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# *Coeliac disease – what do dental health personnel know?*

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## Abstract

**Introduction:** This master thesis investigates the knowledge which dental health personnel possesses regarding the correlation between coeliac disease and oral health, and the factors that may influence this knowledge.

**Material and methods:** A questionnaire have been sent out to all dentists and dental hygienists employed in the public dental service in Nordland and Troms. One hundred and forty-three answered the questionnaire, giving a response rate of 58 percent. The respondents were divided into three groups according to the result of the questionnaire, a “high score” group, a “middle score” group and a “low score” group. The “high score” and the “low score” groups, a total of 59 participants, were included in the final analysis.

**Results:** Dental health personnel reported in this study that they do not have enough information regarding the correlation between coeliac disease and oral health. The results indicate that several information sources are beneficial for increased knowledge.

**Keywords:** Coeliac disease, oral health, dental enamel defects, dental personnel.



*Figure 1: Grooves in teeth from dental enamel defects in a child with coeliac disease(1)*

## **1. Introduction**

Until recently, coeliac disease has been considered a rare condition. However, unlike earlier beliefs, coeliac disease is relatively common, with many patients going undiagnosed due to atypical symptoms of the condition. Coeliac disease is one of the most frequent conditions due to food intolerance, and it has been estimated that the prevalence in the general population of Western Europe and North America is close to one percent (2-4). During the last decade, new knowledge has been obtained in the understanding of coeliac disease and its various, wide, and often unsuspected, range of clinical presentations. This wide range of clinical manifestations include several oral manifestations like dental enamel defects, recurrent aphthous stomatitis, and low salivary flow/xerostomia (3).

Coeliac disease is an autoimmune, chronic, and inflammatory disease, which attacks the small intestine through an immunological response to ingested gluten (3). The disease can also be defined as gluten-sensitive enteropathy to the gluten contained in wheat, rye and barley, causing an immune reaction against the individuals' small intestine cells. This results in an atrophy of the villi in the duodenum and the proximal jejunum causing a destruction, and a reduction of the surface of the intestine. This atrophy leads to malabsorption of nutrients and deficiency of several important substances such as iron, folate and vitamin B12. In cases with coeliac disease, a biopsy will confirm atrophic villi in the small intestine (3, 4).

The classic symptoms of coeliac disease is chronic diarrhoea, tiredness, abdominal distension/bloating and pain, vomiting, weight loss, and muscle weakness (4). Lack of iron may lead to anaemia, and lack of other nutrients may cause conditions such as hypocalcaemia, tetany, osteoporosis, peripheral neuropathy and infertility. If not being diagnosed, and treated, coeliac disease may be associated with malignancy, such as neoplasm in the gastrointestinal tract (4).

Coeliac disease is diagnosed by blood sample and a biopsy of the small intestine after a period of provocation with food that contains gluten. Patients with coeliac disease have high occurrence of immunoglobulin A and G antibodies (IgA and IgG) in the blood. IgA and IgG antibodies have a high specificity of the disease, but it is first after a positive outcome of a biopsy, confirming atrophic villi of the intestine, that the definitive diagnosis will be

confirmed. In Norway, a biopsy is required to qualify for financial support from NAV (Norwegian Labour and Welfare Service). NAV gives financial support to persons with confirmed coeliac disease due to a more expensive diet. Until recently, this support was 1999 NOK per month. But the government has reduced it to 1047 NOK per month for persons older than 30 years old. For persons from 5 to 30 years old the support is 1372 NOK per month. (5-7)

Coeliac disease is a chronic and life-long disease. The treatment is gluten-free diet that will lead to disappearance of the increased level of IgG and IgA antibodies, and that the villi in the small intestine will regenerate after a period without provocation by gluten. However, the antibodies and the atrophic villi of the intestine will return in case of provocation by gluten in the diet. If this illness appears in young children, during period of permanent tooth development and enamel mineralisation, structural abnormalities in the enamel may occur. This is due to the fact that the permanent teeth are developing (8). Studies have found correlations between coeliac disease and dental enamel defects, recurrent aphthous stomatitis and low salivary flow/xerostomia. Dental enamel defects may be caused by several genetic and/or environmental factors affecting the formation of the hard tissue of the teeth. These factors will cause quantitative or qualitative dental enamel defects during enamel matrix deposition and/or calcification/mineralisation. Quantitative defects is the result of disturbances in matrix secretion that leads to enamel hypoplasia. Qualitative defects appears as enamel opacities/hypomineralizations and are caused by lack of, or disruption of the incorporation of minerals during the calcification phase of enamel formation (4). Dental enamel defects are graded I to IV according to Aine's classification (3). Grade I is defects in enamel colour, grade II is slight structural defects, and grade III is evident structural defects. Grade IV shows severe structural defects. The Aine classification may be presented as five groups, since grade 0 can be classified as no enamel defects (3).

