Norwegian</i>	15.8	2.0	87.8	3.0
Norwegian	—*	3.5	97.5	1.8

Sámi was defined as answering YES to all three following questions: 'I consider myself Sámi', 'My ethnic background is Sámi' and 'My home language is Sámi'.

Mixed Sámi/Norwegian was defined as answering Yes to minimum one (one or two) of the three following questions: 'I consider myself Sámi', 'My ethnic background is Sámi' and 'My home language is Sámi', but not Yes to all three questions.

Norwegian: Manly Norwegians, including Kven affiliation ( $n=99$ ) and Sámi without subjective Sámi criteria ( $n=165$ ). Those respondents reported use of the Sámi language or ethnicity for grandparents and/or parents, but did not consider themselves to be Sámi or personally consider they were having a Sámi ethnic background or had Sámi as home language.

All three questions had the available responses were Sámi, Norwegian, Kven or Other (specify).

<sup>a</sup>Row percent's add up to more than 100% due to the possibility of answering more than one category.

<sup>b</sup>The response options: 'Norwegian', 'Sámi', 'Kven' or 'Other' in questionnaire for the following ethnicity questions.

\*0.0%.

group had strong affiliation to both Sámi and Norwegian ethnicity (80.0%; 58.0%) and self-perceived Sámi, and Norwegian ethnicity (75.5%; 66.3%), but few Sámi in the 'Mixed Sámi/Norwegian' had Sámi as home language (15.8%) and 87.3% with Norwegian as home language. In this latter group, one out of seven reported Kven ethnicity.

## Discussion

To increase knowledge about oral health conditions in the indigenous population in the circumpolar areas, a development of good epidemiological research designs with high methodological quality is required. Local ownership and participatory models in the planning, implementation and interpretation of results are all essential elements to achieve reliable and valid data.

This study has several methodological strengths. In summary, these advantages are as follows. First, the external validity of the results is likely to be strong, due to the high participation rate. Second, the comprehensive questionnaire with questions and established instruments used in other population-based surveys, and questions of particular cultural relevance for the Sámi population provide data for analysis of a broad spectra of predictors for oral health. The collected data can thus be analyzed from a cultural relevant perspectives, and in relation to other comparable investigations for comparison purposes. The linkage of both questionnaire data and dental record is considered of great methodological benefit. Finally, the test for reliability and calibration

assessments done on the clinical data showed satisfactory accuracy in the measurements.

The indigenous Sámi population's oral health conditions were an essential focus in this study. Ethnicity is, however, a complex phenomenon. It has both objective and subjective dimensions [32]. To measure ethnicity, at least some reasonable indicators of each one of these dimensions are needed. Objective aspects are those that can be observed as facts, including that of kinship, descent and spoken language. Subjective approaches refer to subjective dimensions as attitudes, values and feeling of belonging at the individual level. In our definition of the Sámi, we used both objective and subjective criteria to define Sámi ethnicity. To be categorized into 'The Sámi' group, the participants reported on an objective level Sámi kinship (parents, grandparents being Sámi) and Sámi language spoken at home, together with subjective feeling of belonging to the Sámi culture (subjective Sámi criteria). This group had, so to speak, a very strong Sámi ethnicity. 'The mixed Sámi/Norwegian' group had a multiple ethnic identity with individual's identification to both the society at large and Sámi and Kven ethnicity. 'The Norwegian' group were manly Norwegians, including Kven affiliation ( $n=99$ ) (without Sámi affiliation) and Sámi with some affiliation, but without subjective Sámi criteria ( $n=165$ ). Those respondents reported use of the Sámi language or ethnicity for grandparents and/or parents, but did not consider themselves to be Sámi or personally consider they were having a Sámi ethnic background or had Sámi as home language. This group reported similar ethnic characteristics as the Norwegians (93.3% reported Norwegian ethnicity; 97.0% reported self-perceived Norwegian ethnicity and 99.4% reported Norwegian as home language, data not shown) and therefore we merged them with the Norwegians.

Due to its diverse nature, both the classification of ethnicity and its use as an independent variable in epidemiological research are complex and have been described as controversial [2,33]. Thus, for future analysis and work based on this data collection, we recommend ethnic categorizations to be created in line with and transparently explained for each research theme/question under study.

We achieved a remarkable high participation rate. The external validity of the study could still be questioned due to the fact that the eligible for the study where those in contact with the public dental clinic during the data-collection period. The question is whether the population who attended the clinics reflects the population, in general. The proportion of the population regularly attending the public clinics in these municipalities is likely to be high because, except for one municipality (Porsanger), there are no private clinics, unless crossing the border to Finland or going to larger towns in the region. Nationally about 70% of the adult population report using the dental clinics at a regular basis [34]. Unpublished data from the SAMINOR 2 study [18], 83% of the adult population reported using dental clinics regularly, among study participants living in the core area for Sámi settlement. In a recent epidemiological population-based study conducted in Northern Norway, about 67% of

the adult population reported dental attendance at least every other year. However, in that study the youngest participants (<35 years) reported least regular attendance (50%), whereas about 72% of the older participants (35–79 years) reported regularly dental attendance [35].

As summarized in Table 3, more than 90% of the participants had been to the clinic during the last years, thus indicating that the actual participants in the study, to a large extent, represented the part of the population attending the clinics frequently. It is likely that the proportion of the population not or seldom attending the dental clinic could differ with respect to oral health, lifestyle and oral health-related behaviours compared to the regular attenders. That non-attendees differ from participants in epidemiological surveys are well known [36]. Because the general adult population in Norway is not prioritized under the legislation on dental health care, dental care can be costly. As such, one may expect social inequality in oral health status and in the use of dental health services, as they have been observed in other aspects of health [37,38].

We experienced in the former mentioned pilot study conducted in Finnmark [21] that participation was very low when posting an invitation directly from the research institution to the general population with a questionnaire and invitation to come for an oral health check (<30%). Response rate in population-based oral health projects conducted in recent years in Scandinavia with similar recruitment approach as our pilot have been reported at around 50–68% [16,30]. In the five municipalities where our study was conducted, only one private clinic was available. Thus, the Public Dental Services are the only accessible unless going abroad for oral health treatment; however, the extent of this is unknown.<sup>2</sup> This situation where the majority of the adult population is covered by Public Dental Services (as paying patients), is somewhat unique for this northern region in Norway. This was one of the main reasons why we decided to change the recruitment procedure from the pilot to the main study, by using the local public dental clinics (and not the UiT The Arctic University of Norway) as the arena for recruiting participants.

Advantages of the study design are related to local ownership, credibility and cultural sensitivity. The large majority of employees at the clinics were from the local communities and all clinics had Sámi-speaking health workers. More than half of the employees were of Sámi ethnicity (16 out of 29) (personal communication, A-KSB December 2018). In this perspective, the dental clinics represent institutions with strong ties to the local communities and the Sámi population. However, these listed advantages could also be viewed as potential weaknesses as our recruiting lays more to the *convenience sampling* procedure where people *easy to reach* are invited. This, in combination with *social desirability bias* where people tend to participate based on loyalty or report in line with what are assumed favourable, could have affected both the external and the internal validity of our study. In this perspective, an ethical awareness on the implications of recruiting individuals to a research project in a setting where health treatment is being sought, is essential.

Local involvement, like enrolling the data collection into daily clinical work at the clinics and inviting the employees to take part in all parts of the project journey, could cause positive spin-off effects for the included clinics. Especially related to quality improvements in the clinical routine-work, but also local capacity building related to increased knowledge and skills on how to do epidemiological oral research. These likely benefits must, however, be viewed at in relation to any potential extra work burden for the clinics involved.

The internal validity of the clinical data has shown to be satisfactory based on the comprehensive calibration, reliability assessments and quality procedure thoroughly described in our study. These method assessments provide solid documentation that public dental clinics are suitable as arenas for data collection in epidemiological oral health studies in the Sámi population in this region. We do recommend that this approach can be considered in epidemiological studies in other communities, provided a broad population coverage for the public oral health clinics and a tradition of frequent visits to the Public Dental Services.

As summarized in Table 1, the questions in the questionnaire have been used in other oral health studies in the Nordic countries and some are based on well-established scale instruments like the Q36 Oral health related quality of life (OHIP-14) and Q37 Dental anxiety scale. Both scales have been validated in a Norwegian context and found to be satisfactory [28,39]. However, the questionnaire was not validated in the Sámi population prior to the study. Nor was the Sámi version of the questionnaire back translated in the traditional way, but workers at the clinics critically reviewed the questionnaire at workshops together with the research-team in charge of the study, and gave their input before the final questionnaire was settled.

## Conclusion

In conclusion, our study has shown that enrolling and incorporating an epidemiological data collection into public dental clinics daily work routines was feasible and gave clinical data with satisfactory level of validity. We have presented a transparent way of creating ethnic categories for use in further analysis on dental health.

The outlined potential challenges related to the external validity, specifically the calibration of a high number of examiners must be taken into consideration when interpreting the data in a population perspective. The study is the first in its kind, providing questionnaire and clinical data on oral health from a Sámi population attending the Public Dental Services in Norway. Given the majority of the population do attend dental health services regularly, the methodological advantages described indicate that this study will be of great value for further analytical approaches to investigate the predictors for oral and dental health in the Sámi population.

In general, we recommend that relevant representatives from the involved ethnic groups are invited to take part in the process from planning to the interpreting of the results in epidemiological research where ethnicity is a variable.

When questionnaire data are developed, concerns related to cultural sensitive issues, especially when life-style related questions are included, must be validated in relevant fora with adequate representations. Finally, potential selection and information bias caused by conducting data collection in a setting where the study participants initially are searching health services and help must be carefully addressed.

## Notes

1. *Kven* is an ethnic minority group in Norway. They descended from Finnish farmers and fishermen who emigrated from the northern parts of Finland and Sweden to Northern Norway from the 16th to 19th centuries. In 1996, the *Kvens* were granted minority status in Norway, and in 2005 the *Kven* language was recognized as a minority language in Norway.
2. For this geographical area, the use of dental care services in Finland (most of these municipalities are located near the Finish border), due to lower costs is a relevant issue, but the extent of this is also unknown.

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## Disclosure statement

The authors report no conflict of interest.

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## Paper II

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Periodontal health in an indigenous Sámi population in Northern Norway: a cross-sectional study

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RESEARCH ARTICLE

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# Periodontal health in an indigenous Sámi population in Northern Norway: a cross-sectional study

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## Abstract

**Background:** The aim of the study was to describe prevalence, severity and distribution of periodontal disease as well as associated risk factors in an indigenous Sámi population in Northern Norway, and to investigate differences between the indigenous Sámi and the non-Sámi population.

**Methods:** This cross-sectional study included data from the Dental Health in the North study ( $N = 2078$ ; 18–75 years). Data on Ethnicity, household income, education, smoking habits, dental attendance, and tooth brushing habits were collected by a questionnaire. Periodontal conditions were assessed by clinical examination. A modified version of the new AAP/EFP classification system of periodontal disease was used to estimate the severity of periodontitis. Three stages were used: 'Non-severe periodontitis', 'Stage II', and stage 'III/IV'.

**Results:** Of the total study population 66.5% reported Sámi affiliation. The total prevalence of periodontitis was 49.7%, with 20.1% in Stage III/IV, but no differences between Sámi and non-Sámi. When controlled for sex, age, education, smoking and dental attendance the Sámi had higher probability of having more severe stages of periodontitis; Odds Ratio<sub>Stage II</sub> (OR) = 1.3; 95% CI: 1.1–1.7; and OR<sub>Stage III/IV</sub> (OR) = 1.6; 95% CI: 1.1–2.2) compared to non-Sámi. A higher proportion of Sámi had one or more PD  $\geq 6$  mm than the non-Sámi ( $p < 0.05$ ).

**Conclusions:** The prevalence of periodontitis was high in communities in the core area of Sámi settlement in Northern Norway, regardless of ethnicity. People with Sámi ethnicity had deep periodontal pockets and an increased odds of having severe stages of periodontitis. Future studies should address possible explaining factors behind the potential higher risk of having more severe periodontitis among indigenous people in Sámi settlements.

**Keywords:** Epidemiology, Alveolar bone loss, Periodontitis, Indigenous, Sámi, Oral health

## Background

The Sámi are the indigenous people living in the region called Sápmi, which today encompasses northern parts of Norway, Sweden and Finland and the Kola Peninsula in Russia [1]. The Sámi people are the minority in Norway

and the Norwegian parliament has acknowledged the ethnic group, Sámi, as the only indigenous people in the nation. Due to legal restrictions on the registration of ethnic minority identity, estimating the size of the indigenous Sámi today is not straightforward, though it is currently assumed that Norway has the largest proportion of the total Sámi population.

At present, there are no peer-reviewed studies on periodontal conditions among the Sámi population published in Norway, Sweden, Finland, or Russia. Holst and

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colleagues [2] published a study in Norwegian of adults (25–60 years old) in Northern Norway back in the 1980's. They reported that the prevalence of periodontitis was 62%, but only a small part of the study population had severe periodontitis. They found periodontitis to be associated with the region and oral hygiene habits, but not with ethnicity. Studies on indigenous people worldwide have found that indigenous populations generally have poorer oral health than their non-indigenous counterparts [3–5]. The prevalence of periodontitis in indigenous people in Australia [6, 7], Canada [8], New Zealand [9] and USA [10] is reported to be higher than in their non-indigenous counterparts, and the odds of having advanced periodontal disease is also higher [11, 12].

Knowledge about the oral health status of the adult population in Norway in general is quite scanty. For northern Norway, periodontal conditions in an adult population (20–69 years) in a coastal community were described by a study from 1979 [13], and for Troms county by a more recent study of a random sample of adults (20–79 years), in which about half of the study population had periodontitis [14]. Other Norwegian studies have described the periodontal conditions in an age cohort of 35 year olds in Oslo [15], and in a random sample of the elderly population in Norway (> 67 years old) [16]. Studies from Jönköping in Sweden have reported a decrease in the prevalence of periodontitis in adults (20–80 years), from 57% in 1983 to 40% in 2013 [17–19], but the prevalence of severe periodontitis has remained almost the same over the same decades: 16% in 1983 and 11% in 2013 [19]. Also in a Finnish adult population (30–65+ years) [20] the prevalence of deep periodontal pockets has slightly decreased over the last decade, however with difference between genders. In 2011, the prevalence was 21% in men and 14% in women.

The Norwegian government has asked for and allocated resources to research on the oral health of the Sámi population because of the lack of scientific research-based knowledge [21]. In an indigenous context, research on the periodontal conditions in an adult Sámi population is both important and necessary. At present, we know very little about the oral health of the Norwegian indigenous population, notwithstanding that nearly all indigenous studies report that indigenous people worldwide have poorer oral health than their non-indigenous counterparts [4, 5, 8].

The aim of the study was to describe prevalence, severity and distribution of periodontal disease as well as associated risk factors in an indigenous Sámi population in Northern Norway. A further aim was to investigate differences regarding periodontal disease between the indigenous Sámi and the non-Sámi population.

## Methods

### Study population

To describe periodontal conditions in the Sámi population in Northern Norway, data from the “Dental Health in the North” study was used. This study and its methodology is described in detail in Brustad et al. [22]. The study was a cross-sectional study of adults 18–75 years old in Finnmark County in Northern Norway. Data was collected between February 2013 and May 2014. All patients attending public dental care services in five municipalities (Tana, Nesseby, Porsanger, Karasjok and Kautokeino) during the study period were invited to participate in the study regardless of the reason for their appointment at the clinic. Of a total of 2520 persons invited to participate, 285 persons declined (crude response rate at 88.7%) and 157 participants were not included in the final sample. Reasons for non-inclusion were the following: missing questionnaire, missing clinical data or both, unknown target age, missing written consent, or not accounted for and thus given missing unknown status. The final sample consisted of 2078 participants.

The regional committee for medical and health research ethics of the University of Tromsø, Norway, approved the study (2012/1902/REK Nord). All participants provided written informed consent.

### Questionnaire

Population characteristics were collected by self-reported questionnaire. The questionnaire covered information about ethnicity, household income, education, smoking habits, use of dental health care services, and oral hygiene related behaviours. Self-reported ethnicity was based on three questions: 1) Which language do/did you/your parents/grandparents speak at home? 2) What is your/ your parents' ethnic background, and 3) What ethnicity do you consider yourself to be? The response options were ‘Norwegian’, ‘Sámi’, ‘Kven’ and ‘other’. For a more thorough description of questions included in the questionnaire, including ethnic categorization, see Brustad et al. [22]. Brustad et al. describe the ethnicity as a complex phenomenon, were both the objective factors (parents and grandparents being Sámi) and the subjective feelings of belonging to the Sámi culture have to be taken into account when creating the ethnicity variable [22]. In this study, ethnic affiliation was categorised as ‘Sámi’ and ‘non-Sámi’. The ‘Sámi’ category represented those who answered ‘Sámi’ on at least one of the two questions about language and ethnic background, in addition, reported that they consider themselves as Sámi. All other respondents were categorised as ‘non-Sámi’ even though some of the participants reported that they had Sámi heritage but did not consider themselves as Sámi. The ‘non-Sámi’ group were mainly Norwegians,

Kven (without Sámi affiliation,  $n = 99$ ) and Sámi with some affiliation, but without subjective Sámi criteria ( $n = 165$ ).

Education in Norway is mandatory for all children aged 6–16 years. The education system is made up of primary school (6 years), secondary school (4 years), High school (3 years) and Higher education (University level). Participants' educational level was assessed with one question that elicited responses in number of years, and grouped into three categories: [1] 1–9 years, [2] 10–13 years and [3]  $\geq 14$  years. Tooth brushing habits were assessed with one question with four response options from two or more times per day to never. These four options were merged into three categories: [1] less than daily, [2] 1 time/day, and [3]  $\geq 2$  times/day. Smoking habits were assessed with two questions 1) Do you smoke daily? 2) How many cigarettes do you smoke per day? Age was divided into four age groups: 18–34, 35–49, 50–69 and 65–75 year olds.

#### Clinical dental examination

Nine dentists and six dental hygienists with assisting nurses, in six separate dental offices, carried out the clinical examination. Data on a participant's periodontal condition was collected from a clinical examination including four bitewing radiographs. Periodontal probing depth (PD) at six sites per tooth was measured to the nearest millimetre with a periodontal probe with single millimetre graduations (WHO-probe LM555B). Clinical attachment level (CAL) was not assessed, so the alveolar bone level (ABL) based on the radiographs was used as main criteria classifying prevalence and severity of periodontitis. Third molars and implants were examined but excluded from analysis.

Calibration of the examiners were done as follows: First, the examiners had a workshop regarding the diagnostic criteria and examination procedures. Secondly, all examiners were trained and calibrated towards an experienced periodontist who was the gold standard (NO). This calibration included radiographic examination technique and periodontal pocket probing on one patient each. Third, the examiner (A-KSB) was trained by an experienced periodontist (NO). ABL based on radiographs of randomly chosen participants were measured and an inter-examiner reliability was conducted,  $\kappa = 0.97$ . Examiner (A-KSB) measured the ABL twice, and intra-examiner reliability for the ABL measurements was conducted,  $\kappa = 0.95$ .

The clinical dental examination procedure and the post clinical measurements of bone level, including validity, is described in details elsewhere [22].

#### Classification of periodontitis

A modified classification system based on the new AAP/EFP<sup>1</sup> classification system of periodontal disease was used to present prevalence of periodontitis [23, 24]. In this study, stages of periodontitis were classified by radiographic bone loss (RBL) and PD. Missing teeth and furcation involvement were not included. Stage I is the borderline between gingivitis and periodontitis and represents the early stages of attachment loss. Because  $RBL < 15\%$  can be difficult to measure on radiographs without having the exact root length, Stage I was not included as a periodontal case. A patient was classified as a Stage II periodontitis case if the RBL was between 15 and 33% and as Stage III/IV if the RBL was extending to middle or apical third of the root in two or more non-adjacent teeth. The complexity factor (PD) was included and may shift the stage to the higher level; PD 4–5 mm classified to Stage II and PD  $\geq 6$  mm classified to stage III/IV. Cases with no periodontitis and early stage of periodontitis were classified as 'Non-severe periodontitis' (NSP).

#### Statistical analysis

Missing data occurred at a low frequency (0.1–5.0%). There were no internal loss in regards to ethnicity. The greatest proportion of loss was for household income followed by education (3.3%).

Differences between the Sámi- and the non-Sámi groups, as well as classification of periodontal disease, were calculated for demographic and socioeconomic status (age, sex, household income and education), smoking habits and tooth brushing frequency. Prevalence of periodontitis was presented as the frequency distribution for AAP/EFP classification method and presented as 'Non-severe periodontitis', 'Stage II' and Stage 'III/IV'. Differences in prevalence of stages of periodontitis between Sámi and non-Sámi was stratified by age group, and assessed with z-test and analysed by univariate regression analysis.

Differences in background characteristics between Sámi and non-Sámi group and between classifications of periodontitis were assessed with Pearson  $\chi^2$  test, and differences between groups were assessed with z-test. Age and number of teeth were presented as means and standard deviation (SD).

RBL and PD are presented as percent and proportions (SE) of affected sites and teeth for the total study population, stratified by age group and ethnicity. Differences between groups were assessed with  $\chi^2$ -test and t-test.

<sup>1</sup>AAP/EFP classification is based on a World workshop on the classification of Periodontal and Peri-Implant Diseases co-sponsored by the American Academy of Periodontology (AAP) and European Federation of Periodontology (EFP)

Multinomial logistic regression was performed to determine the relationship between stages of periodontitis in relation to ethnicity, socio-demographic and behavioural factors. Ethnicity, sex, age, education, smoking and dental service attendance were used as independent variables. The logistic regression model was done in two steps: 1) associations for each variable with the odds of having different stages of periodontitis were studied in a univariate model. 2) Multivariate models were used to study the adjusted associations. The analysis in the univariate and the multinomial regression were done first in the total population, where the ethnicity was one of the confounding variables and secondly in Sámi population and non-Sámi population separately. 'NSP' and 'Stage II' were used as reference categories. Differences were assessed using Odds Ratio and 95% confidence intervals. In all analyses the significance level was set at 0.05. Data were analysed using the IBM® SPSS® Statistics, version 25.

## Results

Of the total 2078 participants included in the study, 1381 (66.5%) reported Sámi affiliation. The mean number of teeth in the total study population was 25.1 (SD 3.8). There were no differences in mean number of teeth between Sámi and non-Sámi (25.1 vs. 25.2,  $p = 0.173$ ). The mean age for the participants with Sámi affiliation was 46.7 (SD 14.7) years and 48.9 (SD 13.4) years for non-Sámi ( $p < 0.001$ ). The mean age of all participants was 47.5 (SD 14.3) years. There were more participants with Sámi affiliation in the youngest age group compared to the other age groups (Table 1). More participants with non-Sámi affiliation had a higher yearly household income (> 900,001) than the participants with Sámi affiliation. On the other hand, in the Sámi population more participants had longer education ( $\geq 14$  years). A majority of the population brushed their teeth at least twice a day, but around 10% of the Sámi participants reported brushing their teeth less than once a day.

### Prevalence and distribution of periodontitis

The prevalence of periodontitis (Stage II and III/IV) was 49.7%, with 20.1% in Stage III/IV. The estimated prevalence and distribution of periodontitis by ethnicity, age and gender, as well as socioeconomic status, smoking habits, toothbrushing habits, and frequency of dental visits are presented in Table 2 for the total sample and in Table 3 for the Sámi participants only. There were no significant differences between Sámi and non-Sámi in the distribution of disease related to stages (Table 2). However, in the Sámi group, the prevalence and severity of periodontitis increased with age; in the oldest age group, a vast majority had periodontitis, and of those 36.4% were classified in Stage III/IV. In the youngest age group, 4.2% had periodontitis and 1.6% had Stage III/IV

periodontitis. The prevalence of severe periodontitis decreased with increasing education level / years at school both for the total sample, and for the Sami subsample separately (Tables 2 and 3). More men than women had periodontitis Stage III/IV and more participants attending dental services yearly were classified as Stage III/IV compared to those attending every other year or less often.

There were no significant differences in prevalence of NSP, Stage II and Stage III/IV periodontitis between Sámi and non-Sámi stratified by age group. In Table 4 prevalence of radiographic bone loss (RBL) and periodontal pocket depth (PD) for the Sámi and the non-Sámi group are presented in age groups. The prevalence of RBL and PD increased with age in both ethnic groups. In total (18–75 years), a higher proportion of Sámi had one or more PD  $\geq 6$ mm compared to non-Sámi ( $p < 0.05$ ).

### Periodontitis association to ethnicity, socio-demographic and behavioural factors

In the univariate analysis of the total population (Table 5), the odds of having severe periodontal disease (Stage III/IV) were associated with age, low education level, smoking and attended dental services yearly. Men had higher probability of having periodontitis than women, with the highest odds observed for Stage III/IV (OR = 1.7; 95% CI: 1.2–2.4). When the model was adjusted for all significant variables in the multivariable model, the odds of having stage III/IV of periodontitis was significantly higher among those with Sámi affiliation compared to non-Sámi (adjusted Odds Ratio (aOR) = 1.6; 95% CI: 1.1–2.2).

In the multivariable analyses (Table 6) for the subpopulations (Sámi and non-Sámi,  $n = 1972$ ), the strongest associations of having periodontitis were age, education and smoking. The adjusted odds of having periodontal disease increased with increasing age in both groups. The odds of having severe periodontitis was also consistently associated with smoking. In the Sámi group likelihood of having periodontitis, stage III/IV, was higher among men compared to women and in adults with less than a high school education (< 14 years).

## Discussion

This study showed that there were no difference in prevalence of periodontitis between Sámi and non-Sámi. However, the Sámi had deep periodontal pockets and a higher probability of having severe stages of periodontitis compared to non-Sámi, when controlling for age, sex, education, smoking habits and dental attendance. In general, half of the participants with Sámi affiliation had periodontitis, and two out of ten had a stage III/IV periodontitis, i.e. severe periodontitis. Prevalence and severity increased with age and lower

**Table 1** Characteristics of study participants stratified by ethnic affiliation

	Total n (%)	Sámi n (%)	Non-Sámi n (%)	P value*	Internal loss n (%)
Participants	2078 (100%)	1381 (66.5)	697 (33.5)		
Age				< 0.001	0 (0)
18–34	419 (20.1)	313 (22.7) <sup>a</sup>	106 (15.2) <sup>b</sup>		
35–49	687 (33.1)	435 (31.5) <sup>a</sup>	252 (36.2) <sup>b</sup>		
50–64	709 (34.1)	468 (33.9)	241 (34.6)		
65–75	263 (12.7)	165 (11.9)	98 (14.1)		
Sex				0.155	0 (0)
Men	894 (43.0)	579 (41.9)	315 (45.2)		
Women	1184 (57.0)	802 (58.1)	382 (54.8)		
Household income				0.035	104 (5.0)
< 300,000	276 (14.0)	184 (13.3)	92 (13.2)		
300,001–600,000	792 (40.1)	547 (39.6) <sup>a</sup>	245 (35.2) <sup>b</sup>		
600,001–900,000	615 (31.2)	400 (29.0)	215 (30.9)		
> 900,001	291 (14.7)	174 (12.6) <sup>a</sup>	117 (16.8) <sup>b</sup>		
Education				< 0.001	69 (3.3)
1–9 years	242 (12.0)	178 (13.4) <sup>a</sup>	64 (9.3) <sup>b</sup>		
10–13 years	781 (38.9)	462 (34.9) <sup>a</sup>	319 (46.6) <sup>b</sup>		
≥ 14 years	986 (49.1)	684 (51.7) <sup>a</sup>	302 (44.1) <sup>b</sup>		
Smoking				0.198	28 (1.3)
Yes	443 (21.3)	283 (20.5)	160 (23.0)		
No	1607 (77.3)	1079 (78.1)	528 (75.8)		
Toothbrushing frequency				< 0.001	3 (0.1)
< 1 time/day	175 (8.4)	142 (10.3) <sup>a</sup>	33 (4.7) <sup>b</sup>		
1 time/day	631 (30.4)	462 (33.5) <sup>a</sup>	169 (24.3) <sup>b</sup>		
≥ 2 times/day	1269 (61.2)	775 (56.1) <sup>a</sup>	494 (70.9) <sup>b</sup>		
Dental attendance				0.004	20 (1.0)
Yearly	1150 (55.3)	729 (52.8) <sup>a</sup>	421 (60.4) <sup>b</sup>		
Every other year	721 (34.7)	501 (36.3) <sup>a</sup>	220 (31.6) <sup>b</sup>		
Seldom	187 (9.0)	136 (9.9)	51 (7.3)		

\*P-value for differences between groups using the  $\chi^2$  test. When numbers in columns do not equal n or 100%, there is an internal drop out in background data. Different superscript letters denotes significant differences in periodontitis prevalence between characteristics (row proportions) at the 0.05 level

education level. Men had more severe periodontitis compared with women, and smokers had more periodontitis than non-smokers.