Several studies have found significant correlation between coeliac disease and dental enamel defects (2-4, 9-12). The ethology between dental enamel defects and coeliac disease remains unclear. However, it has been proposed that the defects are due either to hypocalcaemia or to a specific genetic condition, which causes an immune response to gluten (4, 9).

Hypocalcaemia from malabsorption in the intestine could lead to low serum calcium concentration during the time of enamel formation. On the other hand, no significant difference in mean values of serum calcium concentration is shown between children having

coeliac disease, and diagnosed with or without enamel defects (4). Therefore, it is implied that malabsorption may not be the sole cause of dental enamel defects, even though hypocalcaemia from malabsorption could be a contributing factor in inducing defects in enamel formation (9). Another hypothesis is that immunological and genetic factors could cause the developmental enamel defects. Consistently to this hypothesis, a specific antigen, human leukocyte antigen (HLA) alleles DR3 and DQ2, has strong association with dental enamel defects in patients with coeliac disease (9).

Recurrent aphthous stomatitis (RAS) is a common oral mucosal disease affecting five to 60 percent of the normal population, depending on the group studied (9). RAS is characterized by recurrent attacks of solitary or multiple shallow, painful, and discrete ulcers on the unattached mucous membranes. The ulcers are round or ovoid and have erythematous halos surrounding a grey or yellow base. RAS comes at intervals of a few months to a few days in patients that are otherwise healthy (9). The aetiology of RAS is unknown, although genetic, immunological or microbial factors is thought to play a role in the occurrence. In addition, vitamin- and trace element deficiencies, stress, allergies, trauma, hormonal imbalance, infections, food intake, and specific drugs influence the occurrence of RAS. Vitamin- and trace element deficiencies in this aspect is iron, folate and vitamin B12 deficiencies. A possible explanation, to the correlation between coeliac disease and RAS, is that oral aphthae in coeliac disease patients could be related to hematic deficiencies (iron, folic acid or vitamin B12). The serum levels of iron, folic acid and vitamin B12 are usually low in patients with untreated coeliac disease and about 20 percent of the patients with RAS could have hematinic deficiencies (9).

Studies shows mixed results regarding the correlation between coeliac disease and RAS. Three studies find significant correlation (2-4), one study find no significant correlation (10), and one study presents conflicting results (9).

It is assumed that immunological and genetic factors could be involved in the aetiology for RAS in patients with coeliac disease. Occurrence of HLA-antigens DRw10 and DQx1 were significant higher in patients with coeliac disease and RAS, compared to patients with coeliac disease only (9).

Xerostomia is a symptom usually caused by low salivary flow or reduction in the quality of

the saliva. One study shows significant correlation between coeliac disease and reduction in salivary flow (3). Another study shows that in a group of individuals with coeliac disease, less individuals have normal salivary flow compared to a control-group (4).

Interesting correlations in regards to coeliac disease and oral health are found in earlier reported studies. Dental enamel defects has the strongest evidence of correlation with coeliac disease. RAS and xerostomia have also shown correlations, however the evidence is not as strong as between the correlation of dental enamel defects and coeliac disease.

Little is known about how much, and what, dental personnel know about the connection between coeliac disease and oral health. This master thesis will focus on the current knowledge of dental personnel and the possible need for awareness regarding this connection.

The aim of this master thesis is to illuminate the level of knowledge that dentists and dental hygienist possesses about the correlation between coeliac disease and oral health. This will highlight a possible need for further education regarding this connection.



## **2. Material and Methods**

### **Method**

A literature search about the present topic gave, after source criticism, seven scientific articles. These articles were used as background knowledge for this master thesis. Search items in Pubmed were “dental health” or “oral health” together with “celiac disease”, “celiak disease”, “coeliac disease” or “coeliaki”.

It was decided to focus on dental enamel defects in the questionnaire and further in the master thesis. This is because of stronger evidence for dental enamel defects being related to coeliac disease than for recurrent aphthous stomatitis and xerostomia, and as well as in order to narrow the thesis.

A quantitative research method and approach was used in order to investigate dentists and dental hygienists knowledge about coeliac disease, and its effect on oral health. There is little information about the knowledge dentists and dental hygienist possesses, and a larger group of respondents was preferable. A questionnaire was therefore distributed to all general dentist and dental hygienist in Nordland and Troms. This became a group consisting of a total of 172 dentists and 77 dental hygienists. All were employed within Public Dental Service (PDS) in Nordland and Troms county. Specialists, general dentists, and dental hygienists employed at the university clinic were excluded.

The questionnaire was a three-part questionnaire with twenty questions; the first part collected background information about the participants. The second part was a self-reporting questionnaire with questions about the participants experience concerning patients with coeliac disease. The third and last part contained multiple-choice questions about coeliac disease and oral health. The entire questionnaire can be reviewed in appendix two.

The questionnaire was pilot-tested on three test subjects, two dental hygienists and one dentist, in order to make sure that the online service “Nettskjema” was properly functioning. UiT the Arctic university of Norway has a user agreement in regard to “Nettskjema” with the

university in Oslo. This was also a test to see if the questions were relevant and understandable.

In addition, emails were sent to the top governing chiefs (Fylkestannlege) of the public dental health service (PDS) in both counties, Nordland and Troms. The email was a request for their approval to contact the dentists and dental hygienists employed in PDS in their respective counties. Both of them had the opportunity to review the questionnaire before they gave their approval. They both approved the distribution and provided a list with email addresses to the dentists and dental hygienists in their respective counties.

The questionnaires were distributed to the 246 informants email addresses (172 dentists and 77 dental hygienists) by using the online service “Nettskjema”. The questionnaires were sent to the personal work email of each participant. However, when the participants submitted their answer the online service anonymized them. Hence, it was not possible to identify which participants had responded or which answer belonged to a specific participant. By answering the questionnaire, the participants gave their consent for the data to be collected and used in the study.

All the participants received an email with information about the study and what the data would be used for. They were all given the opportunity to withdraw their consent if they were worried that they could be identified in the data set.

An email was also sent to the main email address of each of the dental clinics in the respective county. This was done because the emails, containing the questionnaires, could end up in the trash-filter of the email-service that the participants used, an experience that one of the test subjects had.

Since the questionnaires were sent directly to the respondent’s personal work email, and some background information could be used to indirectly identify the participants, an application was sent to Norwegian Centre for Research Data (NSD) for an approval of the questionnaire. It was approved with some minor changes of the initial research proposal (Appendix one). None of the questions were considered inappropriate.

After the data was gathered the material was split into three groups based on the result from the third part of the questionnaire, the multiple-choice part. In this part there were eight questions and each question was given a score of one or zero, based on whether or not the answer was correct. The highest possible score was eight and the lowest possible score was zero, giving a total of nine possible scores. The scores were divided into three equal groups; the “high score”, the “middle score” and the “low score” group. The “high score” group ranged from eight to six, the “middle score” group from five to three and the “low score” group from two to zero. Then the score of each participant was summed together and put into one of the three groups. The final analysis focused on the difference between the “high score” and “low score” groups. The reason for the removal of the “middle score” group from the main analysis is clarified in the discussion. The percentages in the tables are rounded off to the closest whole percentage, and the total may therefore deviate from one hundred percent. Some participants were removed from the selection because one or more of their answers were unclear. The answers were considered ‘unclear’ when there was more than one multiple-choice answer given and only one answer was correct.

Prior to the removal of the unclear answers the “high score” group consisted of 37 participants and the “low score” group consisted of 25 participants. The final number of participants in each group are shown in the results part.

## **Material**

Questionnaires regarding professional background and knowledge about coeliac disease were sent to 246 dentists and dental hygienists in the counties of Nordland and Troms in northern Norway. All replies to the questionnaire were anonymous. The questionnaires were sent out 14.03.18 and dead-line for the study was 30.08.18. One person replied as not being clinically active and did not want to participate in the study.

The first email with the questionnaire yielded 59 answers, a response of 24 percent. Following a first reminder, another 21 answers were received (a total of 80 answers and 33 percent) and by late august 2018, about six months after the initial email, 143 answers in total were received (58 percent).

A question regarding gender was excluded from the questionnaire. It would have been possible to find out which participants had answered the questionnaire, as there are few male dental hygienists in both counties.

### 3. Results

The “middle score” group consisted of 81 participants with a similar average age and covering a similar age range as the two other groups. The average years of clinical experience in the “middle score” group was shorter than in the “high score” and “low score” group. The portions of dentist and dental hygienist was similar to the other groups.

The difference between the “high score” and “low score” groups in regards to the achieved results of part one and part two of the questionnaire, as well as of question twenty, was analysed in view of the participants educational background, current work place and profession.

The “high score” group consisted of 36 participants. The “low score” group consisted of 23 participants. The average age of the participants in the “high score” group was 40 years, and in the “low score” group 44. The average number of years since they finished their education was 15 in the “high score” group and 19 in the “low score” group.