Comparing the prevalence of periodontitis in this study with previous findings in Norway is not straightforward because different case definitions have been used. The prevalence of periodontitis in the current study was in range of the results from another study on adults in Troms County, northern Norway [14, 25] where almost half of the study population had periodontitis and about 9% had severe periodontitis when classified according to the CDC/AAP definition [26]. Holde [25] re-classified the same study population using the new case definition according to AAP/EFPP [23, 24, 27], and found that the total prevalence of periodontitis

(Stage I–IV) was 48%. Prevalence of Stage II was 19.5, and 20.8% of the participants were classified as having severe periodontitis i.e. Stage III/IV. The findings are consistent with findings in the current study regarding Stage III/IV. However, the prevalence of stage II was around 50% higher in the present study, which means that the total prevalence of periodontitis was higher in Finnmark. The prevalence of periodontitis in adults differs between European countries, and has been reported to be around 50% in Germany [28], 33–40% in Sweden [18, 19, 29], and 64% Finland [20, 30]. However, because different case definitions for periodontitis were used, any direct comparisons should be made with caution.

Pocket depths  $\geq 4$  mm or  $\geq 6$  mm (one or more pockets), the basic clinical measurement for the

**Table 2** Distribution of periodontitis in relation to demographic, socioeconomic and behavioral factors for the total sample,  $n = 2078$ 

	Periodontitis			P value
	NSP n (%)	Stage II n (%)	Stage III + IV n (%)	
Total	1046 (50.3)	615 (29.6)	417 (20.1)	
Ethnicity				0.630
Sámi	693 (50.2)	403 (29.2)	285 (20.6)	
Non-Sámi	353 (50.6)	212 (30.4)	132 (18.9)	
Age				< 0.001
18–34	400 (95.5) <sup>a</sup>	13 (3.1) <sup>a</sup>	6 (1.4) <sup>a</sup>	
35–49	453 (65.9) <sup>b</sup>	152 (22.1) <sup>b</sup>	82 (11.9) <sup>b</sup>	
50–64	142 (20.0) <sup>c</sup>	332 (46.8) <sup>c</sup>	235 (33.1) <sup>c</sup>	
65–75	51 (19.4) <sup>c</sup>	118 (44.9) <sup>c</sup>	94 (35.7) <sup>c</sup>	
Gender				0.001
Men	418 (46.8) <sup>a</sup>	265 (29.6)	211 (23.6) <sup>a</sup>	
Women	628 (53.0) <sup>b</sup>	350 (29.6)	206 (17.4) <sup>b</sup>	
Household income				0.884
< 300,000	133 (48.2)	91 (33.0)	52 (18.8)	
300,001–600,000	398 (50.3)	231 (29.2)	163 (20.6)	
600,001–900,000	314 (51.1)	182 (29.6)	119 (19.3)	
> 900,000	145 (49.8)	83 (28.5)	63 (21.6)	
Education				< 0.001
1–9 years	74 (30.6) <sup>a</sup>	77 (31.8) <sup>a</sup>	91 (37.6) <sup>a</sup>	
10–13 years	382 (48.9) <sup>b</sup>	245 (31.4) <sup>a</sup>	154 (19.7) <sup>b</sup>	
> 14 years	562 (57.0) <sup>c</sup>	275 (27.9) <sup>a</sup>	149 (15.1) <sup>c</sup>	
Smoking				< 0.001
Yes	159 (35.9) <sup>a</sup>	145 (32.7)	139 (31.4) <sup>a</sup>	
No	875 (54.4) <sup>b</sup>	461 (28.7)	271 (16.9) <sup>b</sup>	
Toothbrushing				0.220
< 1 time a day	99 (56.6)	40 (22.9)	36 (20.6)	
1 time a day	322 (51.0)	180 (28.5)	129 (20.4)	
≥ 2 times a day	623 (49.1)	394 (31.0)	252 (19.9)	
Frequency of dental visits				< 0.001
Yearly	517 (45.0) <sup>a</sup>	351 (30.5)	282 (24.5) <sup>a</sup>	
Every other year	419 (58.1) <sup>b</sup>	204 (28.3)	98 (13.6) <sup>b</sup>	
Seldom	102 (54.5) <sup>b</sup>	55 (29.4)	30 (16.0) <sup>b</sup>	

NSP; No severe periodontitis, Stage II and stage III/IV classified according to a modified AAP/EFP classification method. \*P-value for differences between groups using the  $\chi^2$  test.

Differences between groups were assessed with z-test. Different superscript letters denotes significant differences in periodontitis prevalence between characteristics (column proportions) at the 0.05 level

preliminary diagnosis of periodontitis, is often reported. A larger proportion of Sámi had one or more PD  $\geq 6$  mm compared to non-Sámi, with no ethnic difference in prevalence of PD  $\geq 4$  mm and PD  $\geq 6$  mm. The proportion of individuals with PD  $\geq 6$  mm in the present study was in range with findings from previous studies of comparable age groups in northern Norway (18.7%) [14], and in Oslo (8%) [15]. However, in the oldest age group

(65–75 year) the proportions of periodontitis in the present study were somewhat lower compared to a study of Norwegian pensioners (33%) [16]. Comparing the present findings with other Scandinavian studies, the prevalence of individuals with periodontal pockets ( $\geq 4$  mm) was lower than in a Swedish study (75%) [19], but in range with a Finnish study (64%) [20]. Edman et al. [29] used the alveolar bone loss (ABL) in premolars

**Table 3** Distribution of periodontitis in relation to demographic, socioeconomic and behavioral factors for participants reporting Sami affiliation,  $n = 1381$ 

	Periodontitis			P value
	NSP n (%)	Stage II n (%)	Stage III + IV n (%)	
Total	693 (50.2)	403 (29.2)	285 (20.6)	
Age				< 0.001
18–34	300 (95.8) <sup>a</sup>	8 (2.6) <sup>a</sup>	5 (1.6) <sup>a</sup>	
35–49	278 (63.9) <sup>b</sup>	101 (23.2) <sup>b</sup>	56 (12.9) <sup>b</sup>	
50–64	81 (17.4) <sup>c</sup>	223 (47.6) <sup>c</sup>	164 (35.0) <sup>c</sup>	
65–75	34 (20.6) <sup>c</sup>	71 (43.0) <sup>c</sup>	60 (36.4) <sup>c</sup>	
Gender				0.011
Men	271 (46.8) <sup>b</sup>	167 (28.8)	141 (24.4) <sup>b</sup>	
Women	422 (52.6) <sup>a</sup>	236 (29.4)	144 (18.0) <sup>a</sup>	
Household income				0.602
< 300,000	90 (48.8)	63 (34.4)	31 (16.8)	
300,001–600,000	267 (48.8)	163 (29.8)	117 (21.4)	
600,001–900,000	205 (51.2)	109 (27.3)	86 (21.5)	
> 900,000	88 (50.6)	47 (27.0)	39 (22.4)	
Education				< 0.001
1–9 years	57 (32.0) <sup>a</sup>	55 (30.9)	66 (37.1) <sup>a</sup>	
10–13 years	223 (48.3) <sup>b</sup>	140 (30.3)	99 (21.4) <sup>b</sup>	
> 14 years	391 (57.1) <sup>c</sup>	192 (28.1)	101 (14.8) <sup>c</sup>	
Smoking				< 0.001
Yes	100 (35.3) <sup>a</sup>	90 (31.8)	93 (32.9) <sup>a</sup>	
No	583 (54.0) <sup>b</sup>	309 (28.7)	187 (17.3) <sup>b</sup>	
Toothbrushing				0.406
< 1 time a day	79 (55.6)	32 (22.6)	31 (21.8)	
1 time a day	235 (50.9)	133 (28.8)	94 (20.3)	
≥ 2 times a day	378 (48.8)	237 (30.6)	160 (20.6)	
Frequency of dental visits				< 0.001
Yearly	325 (44.5) <sup>a</sup>	222 (30.5)	182 (25.0) <sup>a</sup>	
Every other year	292 (58.3) <sup>b</sup>	134 (26.7)	75 (15.0) <sup>b</sup>	
Seldom	70 (51.5) <sup>c</sup>	44 (32.3)	22 (16.2) <sup>b</sup>	

NSP; No severe periodontitis, Stage II and stage III/IV classified according to a modified AAP/EFP classification method. \*P-value for differences between groups using the  $\chi^2$  test

Differences between groups were assessed with z-test. Different superscript letters denotes significant differences in periodontitis prevalence between characteristics (column proportions) at the 0.05 level

and molars to investigate and classify the severity and prevalence of periodontitis in an adult population (20–85 years) in Sweden, and found that 33% of the study population had moderate bone loss and 6% had severe bone loss. Comparing this findings with the present study, the prevalence of moderate bone loss was equal, but severe bone loss was more common in northern Norway than in study from Sweden.

Smoking is a factor strongly associated with periodontal disease [31]. Consistent with previous studies [32, 33] the odds of having periodontitis was higher among

smokers than non- smokers. The number of smokers in the present study was higher than among adults in Troms County (15%) [14], and also higher than the national averages in 2013 (15%) [34], which could have had an impact on the higher prevalence of total periodontitis. Furthermore, Finnmark County has a history of irregular access to dentists, dental hygienists and/or specialists [35], and the distance to a dental clinic could have made it difficult for inhabitants to seek treatment. Studies have shown that higher availability of dentists decreased the likelihood of periodontitis [31, 36].

**Table 4** Prevalence and extent of radiographic bone loss and periodontal pocket depth by age group, ethnicity and in total

Periodontal measurements	Age Groups (years)								Total	
	18–34		35–49		50–64		65–75		18–75	
Ethnicity	Sámi	Non-Sámi	Sámi	Non-Sámi	Sámi	Non-Sámi	Sámi	Non-Sámi	Sámi	Non-Sámi
Number of individuals	313	106	435	252	468	241	165	98	1381	697
RBL, proportions <sup>a</sup>										
RBL 15–33%	3.8	5.7	<b>32.6</b>	<b>25.0</b>	59.4	53.5	53.9	57.1	37.7	36.4
RBL > 33%	0.3	0.0	3.5	5.6	23.3	21.2	25.5	25.5	12.1	12.9
PD, proportions <sup>a</sup>										
One or more PD ≥ 4 mm	40.6	40.6	63.7	56.4	71.6	63.1	73.3	81.6	62.3	59.8
One or more PD ≥ 6 mm	5.1	5.7	<b>16.1</b>	<b>10.3<sup>b</sup></b>	<b>29.1</b>	<b>19.9</b>	27.3	27.5	<b>19.4</b>	<b>15.6</b>
PD, mean (SE) <sup>b</sup>										
Proportions of sites/mouth										
PD ≥ 4 mm	3.5 (0.4)	3.8 (0.7)	7.7 (0.5)	6.8 (0.7)	10.5 (0.7)	10.1 (1.0)	<b>8.8 (0.9)</b>	<b>11.7 (1.4)</b>	8.0 (0.3)	8.2 (0.5)
PD ≥ 6 mm	0.2 (0.0)	0.1 (0.1)	0.5 (0.1)	0.4 (0.1)	1.3 (0.2)	1.1 (0.2)	1.2 (0.2)	1.2 (0.3)	0.8 (0.1)	0.7 (0.1)

RBL = radiographic bone loss; PD = periodontal pocket depth. SE = standard error. Bold-face = statistically significant differences between Sámi and non-Sámi in each age group  $p < 0.05$

Statistical analyses were done with <sup>a</sup>= $\chi^2$ -test and <sup>b</sup>= independent t-test

**Table 5** Periodontitis stage II and stage III/IV in relation to demographic, socioeconomic and behavioral factors

Background characteristics	NSP vs. Stage II (total $n = 1661$ )		NSP vs. Stage III/IV (total $n = 1463$ )	
	Unadjusted OR (95% CI)	Adjusted OR (95% CI) $n = 1633$	Unadjusted OR (95% CI)	Adjusted OR (95%CI) $n = 1434$
Ethnicity				
Sámi	1.0 (0.8–1.2)	1.3 (0.9–1.7)	1.1 (0.9–1.4)	<b>1.6 (1.1–2.2)</b>
Non-Sámi	Ref.	Ref.	Ref.	Ref.
Sex				
Men	1.1 (0.9–1.4)	<b>1.3 (1.1–1.7)</b>	<b>1.5 (1.2–1.9)</b>	<b>1.7 (1.2–2.4)</b>
Women	Ref.	Ref.	Ref.	Ref.
Age (years)				
65–75	<b>6.9 (4.7–10.0)</b>	<b>9.7 (6.4–14.9)</b>	<b>10.2 (6.7–15.4)</b>	<b>12.2 (7.6–19.7)</b>
50–64	<b>7.0 (5.3–9.1)</b>	<b>8.4 (6.2–11.2)</b>	<b>9.1 (6.7–12.5)</b>	<b>10.6 (7.3–15.1)</b>
35–49	Ref.	Ref.	Ref.	Ref.
18–34	<b>0.1 (0.05–0.2)</b>	<b>0.1 (0.06–0.2)</b>	<b>0.08 (0.04–0.2)</b>	<b>0.1 (0.04–0.2)</b>
Education (years)				
1–9 years	<b>2.1 (1.5–3.0)</b>	0.9 (0.6–1.4)	<b>4.2 (2.9–6.0)</b>	<b>2.0 (1.3–3.1)</b>
10–13 years	<b>1.3 (1.1–1.6)</b>	1.3 (0.9–1.7)	<b>1.4 (1.1–1.8)</b>	<b>1.5 (1.1–2.1)</b>
> 14 years	Ref.	Ref.	Ref.	Ref.
Smoking				
Yes	<b>1.7 (1.3–2.2)</b>	<b>2.9 (2.1–4.1)</b>	<b>2.8 (2.1–3.7)</b>	<b>4.4 (3.0–6.4)</b>
No	Ref.	Ref.	Ref.	Ref.
Dental attendance				
Seldom	1.1 (0.8–1.6)	1.4 (0.9–1.6)	1.3 (0.8–2.0)	1.6 (0.8–2.9)
Every other year	Ref.	Ref.	Ref.	Ref.
Yearly	<b>1.4 (1.1–1.7)</b>	1.2 (0.9–1.5)	<b>2.3 (1.8–3.0)</b>	<b>2.0 (1.4–2.9)</b>

NSP = non-severe periodontitis. Ref. = Reference group. Adjusted for all variables in the model. In the adjusted model participants with missing values are excluded. Bold = significant differences compared to reference group



**Table 6** Ethnicity-stratified Odds ratio for Periodontitis stage II and stage III/IV by demographic, socioeconomic and behavioral factors