The largest difference between the two groups, considering education, was the percentage of participants educated abroad. As shown in **Table 1**, twice as many in the “low score” group (30 percent) as in the “high score” group (14 percent) were educated abroad. Twice as many in the “high score” group (19 percent) as in the “low score” group (9 percent) were educated in Oslo. The difference between the groups in regard to other places of education was less, see **Table 1**

<b>Table 1. Place of education</b>	<b>High:</b>	<b>Low:</b>
Oslo:	19 %	9 %
Bergen/Elverum/Tromsø:	67 %	61 %
Abroad:	14 %	30 %
This table shows where the participants had their undergraduate dental education.		

There was no significant difference between the groups regarding occupation; with dentists making 67 percent of the “high score” group and 70 percent in the “low score” group, and

dental hygienists making 33 percent in the “high score” group and 30 percent in the “low score” group (**Table 2**).

<b>Table 2. Occupation</b>	<b>High:</b>	<b>Low:</b>
Dentist:	67 %	70 %
Dental hygienist:	33 %	30 %
This table shows how large a portion that dentist and dental hygienists makes of the groups.		

However, there was a difference between the groups when it came to where the respective participants were working. Nordland counted for 72 percent of the participants in the “high score” group and 57 percent of the “low score” group, and Troms for 28 percent of the “high score” group and 43 percent of the “low score” group (**Table 3**).

<b>Table 3. County</b>	<b>High:</b>	<b>Low:</b>
Troms:	28 %	43 %
Nordland:	72 %	57 %
This table shows the percentage representation of the two counties in the “high score” and “low score” groups.		

**Table 4** and **Table 5** showed a difference between the two groups when considering where, and from how many sources, the participants gathered information about coeliac disease. The participants had the possibility to mention one or several sources in the questionnaire. The right part of the table shows how many of the participants in total named one or more source. The middle part of the table shows the percentage of the participants that named more than one source. The left part of the table shows the percentage of the participants that named only one source. The category “Other” (“Annet”) was any source the participants had used, and which did not fit any of the outlined categories.

Table 4. "Low score" group						
	Only one source		More than one source		Total	
	Number	Percent	Number	Percent	Number in "low score" group	Percent
	20	87 %	3	13 %	23	100 %
Sources of knowledge						
Undergraduate education/Grunnutdanning:	5	22 %	2	9 %		30 %
Courses/ Kurs:	0	0 %	1	4 %		4 %
Clinical experience/Klinisk erfaring:	7	30 %	2	9 %		39 %
Further education/Videreutdanning:	0	0 %	0	0 %		0 %
Other/Annet:	8	35 %	2	9 %		43 %
This table shows the sources of knowledge in the "low score" group. The percentages are calculated in regards to the "low score" group.						

Table 5. "High score" group						
	Only one source		More than one source		Total	
	Number	Percent	Number	Percent	Number in "high score" group	Percent
	16	44 %	20	56 %	36	100 %
Sources of knowledge						
Undergraduate education/Grunnutdanning:	9	25 %	14	39 %		64 %
Courses/ Kurs:	0	0 %	7	19 %		19 %
Clinical experience/Klinisk erfaring:	1	3 %	10	28 %		31 %
Further education/Videreutdanning:	1	3 %	2	6 %		8 %
Other/Annet:	5	14 %	13	36 %		50 %
This table shows the sources of knowledge in the "high score" group. The percentages are calculated in regards to the "high score" group.						

Twenty five percent of the participants in the "high score" group thought their undergraduate education gave them sufficient knowledge, while 18 percent of the "low score" group thought the same. In the "high score" group 39 percent thought they had sufficient knowledge with 17 percent from the "low score" group feeling the same way. The results are shown in **Table 6** and **Table 7**.

<b>Table 6. Primary education</b> <b>Statement: The undergraduate education gave me sufficient knowledge about coeliac disease and oral health</b>	<b>High:</b>		<b>Low:</b>	
Agreed/Enig:	6 %	25 %	9 %	18 %
Partly agreed/Delvis enig:	19 %		9 %	
Partly disagreed/Delvis uenig:	39 %	75 %	22 %	83 %
Disagreed/Uenig	36 %		61 %	
This table shows the portion of the participants that agreed or disagreed with the statement "The primary education gave me enough information about coeliac disease".				

<b>Table 7. Level of knowledge</b> <b>Statement: I have enough knowledge regarding coeliac disease and oral health.</b>	<b>High:</b>		<b>Low:</b>	
Agreed/Enig:	11 %	39 %	4 %	17 %
Partly agreed/Delvis enig:	28 %		13 %	
Partly disagreed/Delvis uenig:	44 %	61 %	39 %	82 %
Disagreed/Uenig	17 %		43 %	
This table shows the portion of the participants who agreed or disagreed with the statement that they had had enough knowledge about the connection between coeliac disease and oral health issues.				

As shown in **Table 8** a similar portion of both groups thought that the number of patients with the diagnose coeliac disease had increased over the last five years. None of the groups believed that the number had decreased. Twice as many in the "high score" group as in the "low score" group thought that the number was unchanged. Nearly twice as many in the "low score" group as in the "high score" group could not tell if there had been any change.

<b>Table 8. Change in number of patients</b>	<b>High:</b>	<b>Low:</b>
Increased/Flere:	19 %	17 %
No change/Uendret:	46 %	22 %
Decreased/Færre:	0 %	0 %
Do not know/Vet ikke:	35 %	61 %
This table shows the participants answers when asked if they had seen a change in the number of patients with coeliac disease over the last five years.		

In **Table 9** it is shown that almost twice as many in the "low score" group (57 percent) as in the "high score" group (33 percent) did not know how many of their patients that had coeliac disease.



When asked about the approximate number of patients with coeliac disease 47 percent of the “high score” group and 39 percent of the “low score” group estimated a number between zero and ten, while three and four percent of the “high score” and “low score” groups respectively estimated 11 to 20 patients. None of the members in the “low score” group had more than 20 patients, while 17 percent of the “high score” group had over 20 patients.

<b>Table 9. Approximate number of patients with coeliac disease:</b>	<b>High:</b>	<b>Low:</b>
0 – 10:	47 %	39 %
11 – 20:	3 %	4 %
More than 20:	17 %	0 %
Do not know:	33 %	57 %
This table shows the percentage of participant and the approximate number of patients with coeliac disease		

In regard to what sort of welfare support (“Trygderefusjoner”) patients with coeliac disease are entitled to, the participants answered as shown in **Table 10**. A considerably higher percentage of the members in the “high score” group knew what sort of welfare support these patients are entitled to, as well as where to find the outlined rules. A larger portion of the members of the “low score” group did not know this or were unsure (**Table 10**).

<b>Table 10. Knowledge about welfare support (“Trygderefusjoner”)</b>	<b>High:</b>	<b>Low:</b>
Yes/Ja:	25 %	4 %
No/Nei:	11 %	39 %
Know where I can find this information/ Vet hvor jeg finner det:	47 %	26 %
Unsure/Usikker:	17 %	30 %
This table shows the percentage of the participant answers when asked if they knew what sort of welfare support (“Trygderefusjoner”) patients with coeliac disease are entitled to.		

When asked if the participants consider coeliac disease as possible aetiology when they discover hypomineralizations of the enamel, 58 percent of the “high score” and 26 percent of the “low score” group said *yes*, 42 percent and 74 percent of the respective groups, said *no* (**Table 11**).

<b>Table 11. Is coeliac disease a possible aetiology for enamel defects</b>	<b>High:</b>	<b>Low:</b>
Yes:	58 %	26 %
No:	42 %	74 %
This table shows the percentage of participants who consider coeliac disease as a possible aetiology for hypomineralizations of the enamel		

## 4. Discussion

The results indicated that some of the dentists and dental hygienists have little knowledge about the correlation between coeliac disease and oral health. Also, the participants said that they felt that they did not have enough knowledge about this correlation.

There are few scientific studies available on this topic, investigating dental personnel's knowledge of the correlation between coeliac disease and oral health issues. This makes it difficult to compare this thesis with any earlier studies. The ambition was to illuminate the level of knowledge about coeliac disease and oral health. The attention regarding coeliac disease has increased over the last years, and the question was how much dental personnel knew about the disease in relation to its possible effects on oral health. There is an increase in the number of individuals diagnosed with coeliac disease (13) which means that knowledge regarding this subject is increasingly important. *"If Norway has the same prevalence as Sweden and Finland, at least 35 000 people are living [in Norway, authors remark] with undiagnosed coeliac disease."* (13). This could mean that dental health personnel, who possess knowledge of the symptoms of coeliac disease, would be able to inform patients that they may have this diagnose and recommend a contact with a general practitioner for further diagnosis and help. Since the correlation between coeliac disease and oral health is not well illuminated, and as there are few articles considering this correlation, there is a need for systematic reviews and further research on this topic. It would be highly appreciated if the scientific community would continue research on this subject.

Coeliac disease has many possible symptoms and the symptoms may vary between patients. Since the symptoms are variable, and sometimes atypical, it is difficult for dental personnel to know when, or if, they should refer a patient to a general practitioner for a possible coeliac disease investigation.