Background characteristics	NSP vs. Stage II (total n = 1661)		NSP vs. Stage III/IV (total n = 1463)	
	Adjusted OR (95% CI)		Adjusted OR (95% CI)	
	Sámi n = 1078	Non-Sámi n = 555	Sámi n = 956	Non-Sámi n = 478
Sex				
Men	<b>1.4 (1.1–2.0)</b>	1.2 (0.8–1.9)	<b>2.1 (1.4–3.0)</b>	1.2 (0.7–2.1)
Women	Ref.	Ref.	Ref.	Ref.
Age (years)				
65–75	<b>8.5 (5.0–14.4)</b>	<b>11.9 (6.0–23.7)</b>	<b>10.9 (6.0–20.0)</b>	<b>15.7 (7.3–34.8)</b>
50–64	<b>8.8 (6.1–12.9)</b>	<b>7.5 (4.5–12.2)</b>	<b>11.6 (7.3–18.3)</b>	<b>9.1 (4.9–17.0)</b>
35–49	Ref.	Ref.	Ref.	Ref.
18–34	<b>0.08 (0.4–0.2)</b>	<b>0.1 (0.06–0.4)</b>	<b>0.1 (0.04–0.3)</b>	<b>0.07 (0.01–0.5)</b>
Education (years)				
1–9 years	0.8 (0.5–1.4)	1.1 (0.5–2.6)	<b>2.0 (1.2–3.5)</b>	<b>2.5 (1.1–5.7)</b>
10–13 years	1.3 (0.9–1.8)	1.2 (0.8–1.9)	<b>1.8 (1.2–2.9)</b>	1.1 (0.6–1.9)
> 14 years	Ref.	Ref.	Ref.	Ref.
Smoking				
Yes	<b>2.3 (1.5–3.6)</b>	<b>4.0 (2.3–7.0)</b>	<b>4.7 (2.9–7.6)</b>	<b>4.5 (2.3–8.6)</b>
No	Ref.	Ref.	Ref.	Ref.
Dental attendance				
Seldom	<b>1.9 (1.1–1.9)</b>	0.9 (0.3–2.5)	1.4 (0.6–2.8)	2.9 (0.9–9.5)
Every other year	Ref.	Ref.	Ref.	Ref.
Yearly	1.4 (0.9–3.0)	0.8 (0.5–1.3)	<b>2.1 (1.4–3.2)</b>	<b>1.9 (1.1–3.6)</b>

NSP = non-severe periodontitis. Ref. = Reference group. Adjusted for all variables in the model. In the adjusted model participants with missing values are excluded. Bold = significant differences compared to reference group

Previous studies have shown differences in periodontal health between indigenous and non-indigenous people around the world [5, 12]. In the present study the prevalence of periodontitis was not higher in the indigenous Sámi population compared to non-Sámi. However, there were significantly younger individuals in the Sámi group and when controlling for age, the Sámi had higher odds of having periodontitis.

More persons with Sámi affiliation did not brush their teeth daily. A nearly 30-year old study from Finnmark also reported that participants with Sámi affiliation had no regular tooth brushing habits in their childhood, which affected the tooth brushing habits as adults [2]. This can be seen in the context of the Sámi culture, where the Sámi people raise their children with more freedom and less regular routines [37].

The main strength of the present study is the large sample size ( $n = 1078$ ), the high response rate (88.7%) and the large number of participants with Sámi affiliation ( $n = 1381$ ). As large parts of the traditional Sámi settlement regions were included, the findings of prevalence of periodontitis in Sámi people could be regarded

representative of the Sámi population living in northern Norway. This study has methodological limitations, as described in Brustad et al. [22], where the external validity of the study was questioned because participants in the study were patients at the public dental care services, and not randomly chosen from the population. This may have affected the results and estimates and thus may not represent the situation for the whole population in this region. However, in the area where this study was conducted very few private dentists are available. Thus, most of the inhabitants seeking dental care go to a Public Dental clinic (as paying patients) in the area where they live. There are also limitations due to the clinical dental examination and the post clinical measurements of bone level. The alveolar bone level was measured on premolars and molars on bitewing, and RBL was estimated from mean length on premolars and molars. Not knowing the exact length of the root could mostly affect the measurement of RBL < 15%, and because of that, Stage I periodontitis was classified as non-severe periodontitis. This could lead to an underestimation of early stages of periodontitis in the population, but may not affect the

classification of more severe periodontitis, as stage II and stage III. On the other hand, this study had a full-mouth examination protocol on PD. Brustad et al. [22] concluded that the validity of measurements used in the presents study was acceptable, which is a strength of the study.

## Conclusion

The prevalence of periodontitis was high in communities in the core area of Sámi settlement in Northern Norway, regardless of ethnicity. People with Sámi ethnicity had more deep periodontal pockets and an increased likelihood of having severe stages of periodontitis. Future studies should address possible explaining factors behind the potential higher risk of having more severe periodontitis among indigenous people in Sámi settlements.

## Abbreviations

AAP: American Academy of Periodontology; ABL: Alveolar bone level; A-KSB: Ann-Kristine Sara Bongo; aOR: Adjusted odds ratio; CAL: Clinical attachment level; EFP: European Federation of Periodontology; NSP: non-severe periodontitis; NO: Nils Oscarson; OR: Odds ratio; PD: Periodontal probing depth; RBL: Radiographic bone loss; SD: Standard deviation

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## Authors' contributions

MB, NO and BJ planned the study. AKSB participated in data collection. All authors have made substantial contributions to conception and design of the study. AKSB and BJ drafted the manuscript, carried out the statistical analysis and interpreted the results. All authors have revised the manuscript critically and have given final approval.

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## Availability of data and materials

The datasets generated and/or analyzed during the current study are not publicly available due EU GDPR regulation, we cannot make the data into so called "open access data".

## Ethics approval and consent to participate

The regional committee for medical and health research ethics of the University of Tromsø, Norway, approved the study (2012/1902/REK Nord). All participants provided written informed consent.

## Consent for publication

Not applicable.

## Competing interests

The authors declare that they have no competing interests.

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CORRECTION

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# Correction to: Periodontal health in an indigenous Sámi population in Northern Norway: a cross-sectional study

Ann-Kristine Sara Bongo<sup>1,2,3\*</sup>, Magritt Brustad<sup>1</sup>, Nils Oscarson<sup>2</sup> and Birgitta Jönsson<sup>1,4</sup>

## Correction to: *BMC Oral Health* (2020) 20:104

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Following publication of the original article [1], the authors identified an error in the Table 4.

The correct table is given below:

Furthermore, due to those errors in Table 4, following corrections are related to the text:

1. Statistical analysis on page 3, paragraph 4: 'RBL and PD are presented as percent and proportions (SE) of affected sites and teeth for the total study population, stratified by age group and ethnicity. Differences between groups were assessed with  $\chi^2$ -test and t-test;
2. Results on page 4 under subtitle 'Prevalence and distribution', last sentence: 'In total (18–75 years), a higher proportion of Sámi had one or more PD  $\geq$  6 mm compared to non-Sámi ( $p < 0.05$ );

3. Discussion on page 5, third paragraph, second sentence: 'A larger proportion of Sámi had one or more PD  $\geq$  6 mm compared to non-Sámi, with no ethnic difference in prevalence of PD  $\geq$  4 mm and PD  $\geq$  6 mm';
4. Abstract on page 1 under results, last sentence: 'A higher proportion of Sámi had one or more PD  $\geq$  6 mm than the non-Sámi ( $p < 0.05$ )';

Abstract on page 1 under conclusion: 'People with Sámi ethnicity had deep periodontal pockets and an increased odds of having severe stages of periodontitis.

The original article has been updated.

The original article can be found online at <https://doi.org/10.1186/s12903-020-01098-3>.

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**Table 4** Prevalence and extent of radiographic bone loss and periodontal pocked depth by age group, ethnicity and in total

Periodontal measurements	Age Groups (years)								Total	
	18–34		35–49		50–64		65–75		18–75	
	Sámi	Non-Sámi	Sámi	Non-Sámi	Sámi	Non-Sámi	Sámi	Non-Sámi	Sámi	Non-Sámi
Ethnicity	Sámi	Non-Sámi	Sámi	Non-Sámi	Sámi	Non-Sámi	Sámi	Non-Sámi	Sámi	Non-Sámi
Number of individuals	313	106	435	252	468	241	165	98	1381	697
RBL, proportions <sup>a</sup>										
RBL 15–33%	3.8	5.7	<b>32.6</b>	<b>25.0</b>	59.4	53.5	53.9	57.1	37.7	36.4
RBL > 33%	0.3	0.0	3.5	5.6	23.3	21.2	25.5	25.5	12.1	12.9
PD, proportions <sup>a</sup>										
One or more PD ≥ 4 mm	40.6	40.6	63.7	56.4	<b>71.6</b>	<b>63.1</b>	73.3	81.6	62.3	59.8
One or more PD ≥ 6 mm	5.1	5.7	<b>16.1</b>	<b>10.3</b>	<b>29.1</b>	<b>19.9</b>	27.3	27.5	<b>19.4</b>	<b>15.6</b>
PD, mean (SE) <sup>b</sup>										
Proportions of sites/mouth										
PD ≥ 4 mm	3.5 (0.4)	3.8 (0.7)	7.7 (0.5)	6.8 (0.7)	10.5 (0.7)	10.1 (1.0)	8.8 (0.9)	11.7 (1.4)	8.0 (0.3)	8.2 (0.5)
PD ≥ 6 mm	0.2 (0.0)	0.1 (0.1)	0.5 (0.1)	0.4 (0.1)	1.3 (0.2)	1.1 (0.2)	1.2 (0.2)	1.2 (0.3)	0.8 (0.1)	0.7 (0.1)

RBL = radiographic bone loss; PD = periodontal pocket depth. SE = standard error. Bold-face = statistically significant differences between Sámi and non-Sámi in each age group ( $p < 0.05$ ). Statistical analyses were done with <sup>a</sup> =  $\chi^2$ -test and <sup>b</sup> = independent t-test

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## Paper III

Bongo, A.K.S., Brustad, M. & Jönsson, B. (2020).

Caries experience among adults in core Sámi areas of Northern Norway

*Community Dentistry and Oral Epidemiology*, 49(5), 401-409.



## ORIGINAL ARTICLE

# Caries experience among adults in core Sámi areas of Northern Norway

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**Abstract**

**Objectives:** Dental caries is a major oral health problem among indigenous people worldwide, but knowledge on this issue among the indigenous Sámi people in Norway is scarce. The aim of the study was to describe dental caries experience in an adult population in core Sámi areas of Northern Norway and to assess the corresponding associations with socio-demographic, socioeconomic and oral health-related behavioural factors.

**Methods:** This cross-sectional study is based on data from the Dental Health in the North study (2033 participants aged 18-75 years). A questionnaire was used to collect data on socio-demographic, socioeconomic and oral health-related behavioural factors. Clinical examinations were performed by dentists and dental hygienists at Public Dental Service (PDS) clinics in core Sámi areas of Northern Norway.

**Results:** About 68% (n = 1380) of participants reported Sámi ethnicity, and the mean number of decayed (D), missed (M) and filled (F) teeth (T) was 16.2 (standard deviation [SD] = 6.7). The mean DMFT was 15.7 (SD = 6.7) among Sámi and 17.0 (SD = 6.7) among non-Sámi. The mean DT among Sámi was 1.0 (SD = 1.6), with a significant, higher prevalence among coastal Sámi (DT = 1.3, SD = 1.8) than inland Sámi (DT = 0.8, SD = 1.5). Living in the coastal region, consumption of sugary soft drinks several times a week or daily, toothbrushing less than daily and irregular dental visits were associated with DT.

**Conclusions:** Caries experience among adults in core Sámi areas of Northern Norway was common. Dental caries were more common in the coastal than the inland region, with minor differences in caries experience between Sámi and non-Sámi people within these regions.

**KEYWORDS**

caries, epidemiology, indigenous, oral health, Sámi

## 1 | INTRODUCTION

Dental caries is a major oral health problem among indigenous people worldwide.<sup>1</sup> However, epidemiological information on indigenous oral health is mainly based on studies conducted in Australia, New

Zealand, Canada, the United States or Brazil.<sup>2,3</sup> Population-based scientific knowledge about caries occurrence among the indigenous Sámi population is lacking. The indigenous Sámi is the only minority in the nation that the Norwegian parliament has acknowledged as an indigenous people. The Sámi people have traditionally lived in the

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northern part of Norway, Sweden, Finland and in Kola Peninsula of the Russian Federation.

Epidemiological studies indicate that socioeconomic, behavioural and environmental factors are related to dental caries. Low income and low education level have been associated with a higher occurrence of dental caries,<sup>4-6</sup> and the development of caries is related to frequent sugar intake<sup>7,8</sup> and inadequate oral hygiene.<sup>9</sup> Lack of access to dental services and irregular dental visits are also associated with higher caries experience.<sup>4,7</sup>

In Norway, the Sámi people have the same access to Public Dental Service (PDS) clinics and private dental services as the general population. PDS clinics provide dental health care and treatment free of charge to people aged 0-18 years, to mentally disabled persons living in institutions and at home and to elderly and long-term care patients living in institutions or receiving care at home; youth aged 19 and 20 pay 25% of the public fees.<sup>10</sup> The private sector offers dental services to the general adult population. However, PDS clinics provide services to the whole population in rural areas of the northernmost part of Norway, as there are very few private clinics. The PDS reports the prevalence of decayed (D), missed (M) and filled (F) teeth (T) among children aged 5, 12 and 18 years to Statistics Norway every year.<sup>11</sup> According to this data, the DMFT among children in core Sámi areas (ie municipalities that are included in the 'Sami language administrative district') is higher than the mean DMFT in Norway. Due to legal restrictions in Norway, PDS data do not include information on ethnicity; thus, there is no way to know whether the caries prevalence is equally distributed across different ethnic groups in the same area. Epidemiological studies that used self-reported ethnicity have shown that general health among Sámi is similar to that of a nonindigenous reference population in multi-ethnic areas of Norway,<sup>12</sup> in contrast to most other indigenous populations worldwide.