The questionnaire, and this master thesis, focused on dental enamel defects as they have the strongest correlation to coeliac disease, when considering all of the oral manifestations (2-4, 9-12). Furthermore, dental enamel defects are visible, and in many instances' clear clinical symptoms. If the topic for this master thesis would be subject of further studies, it would be beneficial to incorporate other well correlated symptoms to get a broader view of the subject. Even though there is a strong association between dental enamel defects and coeliac disease, dental enamel defects are common (14) and it is many times difficult to be certain of the aetiology behind a specific defect. A thorough anamnesis during the dental examination is of importance in order to find a potential cause of dental enamel defects.

Friends and family with coeliac disease were available, and willing to answer questions about their own experience of coeliac disease. In addition, they shared their experience on how they have been met by dental health professionals, in relation to the possible problems regarding their own diagnose of coeliac disease. This gave inspiration to write this master thesis and to find out more about the level of knowledge that dental personnel have about coeliac disease and oral health. In order to get a view of the dental health service patients with coeliac disease have experienced, individuals with coeliac disease were contacted and asked a few questions. The participants of this information gathering were acquaintances of the authors of this thesis, and they are therefore not representative, nor is the service which they received from dental health professionals. This task was done only to illuminate issues, which people who do not have coeliac disease may overlook. Listening to the patient's view of how dental professionals responded when being faced with patients with coeliac disease, and the possible problems arising from this condition, has been a good learning base.

All the participants received the questionnaire twice, once before it was approved by Norwegian Centre for Research Data (NSD), and once after. This was due to a misunderstanding. NSD approved the project with no changes in the questionnaire, but with minor changes in the introduction and information letter to the participants. The possibility that someone has answered the questionnaire twice is highly unlikely. It was clearly specified in the second questionnaire that if they had answered the previous one, they should not answer the second one. However this might, of course, be a source of error for the results in this thesis.

The questions in the questionnaire are not ambiguous or leading. The different answer options in the multiple-choice part were close to the correct answer, but with slight variations in order to prevent the correct answer from being obvious. It was decided that one of the possible answers should be “*I don’t know*” preventing the participants from having twenty-five percent chance to get the right answer only by guessing. It was also decided that question number twenty, in regard to detection of enamel defects: “*Do you consider coeliac disease as a possible cause?*” - should be at the end of the questionnaire even though it is a part of the self-reporting form (part 2). This was done in order not to reveal the answers prior to the questions in the multiple-choice part (part 3), since question number twenty contains information about the correlation between coeliac disease and oral health.

The self-reporting part of the questionnaire was subjective. Meaning that the answers are based on whom the participants interact with and compare themselves with. This requires the participant to have a realistic view on their own knowledge. Question number ten (“*How many patients with coeliac disease have you had the last five years?*”) may have been difficult to answer since it may be difficult to remember how many patients, with a certain disease, one has had during the last five years.

In retrospect, it would have been appropriate to have had an additional question: “*Would you like to have more knowledge about coeliac disease and oral health?*” in the questionnaire. However, when participants answer that they have too little knowledge regarding the topic, it is assumable that they want more knowledge.

The multiple-choice test is also somewhat small, with only eight questions, and is therefore to a degree limited in its nuances. It is possible that more questions, especially with other symptoms than dental enamel defects, could have given other answers, and that the participants may have scored differently.

The study was pilot-tested on a total of three personnel from Nordland and Troms. This was three participants that had the opportunity to see the questionnaire prior to the main study, and this could have prepared them for the main study. However, the participants were not told by the questioner their score nor which answers were correct after completing the questioner. It would have been beneficial to have used dental health personnel from other counties in this pilot, or to have left these individuals out of the main study. An advantage in contacting

personnel in Nordland and Troms was to verify that “Nettskjema” worked properly with the respective counties email addresses. There is a possibility that this have affected the results. However this is unlikely since three individuals are only two percent of the total response, nor is it possible to know if the test-personnel participated in the main study.

After all the data were gathered it was decided to split the participants into three groups, according to their score on the multiple-choice questionnaire. If the dataset had been split into only two groups, the difference between the groups would have been less clear, increasing the risk of the two groups becoming too similar. It was therefor decided to split the dataset into three groups, giving a more distinct difference between the participants with high and those with low score. These three groups where named “high score”, “middle score” and “low score” groups. The final analysis was based on the difference between the “high score” and “low score” groups. The intent of this research was to see what dental health professionals knew about coeliac disease, its relevance to oral health, and what factors may affect the participant’s knowledge. Therefore, the analysis focused on the “high score” and “low score” groups, to illuminate the factors that might separate a clinician with a high degree of knowledge from a clinician with little knowledge. This information can be useful when investigating how to increase the general knowledge regarding coeliac disease among dental health personnel.

There is a difference in size between the two groups with 36 participants in the “high score” group and 23 in the “low score” group. This may have affected the results since a smaller group is more vulnerable for extreme values. Every participant in the “low score” group affects the results more than each of the participants in the “high score” group.