At present, no peer-reviewed study has been published on caries experience in the adult Sámi population. A study by Holst et al,<sup>13</sup> published in Norwegian, found that the caries experience of populations in the northernmost county varied according to region, with 25-year-olds who lived in inland municipalities and spoke Sámi ( $n = 50$ ) having lower mean DMF surfaces (S) (33.2) and untreated dental caries (DS = 2.9) than individuals who lived in the same area but spoke Norwegian ( $n = 16$ ) (DMFS = 45.6, DS = 3.1). Among 55-year-olds, the opposite was found (DMFS = 91.8, DS = 4.8 vs DMFS = 94.5, DS = 1.8). Epidemiological studies from elsewhere in Norway have shown minor regional differences in caries experience among adults. A study from Oslo, the capital of Norway,<sup>5</sup> reported a mean DMFS and mean DS of 24.6 and 1.5 for adults aged 35 years, while in Troms County, Northern Norway,<sup>7</sup> the mean DMFS and DS were 17.9 and 1.5, respectively, among adults aged 20-34 years. A nationwide study of the oral health of elderly Norwegians found that the mean DMFT was lower, and mean DT was higher among elderly in the southern (24.3 and 0.59, respectively) than in the northern counties (26.8 and 0.37, respectively).<sup>14</sup> However, no information on ethnicity was reported in the above studies.

Regional differences in caries experience among children in Norway, and knowledge about inequalities in oral health among indigenous peoples worldwide,<sup>2</sup> raise the question of whether the high caries prevalence in the northernmost part of Norway (Finnmark County) differs by ethnicity. Equal access to dental services<sup>15,16</sup> is a likely explanation for the finding of no differences in the prevalence of periodontitis between Sámi and non-Sámi in this area.<sup>17</sup> Population-based studies<sup>18-20</sup> have shown that the dietary pattern in core Sámi areas differs to a certain degree, but the differences are small; Sámi women had a higher intake of added sugars compared to non-Sámi women, and populations from inland regions tended to have a higher intake of added sugars than those from coastal regions. Thus, we hypothesized that caries experience is equal among adults in core Sámi areas, independent of ethnicity. The aim of the study was to describe dental caries experience in an adult population in core Sámi areas in Northern Norway and to assess the corresponding associations with socio-demographic, socioeconomic and oral health-related behavioural factors.

## 2 | METHOD

### 2.1 | Study area and population

This study was based on data from the Dental Health in the North study, a cross-sectional study from rural areas in Northern Norway (municipalities of Kautokeino, Karasjok, Lakselv, Tana and Nesseby). The municipalities included in this study are core Sámi areas, where the Sámi and Norwegian language are equal.<sup>15</sup> Geographic region of residence was categorized as inland region (Kautokeino, Karasjok) and coastal region (Lakselv, Tana and Nesseby). The rationale behind this categorization was that, although both regions are multi-ethnic, with Sámi and Norwegian people, the ethnic and cultural structures of these regions are different. In the inland region, the Sámi are the majority; thus, the main language is Sámi, and the traditional Sámi culture is still strong. In the coastal areas, Norwegians are the majority, and the main language is Norwegian. Historical efforts to assimilate the Sámi people by forcing them to adopt the Norwegian language and change the basic value-structure of their Sámi culture and identity<sup>21</sup> caused many to lose their Sámi identity, language and culture. These assimilation efforts were historically most articulated in the coastal areas. Today, the Sami population has its own indigenous Parliament, The Sámi Parliament, which deals with all matters concerning the Sámi people.<sup>22</sup>

All patients aged 18-75 years who had an appointment scheduled or were on the re-call list at PDS clinics in the selected municipalities between February 2013 and May 2014 were invited to participate ( $n = 2520$ ). In total, 2235 adults accepted (crude response rate: 88.7%). Immigrants ( $n = 44$ ) and participants with missing data ( $n = 158$ ) were then excluded, giving a final study sample of 2033 participants. Data were collected from questionnaires, and clinical and radiographic examinations. The Dental Health in the North study and methodology have been described previously in detail.<sup>23</sup>



The Regional Committee for Medical and Health Research Ethics of the University of Tromsø, Norway, approved the study (2012/1902/REK Nord). All participants provided written informed consent.

## 2.2 | Questionnaire

Ethnicity was determined by self-reported information from the questionnaire on (1) respondents' home language, (2) their/their parents'/their grandparents' ethnic background and (3) what ethnicity they considered themselves to be (ie subjective appraisal criteria). The response options to these questions were 'Norwegian', 'Sámi', 'Kven' (national minority in Norway that immigrated from Sweden and Finland) and 'other'. Participants who responded that they considered themselves to be Sámi, and that their, their parents' *and/or* their grandparents' home language *and/or* ethnic background is/was Sámi, were classified as Sámi. All others were classified as non-Sámi; this group consisted mainly of Norwegians, Kven (without Sámi affiliation,  $n = 99$ ) and Sámi who did not report any subjective appraisal criteria ( $n = 165$ ).

Information on the potential socio-demographic, socioeconomic and oral health-related confounders region of residence, sex, age, household income, duration of education, consumption of sugary soft drinks, frequency of toothbrushing and frequency of dental visits was also obtained from the questionnaire. Age was divided into four groups: 18-34, 35-49, 50-69 and 70-75 years. Duration of education was assessed with the question: 'How many years have you been studying?' with responses categorized into two groups: 1-13 years and  $\geq 14$  years. Consumptions of sugary soft drinks were divided into seldom or never (including answer options 'never' or 'once a week') and several times a week/daily. Frequency of toothbrushing was categorized as less than daily (including answer options from '6 times per week' to 'less than once a week'), daily, and twice daily or more. Frequency of dental visits was assessed with the question: 'When do you attend dental health services?' The response options were divided into two groups: regular ('regularly convened or booked dental appointments') or irregular ('irregular use of dental health services or attend only when having problems/pain').

## 2.3 | Clinical and radiographic examinations

Nine dentists and six dental hygienists (examiners) performed clinical and radiographic examinations at six PDS clinics in the five municipalities. Prior to the study, the examiners attended a workshop on diagnostic criteria and examination procedures, during which they were trained to diagnose caries using a five-grade scale by an experienced dentist (Nils Oscarson).<sup>24</sup> This scale was used to diagnose caries in both clinical and radiographic examinations (grade 1: white or brown caries lesion in enamel *and/or* radiolucency in outer half of enamel; grade 2: small cavitation in enamel *and/or* radiolucency in inner half of enamel; grade 3: moderate-sized cavity *and/or* radiolucency in outer third of dentin; grade 4: big cavitation *and/or* radiolucency in the middle third of dentin; Grade 5: very big cavity *and/or* radiolucency in the inner

third of dentin). Caries grade 1-2 was classified as enamel caries and caries grade 3-5 as dentin caries. In the present study, the outcomes DT and DS include caries grade 3-5. Root caries and secondary caries were also included in these outcomes. FT and FS included all kinds of fillings (eg temporary fillings and dental crowns).

All examiners were also calibrated for radiographic examinations during the workshop, by diagnosing proximal and occlusal caries on premolars and molars in radiographs from two cases. However, as kappa values were not estimated following this calibration, post-clinical inter-examiner agreement was estimated in order to ensure the reliability of caries registration. For this, the first author (A-KSB) was calibrated with a specially designed software (DIL version 1.21; University of Bergen, Bergen, Norway). Two separate exercises were completed, each consisting of a judgement of 51 occlusal and proximal surfaces from radiographs. For each exercise, the agreement between the diagnoses of the first author and those contained in the software, which were assigned by an expert group, was expressed by weighted kappa (0.67 and 0.70, respectively). Then, the first author registered proximal and occlusal caries on premolars and molars from the radiographs of all participants using the five-grade diagnostic scale. These diagnoses were used as the gold standard for the inter-examiner agreement analysis. The diagnoses were then categorized as 'no caries' (grades 1-2) or 'caries' (grades 3-5). Finally, three participants from each examiner (45 participants in total) were randomly chosen and used to calculate a kappa value for each participant, as well as the mean kappa value for all examiners ( $\kappa = 0.84$ , range 0.55-1.00).

## 2.4 | Statistical analysis

Data were analysed using the IBM® SPSS® Statistics, version 26. Cross-tabulation and the Pearson chi-square test were used to test differences in categorical background characteristics between Sámi and non-Sámi participants. For continuous variables, the Mann-Whitney or Kruskal-Wallis test was used. Binary logistic regression was used to assess the odds of being exposed to selected socio-demographic, socioeconomic and oral health-related behavioural factors among participants with  $DT \geq 1$  versus those with  $DT = 0$  (reference group). Two logistic regression models, adjusted for different confounders, were used (Amrhein, 2019). Model 1 was adjusted for region of residence, sex, age and duration of education. In model 2, we adjusted for the same confounders as in model 1, in addition to consumption of sugary soft drinks, frequency of toothbrushing and frequency of dental visits. All analyses were performed with a significance level at 0.05 and with 95% confidence intervals.

## 3 | RESULTS

Of the 2033 participants, 67.9% reported Sámi ethnicity. The mean age of Sámi and non-Sámi participants was 46.7 years ( $SD = 14.7$ ) and 49.0 years (standard deviation [ $SD$ ] = 13.4) years, respectively.

The majority of Sámi participants lived in the inland region, while the largest proportion of participants in the coastal region were non-Sámi. Frequency of toothbrushing and frequency of dental visits differed between the two ethnic groups, with a larger proportion of Sámi participants brushing their teeth only once daily or less and having irregular dental visits (Table 1).

Mean DMFT and mean DMFS in the study sample was 16.2 and 45.1, respectively. Dental caries experience did not vary substantially by sex. However, some differences in DMFT and DMFS were observed by ethnicity, region of residence and age (Table 2).

Seldom or never consuming sugary soft drinks, toothbrushing twice daily or more, and regular dental visits were all significantly related to a lower mean DT in both ethnic groups (Table 3). After

adjustment for the socio-demographic and socioeconomic factors in model 1, having a DT  $\geq 1$  compared to a DT = 0 was associated with region of residence and age in Sámi participants, and with region of residence and sex in non-Sámi participants. Further adjustment for oral health-related behavioural factors in model 2 revealed an association between a DT  $\geq 1$  and living in the coastal region, consumption of sugary soft drinks several times a week or daily, toothbrushing less than daily and irregular dental visits in both ethnic groups. The factors used as independent variables in model 1 explained 5.8% and 5.4% of the variance in caries (Nagelkerke's  $R^2$  of 0.058 and 0.054) in Sámi and non-Sámi participants, respectively. Model 2 explained 11.1% of the variance in caries (Nagelkerke's  $R^2$  of 0.111) in both ethnic groups (Table 4).

**TABLE 1** Characteristics of the study participants according to ethnicity and region of residence

Background characteristics	Sámi n (%)	Non-Sámi n (%)	Inland region n (%)	Coastal region n (%)
Participants	1380 (67.9)	653 (32.1)	985 (48.5)	1048 (51.5)
Region of residence				
Inland	869 (63.0)	116 (17.8) <sup>a</sup>		
Coastal	511 (37.0) <sup>a</sup>	537 (82.2)		
Sex				
Men	578 (41.9)	297 (45.5)	560 (56.9)	598 (57.1)
Women	802 (58.1)	356 (54.5)	425 (43.1)	450 (42.9)
Age (y)				
18-34	312 (22.6)	101 (15.5) <sup>a</sup>	252 (25.5)	161 (15.4) <sup>a</sup>
35-49	435 (31.5)	233 (35.7)	316 (32.1)	352 (33.6)
50-64	468 (33.9)	226 (34.6)	298 (30.3) <sup>a</sup>	396 (37.7)
65-75	165 (12.0)	93 (14.2)	119 (12.1)	139 (13.3)
Household income				
<300 000	184 (14.1)	83 (13.3)	141 (15.0)	126 (12.7)
300 001-600 000	546 (41.9)	231 (37.0)	405 (43.1)	372 (37.6) <sup>a</sup>
600 001-900 000	400 (30.7)	204 (32.6)	272 (28.9) <sup>a</sup>	332 (33.6)
>900 001	174 (13.3)	107 (17.1)	122 (13.0)	159 (16.1)
Duration of education (y)				
1-13	640 (48.4) <sup>a</sup>	367 (57.1)	446 (47.3) <sup>a</sup>	561 (54.8)
$\geq 14$	683 (51.6)	276 (42.9) <sup>a</sup>	497 (52.7) <sup>a</sup>	462 (45.2)
Consumption of sugary soft drinks				
Seldom/never	1110 (82.4)	514 (81.5)	767 (79.8) <sup>a</sup>	857 (84.3)
Several times a week/daily	237 (17.6)	117 (18.5)	194 (20.2)	160 (15.7) <sup>a</sup>
Frequency of toothbrushing				
Less than daily	142 (10.3)	32 (4.9) <sup>a</sup>	129 (13.1)	45 (4.3) <sup>a</sup>
Once daily	461 (33.5)	161 (24.7) <sup>a</sup>	353 (35.9)	269 (25.7) <sup>a</sup>
Twice daily or more	775 (56.2) <sup>a</sup>	459 (70.4)	502 (51.0) <sup>a</sup>	732 (70.0)
Frequency of dental visits				
Irregular	288 (21.1)	112 (17.3) <sup>a</sup>	207 (21.4)	193 (18.5)
Regular	1074 (78.9) <sup>a</sup>	536 (82.7)	732 (78.6)	848 (81.5)

<sup>a</sup>P < .05; chi-square test for differences between Sámi and Non-Sámi or between inland and coastal.

**TABLE 2** Dental caries experience by ethnicity, sex and age group

Characteristics	N	Number-T	Intact-T	DMFT	DFT	DT	DMFS	DFS	DS
		Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
Total	2033	25.2 (3.8)	10.0 (7.6)	16.2 (6.7)	13.3 (5.7)	1.0 (1.7)	45.1 (26.7)	31.4 (18.5)	1.5 (3.0)
Ethnicity									
Sámi	1380	25.1 (3.8)	10.4 (7.7)	15.7 (6.7) <sup>a</sup>	12.9 (5.7) <sup>a</sup>	1.0 (1.6) <sup>a</sup>	43.7 (26.5) <sup>a</sup>	29.8 (17.8) <sup>a</sup>	1.4 (2.8) <sup>a</sup>
Non-Sámi	653	25.2 (3.8)	9.2 (7.5) <sup>a</sup>	17.0 (6.7)	14.3 (5.8)	1.2 (1.8)	48.3 (27.0)	34.8 (19.4)	1.7 (3.3)
Region-Inland									
Sami	869	25.3 (3.9)	11.4 (7.7)	14.7 (6.6) <sup>a</sup>	12.0 (5.6) <sup>a</sup>	0.8 (1.5)	40.2 (25.8) <sup>a</sup>	27.0 (17.0) <sup>a</sup>	1.2 (2.6)
Non-Sami	116	25.5 (3.5)	10.3 (7.6) <sup>a</sup>	16.0 (6.6)	13.5 (5.8)	0.6 (1.0)	45.9 (27.2)	33.7 (20.7)	0.9 (1.7)
Region-Coastal									
Sámi	511	24.9 (3.8)	8.6 (7.3)	17.5 (6.5)	14.4 (5.5)	1.3 (1.8)	49.6 (26.7)	34.4 (18.0)	1.7 (3.1)
Non-Sámi	537	25.2 (3.8)	9.0 (7.4)	17.3 (6.7)	14.5 (5.8)	1.3 (2.0)	48.8 (26.9)	35.1 (19.2)	1.9 (3.6)
Sex									
Men	875	25.1 (3.9)	10.0 (7.7)	16.1 (6.8)	13.3 (5.8)	1.2 (1.8)	45.2 (27.0)	31.3 (18.6)	1.7 (3.3)
Women	1158	25.2 (3.8)	10.0 (9.5)	16.2 (6.7)	13.4 (5.7)	0.9 (1.6) <sup>a</sup>	45.1 (26.6)	31.4 (18.4)	1.3 (2.7) <sup>a</sup>
Age (y)									
18-34	413	27.2 (1.4) <sup>b</sup>	17.4 (6.4) <sup>b</sup>	9.9 (6.1) <sup>b</sup>	9.1 (5.8) <sup>b</sup>	1.3 (2.0) <sup>b</sup>	19.2 (14.9) <sup>b</sup>	15.3 (12.0) <sup>b</sup>	1.8 (3.3) <sup>b</sup>
35-49	668	26.4 (2.0)	12.7 (6.4)	13.9 (5.7)	12.4 (5.1)	1.0 (1.7)	34.3 (13.9)	26.7 (14.8)	1.5 (2.9)
50-64	694	24.6 (3.4)	5.8 (4.9)	19.8 (4.3)	16.4 (4.3)	0.9 (1.6)	59.1 (19.7)	42.4 (16.1)	1.4 (3.1)
65-75	258	20.3 (5.7)	2.7 (3.4)	22.2 (3.8)	14.5 (5.5)	0.9 (1.5)	77.1 (18.7)	39.6 (18.3)	1.3 (2.4)

Abbreviations: D, Decayed (Dentin caries grade 3-5); F, Filled; M, Missed; N, Number of participants; S, Surface; SD, Standard Deviation; T, Teeth.

<sup>a</sup> $P < .05$ ; Mann-Whitney  $U$  test.

<sup>b</sup> $P < .05$ ; Kruskal-Wallis test.

## 4 | DISCUSSION

Dental caries experience was common among adults in the investigated core Sámi areas of Northern Norway, with a variation in relation to region of residence. Findings from the present study showed that caries experience was lower among Sámi participants, who also had a lower mean DT than non-Sámi participants. On the other hand, dental caries was significantly higher among participants from the coastal region compared to those from the inland region. Having caries was associated with the oral health-related behavioural factors: consumption of sugary soft drinks, toothbrushing less than daily and irregular dental visits.

A strength of this study is the large sample size and the fact that a majority of the participants self-identified as Sámi. This is unlike other studies in indigenous populations, in which the number of indigenous participants was very low compared with nonindigenous.<sup>2,3,25</sup> There are several reasons for the high number of indigenous participants in the present study. The study was conducted in areas with a high density of individuals of Sámi ethnicity, and thus where the Sami culture is strong, reindeer herding is still common, and a majority of the population speaks the Sámi language. Local PDS clinics were used as an arena for clinical examinations. Those clinics were familiar to the inhabitants, and most of the participants reported regular dental visits, which could have contributed to the

high number of participants. Furthermore, the cooperation between local dental healthcare workers and the research team reinforced a culturally safe indigenous methodology, involving examiners who were familiar with the Sámi culture and who speak the Sámi language. More than half of the employees (16 of 29) in the included PDS clinics were of Sámi ethnicity.<sup>23</sup> Even though the present study has a cross-sectional design, it contributes to knowledge about associations between ethnicity and dental caries, as this was the first epidemiological study conducted in core Sámi areas. The present study also has a methodological strength in the questionnaire, which included questions and established instruments used in other population-based surveys.<sup>23,26</sup>

Participants were not chosen randomly, since the majority of them used the PDS clinics regularly. This could affect the external validity of the study, as those in the population who do not attend regular dental visits might be underrepresented. In the present study, 20% of the participants did not attend dentist regularly, but to what extent this correspond to the number of the total population who do not attend dentist regularly, are unknown. The study sample is at large comparable to the general national population stratified by age,<sup>27</sup> however, a slightly larger group aged 50-66 and less proportion of those aged 67-79 (data not shown). More women than men participated in the present study. This comparison reflecting what is known from population-based studies that women and the

**TABLE 3** Mean number of decayed teeth by selected characteristics, stratified by ethnicity

Background characteristics	Mean DT (SD)	
	Sámi N = 1380	Non-Sámi N = 653
<b>Region</b>		
Inland	0.8 (1.5) <sup>b</sup>	0.6 (1.0) <sup>b</sup>
Coastal	1.3 (1.8)	1.3 (2.0)
<b>Sex</b>		
Men	1.1 (1.8) <sup>a</sup>	1.4 (2.0)
Women	0.9 (1.5)	1.0 (1.7) <sup>b</sup>
<b>Age (y)</b>		
18-34	1.1 (1.8) <sup>a</sup>	1.9 (2.3) <sup>c</sup>
35-49	1.0 (1.6) <sup>a</sup>	1.2 (1.7)
50-64	0.9 (1.5)	1.0 (1.8)
65-75	0.9 (1.6)	0.9 (1.3)
<b>Household income</b>		
<300 000	1.0 (1.7)	0.9 (1.5)
300 001-600 000	0.9 (1.7) <sup>a</sup>	1.2 (1.9)
600 001-900 000	1.0 (1.5)	1.2 (2.1)
>900 000	1.0 (1.7) <sup>a</sup>	1.2 (1.6)
<b>Duration of education (y)</b>		
1-13	1.1 (1.8) <sup>a</sup>	1.4 (2.1)
≥14	0.9 (1.5)	0.9 (1.4)
<b>Consumption of sugary soft drinks</b>		
Seldom/never	0.9 (1.9) <sup>a,b</sup>	1.0 (1.7) <sup>b</sup>
Several times a week/daily	1.4 (1.5) <sup>a</sup>	1.9 (2.3)
<b>Frequency of toothbrushing</b>		
Less than daily	1.7 (2.3) <sup>a</sup>	3.1 (3.4)
Once daily	1.1 (1.8) <sup>a</sup>	1.3 (1.6)
Twice daily or more	0.8 (1.3) <sup>a,c</sup>	1.0 (1.7) <sup>c</sup>
<b>Frequency of dental visits</b>		
Irregular	1.7 (2.3) <sup>a</sup>	2.9 (3.0)
Regular	0.7 (1.3) <sup>a,b</sup>	0.8 (1.2) <sup>b</sup>

Abbreviations: DT, Decayed teeth (Dentin caries grade 3-5); SD, Standard Deviation.

<sup>a</sup> $P < .05$ ; Mann-Whitney  $U$  test for differences between ethnic groups.

<sup>b</sup> $P < .05$ ; Mann-Whitney  $U$  test for differences within ethnic groups.

<sup>c</sup> $P < .05$ ; Kruskal-Wallis test for differences within ethnic groups.

middle-aged are more willing to participate in such studies. Another limitation was that the municipalities chosen were all in rural areas, meaning that the results might not represent the caries prevalence among Sámi in urban areas in the north or elsewhere in Norway. Moreover, the data used in the present study are from 2013 to 2014. As Statistics Norway has reported that the number of 18-year-olds without caries (DMFT = 0) is increasing in Norway, and in the northernmost part of Norway the proportion of DMFT = 0 has increased from 11.4% in 2015 to 18.8% in 2019,<sup>11</sup> it is possible that the caries experience among young adults in core Sámi areas also decreased

slightly between 2014 and 2019. To what degree this suggested time trend differs by ethnicity is unknown.

When comparing findings in the present study with those of other studies of indigenous populations, we found some differences. First, the mean DT was lower in the present indigenous Sámi population than that reported in indigenous Australians (2.4-4.4)<sup>25,28-30</sup> and indigenous Brazilians (2.6).<sup>3</sup> Second, we found only minor differences in caries experience between Sámi and non-Sámi when comparing ethnic groups within the inland and coastal regions. Furthermore, regardless of geography, there were differences in mean DT by ethnicity, but when comparing mean DT in the different ethnic groups within the inland and coastal regions, no differences were observed. These findings highlight that, when comparing oral health outcomes between or within ethnic groups, the reference group should come from the same region of residence, as societies and ways of life may differ between urban and rural areas. A review from Australia emphasized the importance of citing rural or urban location when reporting indigenous oral health, as this can influence oral health status in indigenous adults.<sup>31</sup> The high caries experience among indigenous people when compared to nonindigenous people in Australia, Brazil and New Zealand are related lower education levels, limited access to dental services, and scarcity of dentists and other dental healthcare workers of indigenous ethnicity in areas where indigenous people live.<sup>32,33</sup> These challenges are known to result in inequalities in oral health between indigenous and nonindigenous populations in these countries. Although Sámi people generally have the same access to dental health care as their nonindigenous counterparts in core Sámi areas,<sup>16</sup> there is a history of irregular access to dentists in our study area.<sup>34</sup> The situation has improved since the establishment on a program of dental education at the University of Tromsø in 2002, which helped increase the number of dentists in Northern Norway and contributed to an increase in the number of dentists who speak Sámi.<sup>35</sup> In the present study, duration of education was not associated with an increased risk of dental caries, although this duration was higher among Sámi and among participants from the inland region, compared with non-Sámi and participants from the coastal region. These findings are contradictory to those of other studies, in which socioeconomic factors were found to be associated with caries.<sup>4,6</sup> Minor differences in socioeconomic status between Sámi and non-Sámi, and the equal access to dental services may explain the minor differences in caries experience between ethnic groups in same region. These findings are in line with results from studies on general health among adults in core Sámi areas, where minor differences were found between Sámi and non-Sámi.<sup>12,36</sup>

Caries arises as a result of a complex interplay between environmental factors, such as fluoridation, location of primary residence, availability and accessibility of dental services, and individual factors (including diet and lifestyle habits). Within ethnic groups, inland Sámi had a significant, lower mean DT than coastal Sámi, and coastal Sámi were more likely to have caries. In Norway, no fluoride is added to drinking water, and the maximum level of fluoride allowed in drinking water is 1.5 mg/L.<sup>37</sup> The majority of residents in

**TABLE 4** Summary of binary logistic regression models for person with one or more decayed teeth (DT > 0) stratified by ethnicity

Characteristics	Adjusted odds ratio (95% Confidence Interval)			
	Sámi		Non-Sámi	
	Model 1 N = 1323	Model 2 N = 1277	Model 1 N = 643	Model 2 N = 616
<b>Region</b>				
Coastal	2.3 (1.9-2.9)	2.8 (2.2-3.5)	1.6 (1.1-2.5)	1.7 (1.1-2.7)
Inland	Ref.	Ref.	Ref.	Ref.
<b>Sex</b>				
Men	1.0 (0.9-1.3)	0.9 (0.7-1.1)	1.4 (1.1-1.9)	1.2 (0.8-3.2)
Women	Ref.	Ref.	Ref.	Ref.
<b>Age (y)</b>				
18-34	1.8 (1.2-2.7)	1.4 (0.9-2.3)	1.5 (0.9-2.8)	1.0 (0.5-2.0)
35-49	1.5 (0.9-2.2)	1.3 (0.8-1.9)	0.9 (0.6-1.6)	0.9 (0.5-1.5)
56-64	1.4 (0.9-2.0)	1.4 (0.9-2.1)	0.8 (0.5-1.3)	0.8 (0.5-1.4)
65-75	Ref.	Ref.	Ref.	Ref.
<b>Duration of education (y)</b>				
1-13	1.2 (0.9-1.5)	1.1 (0.8-1.4)	1.5 (1.1-2.1)	1.2 (0.9-1.7)
≥14	Ref.	Ref.	Ref.	Ref.
<b>Consumption of sugary soft drinks</b>				
Several times a week/daily		1.6 (1.2-2.2)		1.7 (1.1-2.8)
Seldom/Never		Ref.		Ref.
<b>Frequency of toothbrushing</b>				
Less than daily		2.1 (1.4-3.2)		3.0 (1.1-8.0)
Once daily		1.3 (0.9-1.7)		1.4 (0.9-2.1)
Twice daily or more		Ref.		Ref.
<b>Frequency of dental visits</b>				
Irregular		2.0 (1.5-2.6)		2.2 (1.4-3.6)
Regular		Ref.		Ref.

Abbreviation: Ref., Reference group.

the municipalities (inland and coastal) in core Sámi areas under study receive drinking water from municipal waterworks, which is regulated and controlled by the authorities. It is stated that a diet with low intake of fermentable carbohydrates (ie food/drinks containing sucrose) prevents caries.<sup>38</sup> Studies from core Sámi areas of northern Norway have reported that Sámi women and inhabitants of the inland region, regardless of ethnicity, tended to have a higher intake of added sugar.<sup>18-20</sup> In the present study, there were no differences in the consumption of sugary soft drinks between Sámi and non-Sámi, but the inland population had a higher consumption of sugary soft drinks than the coastal population. The underlying causes of geographic differences in caries experience are unknown, and a different study design would be needed to and to gain knowledge of these contributing factors.

One effective self-care method for preventing caries is toothbrushing with fluoride toothpaste twice daily.<sup>39</sup> While frequency of toothbrushing was one of the strongest predictive factors for DT, about 30%-50% of the participants did not brush their teeth

twice daily. Consequently, oral hygiene education to increase toothbrushing frequency and efficacy may be one of the most effective caries prevention measures in core Sámi areas. In order to provide the best prevention and treatment, dental professionals need to be familiar with the history and culture of the indigenous people and be able to give information about oral health in the patients' language. In general, the high caries prevalence in coastal Sámi areas and the high prevalence of periodontitis in core Sámi areas that were reported in a recent study<sup>17</sup> indicate the need for targeted preventive strategies, with more context-specific, culturally appropriate and community-based oral health promotion to improve oral health.

Compared to other adult populations in Norway, we observed a higher caries experience among adults in Finnmark County. However, caries prevalence in core Sámi areas differed to some degree in relation to region of residence, with participants from the inland region having a mean DS score that was comparable to that of the adult populations in Troms County in Northern Norway

(mean DS = 0.8).<sup>7</sup> Participants from the coastal region had a higher prevalence relative to that in Troms County, regardless of ethnicity. The mean DT and mean DS among the elderly in Troms County were reported to be 0.2 and 0.33, respectively,<sup>40</sup> which is in the same range as findings from a nationwide study (DS = 0.3) among elderly Norwegians (60–94 years old),<sup>14</sup> but lower than what we observed among the elderly in core Sámi areas. Caries experience among young adults in our study sample in Finnmark County was also higher than that among young adults in Troms County<sup>7</sup> and in Oslo, the capital of Norway.<sup>5</sup>

In conclusion, caries experience among adults in core Sámi areas remains common. DT was more common in the coastal region compared to the inland region, with minor differences in caries experience between Sámi and non-Sámi participants within regions. When studying indigenous people's oral health, region of residence must be taken into consideration. Our findings show that, in order to improve oral health, there is a need to focus on caries prevention measures in the population of Northern Norway.