The groups cover a similar age range, with the “low score” from 24 to 75, and the “high score” from 26 to 69 years of age, and the average age of the participants is similar as well. There was a similarity in the clinical years of experience within both groups, having participants ranging from one year to the mid-forties, as well as the average years of experience also being similar in the two groups.

With these results, it seems as the age of the participants and the clinical years of experience is of less importance when it comes to the knowledge they possess. The results show a similar relationship between the possessed knowledge and their professions – dentist or dental

hygienist. With only three percent difference between the two professions (dentist and dental hygienist) there is no data to suggest that either of the professions have more knowledge than the other.

Nordland is represented to a higher degree in the “high score” group. Why this is, is however not clear. It might be possible that the two counties have a different awareness regarding coeliac disease, although this has not been documented. Nordland might in general have had a higher focus on coeliac disease than Troms, or it may be that the personnel in Nordland just happened to have more personal knowledge regarding coeliac disease.

A higher percentage (30 percent) of the “low score” group are educated outside Norway, in comparison to 14 percent in the “high score” group. There is a possibility that Norwegian faculties have focused more on coeliac disease and its impact on oral health, with the Oslo faculty standing out in regard to the difference between the two groups (**Table 1**). Norwegian faculties might have a better program for teaching students about coeliac disease, compared to universities abroad. It would be interesting to investigate why the Oslo faculty seems to give their students a better knowledge about coeliac disease, and if possible incorporate their experiences into the other faculties/universities teaching programme.

It seems as many of the participants in the “high score” group gathered their information from several sources while a larger portion of the “low score” group relied on single sources of information. In the “high score” group the most used source of information was the undergraduate education with 39 percent of the participants giving this as one of several sources, while 25 percent gave this as their only source. In the “low score” group nine percent gave undergraduate education as one of several sources and 22 percent gave it as the only source. This shows that in the “high score” group, the percentage that reported the undergraduate education as one of several sources is four times higher than in the “low score” group. While the percentage that reported undergraduate education as the only source is about the same in the both groups. The same is seen with the rest of the information sources. A possible reason why some participants did not answer “undergraduate education” as a source, is that they did not consider their knowledge about coeliac disease and oral health to come from their undergraduate education. Shown in **Table 4** and **Table 5** the percentage of participants which answered “one source of information” in the “low score” group are nearly twice as many as in the “high score” group. These results indicate that having several sources

of information increases a clinician's knowledge, and further, the likelihood of diagnosing coeliac disease correctly.

A similar portion of both groups had experienced a rise in the number of patients with coeliac disease. However, nearly twice the percentage of the "low score" group, compared with the "high score" group, was unsure of whether or not the number had changed. As shown in **Table 9** the "low score" group had fewer patients with coeliac disease. The majority of the participants in the "low score" group were unsure about the number of patients with coeliac disease, and none of them had more than twenty patients. Paradoxically they relied on clinical experience as their source of knowledge of the disease to a higher degree than the "high score" group did. It is possible that the "high score" and "low score" groups had similar number of patients, but that the "low score" group do not diagnose them correctly as they do not possess the required knowledge to do that.

The "low score" group had less knowledge about welfare support ("Trygderefusjoner") than the "high score" group. A clinician who has more patients with coeliac disease would most likely use this more often. A small portion of the "high score" group reported over twenty patients, which may indicate that they work in areas heavily populated with people with coeliac disease. Or that they are better at recognising coeliac disease.

The "high score" group reported that the majority (58 percent) consider coeliac disease as a diagnosis when enamel defects (hypomineralizations) are discovered, while one quarter of the "low score" group reported the same. If a clinician is aware that a condition can cause certain symptoms, and is confronted with these symptoms, the clinician is more likely to consider the specific condition as a cause.

A majority of both groups reported that the undergraduate education did not give them enough knowledge (**Table 6**) and that they do not possess enough information of coeliac disease (**Table 7**). The results indicate that there is a lack of information and room for improvement when it comes to dental health personnel's awareness of the correlation between oral health and coeliac disease. Perhaps a greater emphasis must be put on the relationship between coeliac disease and oral health in the undergraduate education, with the clinical symptoms as a main point.