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#### CONFLICT OF INTERESTS

The authors have stated explicitly that there are no conflicts of interest in connection with this article.

#### AUTHOR CONTRIBUTION

MB initiated, planned and led the data collection. AKSB participated in the data collection. All authors have made substantial contributions to the conception and design of the study. AKSB and BJ drafted the manuscript, carried out the statistical analysis and interpreted the results. All authors have revised the manuscript critically and have given final approval.

#### DATA AVAILABILITY STATEMENT

The datasets generated and/or analyzed during the current study are not publicly available due to EU GDPR regulation, we cannot make the data into so called "open access data".

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## Paper IV

Bongo, A.K.S., Brustad, M. & Jönsson, B.

Oral health-related quality of life in an indigenous Sámi population in Northern Norway

(Submitted manuscript).



# **Oral health-related quality of life in an adult indigenous Sámi population in Northern Norway**

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## **Key words:**

Epidemiology; oral health-related quality of life; the oral health impact profile; indigenous; Sámi; oral health

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**Authorship:** MB initiated, planned, and led the data collection. A-KSB participated in data collection. All authors have made substantial contributions to the conception and design of the study. A-KSB and BJ drafted the manuscript, carried out the statistical analysis, and

interpreted the results. All authors have revised the manuscript critically and have given final approval.

## **ABSTRACT**

**Objective:** The objective of this study is twofold: 1) to describe the oral health-related quality of life (OHRQoL), measured by the Oral Health Impact Profile-14 (OHIP-14), in an adult indigenous Sámi population and a non-Sámi population from the same area, and 2) to explore associations between the OHIP-14 scores and socioeconomic factors, behavioural factors, and clinically assessed dental health in the Sámi population.

**Methods:** The study sample (n=1913; 18-75 years of age; 1297 Sámi) consist of participants from the Dental Health in the North study, a cross-sectional study conducted in Northern Norway. The OHIP-14 score, and information on sociodemographic, socioeconomic, and behavioural factors were collected by questionnaire. Data on decayed teeth and periodontal pocket depth were collected during clinical dental examinations.

**Results:** The mean OHIP-14 score in the entire study sample was 5.1 (standard deviation [SD] 5.8); mean scores among Sámi and non-Sámi were 5.4 (SD 6.0) and 4.4 (SD 5.2), respectively (p<0.001). The most frequently reported OHIP-14 dimension was physical pain. Factors associated with having problems fairly often, or often in at least one of the 14 items (frequent problems) were female gender, younger age, irregular dental visits, fewer than 20 teeth, or the presence of periodontitis or decayed teeth. Number of teeth had the strongest association (OR 3.1; 95% CI 1.9-3.5).

**Conclusions:** Sámi and non-Sámi populations in core Sámi areas in Northern Norway reported problems related to their teeth and mouth that impacted their daily lives, where a substantial proportion reported frequent problems. Overall perceptions of OHRQoL were associated with female gender, age, dental attendance, along with number of teeth, and the presence of periodontitis and caries.

## **Introduction**

The social impact of oral health on an individual's quality of life has been encapsulated by the term 'oral health-related quality of life' (OHRQoL) [1]. OHRQoL offers a broader definition of oral health, expanding the dimensions to include the concept of social well-being [2]. The World Dental Federation's theoretical framework defines oral health as a combination of subjective and clinically assessed oral health, both of which should be included when describing individual oral health [3]. Subjective oral health is assessed by patient-reported outcome measures (PROMs) that encompass the psychosocial and physiological aspects of oral health, while clinically assessed oral health is based on the outcome of a clinical dental examination. OHRQoL is assessed by PROMs [4], which are often collected from standardised questionnaires that assesses an individual's rating of subjective oral health and quality of life [5].

One of the most common PROMs used to assess the impact of oral health on quality of life is the Oral Health Impact Profile-14 (OHIP-14) [6], which measures people's perception of the social impacts of oral health and problems that compromise oral health and well-being. OHIP-14 has also been used in Norwegian studies to describe social impacts of oral disorders on their well-being among Norwegian adult populations [7-10]. It has been reported that younger adults, women, individuals with less number of teeth, those with poor self-rated oral health and those who attended dental health services irregularly had poorer OHRQoL than others [7]. Knowledge about OHRQoL among minority groups and indigenous people is in general quite scanty, and to the best of our knowledge there are no studies conducted on Sámi populations. The Sámi, an indigenous people of Norway, Sweden, Finland, and the Russian Federation [11], have their own culture, language, and traditions. In Norway, the Sámi are a minority group, recognised both as an indigenous people and as full citizens of Norway [12].

Only minor differences in social determinants and general health have been found between Sámi and non-Sámi in Norway [13-15].

There is a general lack of knowledge about the social impact of oral health on quality of life among indigenous adults all over the world, although indigenous people experience poor oral health [16-19]. Recent results from an indigenous Sámi population in Northern Norway [20,21] showed that dental caries and periodontitis are common among Sámi. However, there is no information about how these oral diseases impact their OHRQoL. A study among Norwegian adults showed that dental caries may impact daily life among young adults[22], but this association was not found among older adults[10]. Studies have shown that adults with periodontitis have a worse quality of life than those without the condition. Moreover, among individuals with periodontitis, those with severe disease have poorer OHRQoL [23,24]. Previous studies have shown that dental caries and periodontitis factor into peoples' perception of their oral health and how it impacts their quality of life [25-28].

As dental caries and periodontitis are common among adults in Northern Norway, we hypothesised that oral health may have similar effects on perceived quality of life, regardless of ethnic background. This study aimed to describe OHRQoL measured by the OHIP-14 in an indigenous Sámi adult population and a non-Sámi adult population from the same area. It also aimed to explore associations between the OHIP-14 score and socioeconomic factors, behavioural factors, and clinically assessed dental health in the Sámi population.

## **Method**

### ***Design and study population***

This study was based on data from The Dental Health in the North Study, a cross-sectional study from five municipalities (Kautokeino, Karasjok, Lakselv, Tana, and Nesseby) in Northern Norway. All participants aged 18-75 years who had an appointment scheduled or

were on the recall list at public dental services (PDS) in the selected municipalities in 2013-2014 were invited to participate. In total, 2235 adults (18-75 years) accepted, while 285 persons declined to participate. Foreign immigrants (n=44) and participants with missing data (n=278) were excluded, giving a final analytical sample of 1913 participants. The methodology of the Dental Health in the North study has been described previously in detail [29]. The Regional Committee for Medical and Health Research Ethics of the University of Tromsø, Norway, approved the study (2012/1902/REK Nord), and all participants provided written informed consent.

### ***Questionnaire***

OHRQoL was measured using the short-form OHIP-14 [6], which is composed of 14 items that assess seven dimensions of the social impact of oral health and problems that compromise oral health and well-being: functional limitations, physical pain, psychological discomfort, physical disability, psychological disability, social disability, and handicaps. The OHIP-14 questionnaire used in this study is not validated in Norwegian, but it has been used previously in Norwegian studies on OHRQoL [8-10,22].

Using the OHIP-14 questionnaire, respondents reported on how often in the past 12 months they experienced issues with their mouth or teeth that caused them oral health related problems. For each of the 14 statements, respondents could choose one of five responses in the form of a Likert scale coded from 0 to 4; 'never' (score=0), 'seldom' (score=1), 'occasionally' (score=2), 'fairly often' (score=3), and 'often' (score=4). The scores for all 14 items were then summed to give a total OHIP score ranging from 0 to 56, with higher scores indicating poorer OHRQoL. Total OHIP-14 score represents the overall burden of oral problems. Two separate classifications were created during analysis: never/seldom/occasionally having problems (i.e., reporting never, seldom or occasionally

having problems in at least one of the 14 items) and frequent problems (i.e., fairly often, or often having problems in at least one of the 14 items).

Information on ethnicity, sex, age, socioeconomic factors (duration of education, household income), behavioural factors (regularity of dental visits, frequency of toothbrushing, smoking), and self-rated oral health was taken from the study questionnaire. Ethnicity was categorised based on questions about ethnic background, home language, and self-perceived ethnicity. Response options for these questions were ‘Norwegian’, ‘Sámi’, ‘Kven<sup>1</sup>’, and ‘other’. Participants included in the ‘Sámi’ group reported Sámi as their ethnic background and/or home language in addition to their perceived ethnicity. All other participants were placed in the ‘non-Sámi’ group, which consisted mainly of Norwegians, Kven (without Sámi affiliation, n=99), and Sámi without subjective Sámi criteria (n=165). Age was divided into four groups: 18-34, 35-49, 50-64 and 65-75 years. Duration of education was assessed by the question, “How many years of education do you have?”, and categorised as 1-9, 10-13, and  $\geq 14$  years. This classification was based on the education system in Norway with primary school (previously 6 years, today 7 years), secondary school (3 years), High school (3 years) and Higher education (University level). Regularity of dental visits was assessed with the question, “How often do you seek dental health services?” Response options were ‘regularly attend, ‘regularly book dental appointments’, ‘irregular use of dental health services’ and ‘attend only when having problems/pain’. In the analysis, these options were dichotomised into ‘regular’ and ‘irregular’. Frequency of toothbrushing was assessed with the question “How often do you brush your teeth?” Response options were ‘less than once daily’, ‘once per week’, ‘2-3 times per week’, ‘4-6 times per week’, ‘once daily’, and ‘twice daily or more’. In the analysis, these options were dichotomised into ‘once daily or

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<sup>1</sup> Kven: ethnic minority in Norway who emigrated from the northern part of Finland and Sweden to Northern Norway.

less often' and 'twice daily or more often'. Smoking was assessed with the question, "Do you smoke daily?"; response options were 'yes' and 'no'. Self-rated oral health was assessed with the question "How do you perceive your oral health?" Response options were on a four-grade scale from poor to very good; in the analyses, these data were grouped into 'poor' and 'good'.

### *Clinical dental examination*

Nine dentists and six dental hygienists across six PDS clinics performed clinical dental examinations. A five-grade diagnostic scale [30] was used for caries registration, clinically and radiographically. Caries grade 1-2 was classified as enamel caries and caries grade 3-5 as dentine caries. In this study, caries was defined as decayed teeth grade 3-5. PPD was measured at six sites per tooth with single-millimetre graduations. Third molars and implants were examined but excluded from the analysis. Periodontitis was defined as periodontal pocket depths (PPD)  $\geq 6$ mm.

Prior to the study, examiners attended a workshop on the diagnostic criteria and examination procedures on caries registration. Examiners were trained and calibrated in radiographic examination of caries and periodontal pocket probing by an experienced periodontist, but kappa values were not calculated. To ensure the reliability of caries registrations, a post-clinical inter-examiner agreement was estimated, and conducted as follows. One examiner was calibrated with a specially designed software (DIL version 1.21: University of Bergen, Norway) on two separate exercises, giving kappa values on 0.67 and 0.70. Then the examiner registered proximal and occlusal caries on premolars and molars on bitewings from all participants. These registrations were used as gold standard for the inter-examiner agreement analysis, giving kappa values for each examiner, ranging from 0.55- to 1.00, and mean kappa value for all examiners on 0.84. Details of the clinical dental examination have been described elsewhere (Brustad, 2018).



## **Statistical analysis**

The Statistical Package for Social Sciences (SPSS) for PC version 26 (IBM corporation, Armonk, NY, USA) was used to analyse the data. Internal consistency and reliability were assessed using Cronbach's alpha. Bivariate analysis was performed by cross tabulations and Pearson's chi-square statistical test. Individuals with more than two missing OHIP-14 items were excluded from the analysis. When two items or fewer were missing, they were replaced with the sample median of the relevant OHIP-14 item (Slade et al. 2005). Differences in mean OHIP-14 scores between groups were analysed with the Mann-Whitney U-test or Kruskal Wallis test. To determine the magnitude of the statistical differences in scores between ethnic groups, Cohen's d was used to calculate the effect sizes (ES) [31]. An ES of around 0.2 is considered as small, 0.5 as moderate, and 0.8 and greater as large.

Binary logistic regression analysis (odds ratio [OR] and 95% confidence interval [CI]) was used to explore associations between never/seldom/occasionally problems (reference group) and frequent problems in relation to ethnicity, sex, age group, regularity of dental visits, number of teeth, periodontitis, and caries. The model fit for the logistic regression models was assessed using Hosmer-Lemeshow and Nagelkerke test statistics. The level of significance for all statistical analysis were  $p < 0.05$ . Data were analysed using the IBM\*SPSS\*Statistics, version 26.

## **Results**

Of the 1913 included individuals, 1297 were classified as Sámi. The mean age of Sámi and non-Sámi participants was 46.4 years (standard deviation [SD]=14.5) and 48.7 years (SD=13.4), respectively. In all, 79.5 % of the participants reported oral health related problems during the last 12 months. The mean OHIP-14 score was 5.1 (SD 5.8) in the entire

study sample, 5.4 (SD 6.0) in Sámi, and 4.4 (SD 5.2) in non-Sámi ( $p < 0.05$ ; ES 0.17) Internal consistency for the OHIP-14, as measured by Cronbach's alpha, was 0.88 for all items of the instrument. Participants who were older, reported regular dental visits, had good self-rated oral health, more than 20 teeth, no caries, and no periodontitis had significantly lower mean OHIP-14 scores in both ethnic groups (all  $p < 0.05$ ) (Table 1). The distribution of individuals according to OHIP-14 score was positively skewed (range: 0 to 44) (Figure 1).

Among Sámi and non-Sámi participants, 11.6 % and 8.6 %, respectively had experienced problems fairly often or often on at least one of the 14 items. In both ethnic groups, significantly more people reported frequent problems if they were women, visited dental services irregularly, had fewer than 20 teeth, had periodontitis or reported poor self-rated oral health ( $p < 0.05$ ). In addition, among Sámi, those with caries ( $p > 0.05$ ) reported frequent problems (Table 1).

// Table 1 and Figure 1 about here //

The most frequently reported dimension among both ethnic groups was physical pain, followed by physical discomfort in Sámi and psychological discomfort in non-Sámi. Sámi reported having significantly more problems in the dimension of functional limitations, physical disability, social disability, and handicaps than non-Sámi (Table 2).

// Table 2 about here //

In the logistic regression analysis (Table 3), the adjusted odds of reporting frequent problems were associated with being female, younger age, irregular use of dental services, having fewer than 20 teeth, periodontitis and caries. Younger age was associated with reporting frequent

problems when adjusted for number of teeth, caries, and periodontitis. When adjusted for all variables in model 3, number of teeth was the variable strongest associated with frequent problems (OR 3.1; 95% CI 1.9-3.5).

// Table 3 about here //

## **Discussion**

This is the first epidemiological study to measure OHRQoL in the indigenous Sámi adult population living in rural areas of Northern Norway. The findings showed that the vast majority of participants reported having at least one problem that impacted their daily lives during the last 12 months, and one of ten reported experiencing frequent problems. There were no differences in proportion of Sámi and non-Sámi reporting frequent problems, but Sámi had a higher mean OHIP-14 score than non-Sámi. This may indicate that Sámi had poorer OHRQoL than non-Sámi in core Sámi areas. However, the small effect size indicates that differences between ethnic groups might not be noticeable from a clinical perspective, nor from the perspective of the individual participant. The mean OHIP-14 among Sámi was also higher than among adults (20-80 years) in a nationwide Norwegian study (OHIP-14=4.1, SD=6.2) [7], which may indicate poorer OHRQoL among Sámi than in the general Norwegian population.

Significantly more women reported frequent problems compared to men in both ethnic groups, but the mean OHIP-score among women was not significantly higher compared to men. As this is in line with previous studies [7,32], it was not surprising.

The self-reported predictor strongest related to poor OHRQoL was irregular use of dental services in both ethnic groups. A substantial proportion of participants in the present study were irregular seekers of dental care, including those who attended dental clinics only

when having problems, in addition to those who reported irregular use of dental services. The individuals not seeking dental care regularly had a significantly higher mean OHIP-14 score compared to regular users and had also a higher odds of reporting frequent problems. This findings are in line with another Norwegian study by Dahl et al. [7]. Irregular dental care may lead to poor oral health and thus to poorer OHRQoL. On the other hand, regular dental attendance provides the opportunity for prevention, early diagnosis, and prompt intervention [33].

Periodontitis and caries are common among Sámi adults in Northern Norway [20,21]. The findings from the present study showed an association between OHRQoL and periodontitis, where those participants with deep periodontal pockets had a higher mean OHIP-14 score and were more likely to report frequent problems than those without deep periodontal pockets. The impact of periodontitis on OHRQoL has been documented in previous studies [23,24,26,27,34], showing that individuals with severe periodontitis report poorer OHRQoL than those with a milder degree of disease, especially in relation to functional limitations and psychological discomfort. Caries has also been reported to have a negative impact on OHRQoL [28,35-37], but existing findings are contradictory [8,38]. In the present study, those with caries had a higher mean OHIP-14 score than those without caries in both ethnic groups. Additionally, in the Sámi group, significantly higher proportion of individuals with caries reported frequent problems compared with those without caries.

The most frequently reported OHIP-14 dimension in the present study was ‘physical pain’, including pain in the mouth and discomfort when eating due to problems with the teeth, mouth, or denture, which agrees with previous studies [7,28]. This finding is not surprising, as around one in five participants in the present study had periodontitis, and almost half of all participants had untreated caries. Both caries and periodontitis trigger the loss of teeth and may have pain-related impacts, limitations, and disabilities [28,39,40]. The results of this

study highlight the importance of disease prevention and treatment to avoid negative impacts on quality of life.

Comparing the finding on OHRQoL among indigenous Sámi in the present study with findings in other indigenous populations shows that mean OHIP-14 is lower among Sámi compared to indigenous Australians [7], with an overall mean OHIP-14 of 15.0. Contradictory to our findings, the Australian study found that young participants had a lower mean OHIP-14 than older ones (13.2 and 16.8, respectively). There are few studies comparing ethnic groups from same area, but a study from Tanzania [41] found that indigenous Maasai had better OHRQoL compared to non-Maasai from the same area. Although OHRQoL differs across indigenous groups and ethnic groups, the risk factors associated with impaired OHRQoL seem comparable. Based on previous results, socioeconomic factors, use of dental services, dental self-care factors, and oral health seem to be the strongest predictors of poor OHRQoL among indigenous people [41-44].

A strength of the present study was the high response rate both among Sámi and non-Sámi participants, which supplied us with valid data regarding OHRQoL in both ethnic groups. A weakness was that the participants were not randomly selected, which may have affected the external validity, since those in the population who do not seek dental care regularly might be underrepresented. Another limitation may be that the instrument (OHIP-14 questionnaire) was not validated in Norwegian or Sámi language and to the culture and lifestyle in the target populations, which may affect the validity, reliability, and responsiveness of the instrument. However, the questionnaire used in the present study has been used in other Norwegian studies on OHRQoL [7-10]. The OHIP-14 was translated from Norwegian to the Sámi language, but few participants (10%) used the Sámi version. Sámi participants had an opportunity to ask questions if they found anything to be unclear, or if

there was something they did not understand in the questionnaire, as more than half of those who worked at public dental clinics spoke Sámi [29].

How individuals perceive their oral health could be affected by the context in which they find themselves when responding to the OHIP-14, in addition to their expectations. Health and disease are two independent conditions; disease does not always affect how persons perceive their health, as poor health is not always linked to disease [45]. Assessment of quality of life, as well as OHRQoL, depends on a subject's expectations and perceptions, which can differ with social, demographic, psychological, cultural, and other factors [6,45,46]. In future studies on OHRQoL among Sámi, cultural aspects (living conditions, familial influence on cultural habits, traditions, norms and religious practices) should be included in the questionnaire, as expectations and perceptions are closely related to people's relationships with their environment [47].

An important clinical implication of this study is that oral health promotion strategies aimed at reducing the prevalence of caries and periodontitis have the potential to contribute to better OHRQoL in the Sámi population. Policies to increase the use of public dental services may also contribute to the prevention of oral disease, and thereby improve OHRQoL.

## **Conclusion**

Sámi and non-Sámi populations in core Sámi areas in Northern Norway reported problems related to their teeth and mouth that impacted their daily lives, where a substantial proportion of adults reported frequent problems. Overall perceptions of OHRQoL were associated with female gender, age, dental care, along with number of teeth, and the presence of periodontitis or caries.

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Table 1. Number of individuals, mean OHIP-14 sum score and frequency of individuals reporting frequent problems (problems fairly often or often)

Characteristics	Number n (%)		OHIP-14 score Mean (SD)		Frequent problems n (%)	
	Sámi	Non-Sámi	Sámi	Non-Sámi	Sámi	Non-Sámi
Total	1297	616	5.4 (6.0)	4.4 (5.2) <sup>d</sup>	150 (11.6)	53 (8.6)
Sex						
Female	755 (58.2)	334 (54.2)	5.5 (6.1)	4.5 (5.4) <sup>d</sup>	100 (13.2)	35 (10.5)
Male	542 (41.8)	282 (45.8)	5.3 (5.9)	4.2 (5.0) <sup>d</sup>	50 (9.2) <sup>a</sup>	18 (6.4) <sup>a</sup>
Age (years)	1297	616				
18-34	297 (22.9)	97 (15.7) <sup>b</sup>	5.7 (5.4)	5.1 (6.3)	34 (11.4)	11 (11.3)
35-49	417 (32.1)	223 (36.2)	5.4 (6.0)	4.8 (5.2)	54 (12.9)	19 (8.5)
50-64	443 (34.2)	213 (34.6)	5.4 (6.3)	3.7 (4.6)	48 (10.8)	15 (7.0)
65-75	140 (10.8)	83 (13.5)	4.9 (6.3) <sup>c</sup>	4.3 (5.1)	14 (10.0)	8 (9.6)
Education (years)	1247	607				
1-9	148 (11.9)	53 (8.7) <sup>b</sup>	5.8 (7.0)	6.4 (7.3)	17 (11.5)	8 (15.1)
10-13	440 (35.3) <sup>b</sup>	287 (47.3)	5.6 (6.2)	4.2 (5.3) <sup>d</sup>	47 (10.7)	24 (8.4)
≥14	659 (52.8)	267 (44.0) <sup>b</sup>	5.2 (5.6)	4.3 (4.7) <sup>d</sup>	79 (12.0)	21 (7.9)
Dental attendance	1290	613				
Regular	960 (74.4)	485 (79.1)	4.7 (5.5) <sup>c</sup>	3.8 (4.5) <sup>c, d</sup>	85 (8.9) <sup>a</sup>	30 (6.2) <sup>a</sup>
Irregular	330 (25.6)	128 (20.9)	8.2 (7.5)	7.1 (7.3)	63 (19.1)	23 (18.0)
Number of teeth	1297	616				
1-19	92 (7.1)	46 (7.5)	8.4 (8.6)	7.5 (8.3)	21 (22.8)	8 (17.4)
≥20	1205 (92.9)	570 (92.5)	5.2 (5.7) <sup>c</sup>	4.1 (4.8) <sup>c, d</sup>	129 (10.7) <sup>a</sup>	45 (7.9) <sup>a</sup>
Caries (DT≥1)	1297	616				
No	718 (55.4)	299 (48.5)	4.7 (5.5) <sup>c</sup>	3.6 (4.6) <sup>c, d</sup>	69 (9.6) <sup>a</sup>	20 (6.7)
Yes	579 (44.6) <sup>b</sup>	317 (51.5)	6.2 (6.5)	5.1 (5.6) <sup>d</sup>	81 (14.0)	33 (10.4)
Periodontitis (PPD≥6 mm)	1297	616				
No	1061 (81.8)	525 (85.3)	5.1 (5.7) <sup>c</sup>	4.1 (4.9) <sup>c, d</sup>	109 (10.3) <sup>a</sup>	40 (7.6) <sup>a</sup>
Yes	236 (18.2)	91 (14.7)	6.6 (7.0)	6.0 (6.6)	41 (17.4)	13 (14.3)
Self-rated oral health	1272	603				
Good	832 (65.4)	409 (67.8)	3.7 (7.6) <sup>c</sup>	3.0 (3.7) <sup>c, d</sup>	47 (5.6) <sup>b</sup>	18 (4.4) <sup>b</sup>
Poor	440 (34.6)	194 (32.2)	8.7 (8.6)	7.3 (6.7) <sup>d</sup>	102 (23.2)	35 (18.0)

Abbreviations: SD= Standard Deviation; DT= Decayed teeth (grade 3–5); PPD: Periodontal pocket depth

<sup>a</sup> P<0.05;  $\chi^2$  test for differences within Sámi or Non-Sámi

<sup>b</sup> P<0.05;  $\chi^2$  test for differences between Sámi or Non-Sámi

<sup>c</sup> P<0.05; Mann-Whitney U-test or Kruskal Wallis test for differences within Sámi or Non-Sámi

<sup>d</sup> P<0.05; Mann-Whitney U-test for differences between Sámi or Non-Sámi

Table 2. Proportion of adults reporting problems related to oral health in the preceding 12 months.

OHIP-14 Dimensions	Items	Never problems (%)		Fairly often/Often problems (%)	
		Sámi n=1297	Non-Sámi n=616	Sámi n=1297	Non-Sámi n=616
<b>FUNCTIONAL LIMITATIONS</b>	Pronouncing words	87.0	91.4 <sup>a</sup>	1.2	0.6
	Sense of taste	80.8	86.9 <sup>a</sup>	1.0	0.6
<b>PHYSICAL PAIN</b>	Pain	46.8	51.3	4.4	4.1
	Uncomfortable to eat	52.8	54.5	3.2	3.6
<b>PSYCHOLOGICAL DISCOMFORT</b>	Self-conscious	62.8	65.4	3.3	2.3
	Felt tense	70.6	74.4 <sup>a</sup>	2.4	0.8 <sup>a</sup>
<b>PHYSICAL DISABILITY</b>	Unsatisfactory diet	59.0	65.6 <sup>a</sup>	1.6	1.1
	Interrupting meals	82.8	88.5 <sup>a</sup>	0.7	0.3
<b>PSYCHOLOGICAL DISABILITY</b>	Difficult to relax	72.8	78.0 <sup>a</sup>	1.9	0.5 <sup>a</sup>
	Embarrassed	70.0	73.7	2.4	1.8
<b>SOCIAL DISABILITY</b>	Irritable	85.2	88.6 <sup>a</sup>	0.5	0.3
	Difficulty doing job	85.8	90.1 <sup>a</sup>	0.5	0.5
<b>HANDICAPS</b>	Life less satisfying	84.3	87.8 <sup>a</sup>	0.8	0.5
	Unable to function	89.5	93.5 <sup>a</sup>	0.4	0.2

<sup>a</sup>P<0.05;  $\chi^2$  test for differences between Sámi and Norwegian on each item.

Table 3. Logistic regression for the association between reporting frequent problems and demographic, behavioural, and clinical characteristics.

Variables	Frequent problems <sup>a</sup>		
	Model 1 <sup>b</sup> OR (95% CI) n=1913	Model 2 <sup>c</sup> OR (95% CI) n=1903	Model 3 <sup>d</sup> OR (95% CI) n=1903
Ethnicity			
Sámi	1.3 (0.9-1.8)	1.3 (0.9-1.8)	1.3 (0.9-1.8)
Non-Sámi	1	1	1
Sex			
Women	1.5 (1.1-2.1)	1.6 (1.2-2.4)	1.8 (1.3-2.5)
Men	1	1	1
Age groups (years)			
18-34	1.1 (0.6-1.9)	1.0 (0.6-1.9)	2.3 (1.2-4.5)
35-49	1.1 (0.7-1.9)	1.2 (0.7-2.0)	2.3 (1.2-4.4)
50-64	0.9 (0.6-1.6)	1.0 (0.6-1.8)	1.7 (0.9-3.0)
65-75	1	1	1
Regularity of dental visits			
Irregular		2.7 (1.9-3.7)	2.5 (1.9-3.5)
Regular		1	1
Number of teeth			
1-19			3.1 (1.9-3.5)
≥20			1
Periodontitis (PPD≥6 mm)			
Yes			2.2 (1.5-3.1)
No			1
Caries (DT≥1)			
Yes			1.4 (1.0-1.8)
No			1

<sup>a</sup> Frequent problem: reporting fairly often, or often having problems in at least one of the OHIP-14 items, never/seldom/occasionally problems used as reference group.

<sup>b</sup> Adjusted for ethnicity, sex, and age

<sup>c</sup> Adjusted for ethnicity, sex, age and regularity of dental visits.

<sup>d</sup> Adjusted for ethnicity, sex, age, regularity of dental visits, number of teeth, periodontitis, and caries.