Further initiatives to educate already practising clinicians should be considered. An article in a well-respected dental journal, with the most common oral symptoms in patients with coeliac disease and what signs the clinician should look for (either already diagnosed or undiagnosed) is a possibility. Courses, either within the counties or courses where participants from all over the country can enter, should be considered. Also, one could consider a cooperation with the Norwegian coeliac association (Norsk cøliakiforening) in order to make a brochure about the correlation between coeliac disease and oral health issues. This brochure could also include the most common oral symptoms of the disease. The patient could bring such a brochure directly to their dentist or dental hygienist at the dental appointment, if they so choose. The Norwegian coeliac association has not been contacted regarding this endeavour yet, nor are there any plans doing so for the time being. If dental health personnel had an increased knowledge of coeliac disease in correlation to oral health issues, they would likely be more inclined/comfortable to refer a patient to a general practitioner for a possible coeliac disease investigation. Furthermore, if dental enamel defects, recurrent aphthous stomatitis and/or xerostomia is discovered on a patient, which in addition reports abdominal pain, diarrhoea, tiredness or/and has muscle weakness, the dentist or the dental hygienist should refer the patient for further investigation. This, of course, require dental professionals to have knowledge of both general and oral symptoms of coeliac disease.

Knowledge regarding coeliac disease is of importance to all dental health personnel. However, in the public dental health service (DOT), which is treating young people with developing permanent teeth, it is especially important. This is because undiagnosed coeliac disease in young age can lead to malnutrition and possibly cause oral symptoms, such as dental enamel defects. With one percent of the population (13) living with coeliac disease, it's highly likely that any dental health personnel at some point will come in contact with a patient with this illness.

## **5. Conclusion**

There is a rise in the awareness around coeliac disease among the public. This will likely increase the importance of knowledge regarding this illness among dental health personnel. The level of knowledge among dental health personnel is not sufficient, as reported by themselves in this thesis. Neither is the undergraduate education good enough. Several steps can be taken in order to increase the knowledge, both among students and already practicing



clinicians. An increase in knowledge among dental health personnel would likely be of importance for patients and clinicians. Further research into this topic would be beneficial, especially in what can be done to increase this knowledge.

## 6. Figure

**Figure 1: Grooves in teeth from dental enamel defects in a child with coeliac disease(1).4**

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## 9. Appendix

### Appendix one: Approval from NSD:



Arne Christer Ullbro

9037 T ROMSØ

Vår dato: 07.06.2018

Vår ref: 60911 / 3 / PEG

Deres dato:

Deres ref:

## Vurdering fra NSD Personvernombudet for forskning § 31

Personvernombudet for forskning viser til meldeskjema mottatt 26.05.2018 for prosjektet:

60911	Tannlegers og tannpleieres kunnskap om cøliaki
Behandlingsansvarlig	UiT Norges arktiske universitet, ved institusjonens øverste leder
Daglig ansvarlig	Arne Christer Ullbro
Student	Erlend Storvolleng

### Vurdering

Etter gjennomgang av opplysningene i meldeskjemaet og øvrig dokumentasjon finner vi at prosjektet er meldepliktig og at personopplysningene som blir samlet inn i dette prosjektet er regulert av personopplysningsloven § 31. På den neste siden er vår vurdering av prosjektopplegget slik det er meldt til oss. Du kan nå gå i gang med å behandle personopplysninger.

### Vilkår for vår anbefaling

Vår anbefaling forutsetter at du gjennomfører prosjektet i tråd med:

- opplysningene gitt i meldeskjemaet og øvrig dokumentasjon
- vår prosjektvurdering, se side 2
- eventuell korrespondanse med oss

Vi forutsetter at du ikke innhenter sensitive personopplysninger.

### Meld fra hvis du gjør vesentlige endringer i prosjektet

Dersom prosjektet endrer seg, kan det være nødvendig å sende inn endringsmelding. På våre nettsider finner du svar på hvilke [endringer](#) du må melde, samt endringskjema.

### Opplysninger om prosjektet blir lagt ut på våre nettsider og i Meldingsarkivet

Vi har lagt ut opplysninger om prosjektet på nettsidene våre. Alle våre institusjoner har også tilgang til egne prosjekter i [Meldingsarkivet](#).

## **Vi tar kontakt om status for behandling av personopplysninger ved prosjektslutt**

Ved prosjektslutt 30.06.2019 vil vi ta kontakt for å avklare status for behandlingen av personopplysninger.

Se våre nettsider eller ta kontakt dersom du har spørsmål. Vi ønsker lykke til med prosjektet!

Dag K iberg

Pernille Ekornrud Grøndal

K ontaktperson: Pernille Ekornrud Grøndal tlf: 55 58 36 41 / [pernille.grondal@nsd.no](mailto:pernille.grondal@nsd.no)

Vedlegg: Prosjektvurdering

K opi: Erlend Storvolleng, [est084@uit.no](mailto:est084@uit.no)

**Personvernombudet for forskning**

## Prosjektvurdering - Kommentar

Prosjektnr: 60911

**MELDEPLIKTIG PROSJEKT**

I prosjektet behandles direkte og indirekte personopplysninger elektronisk (henholdsvis ved registrering av epost i nettskjema, og ved innsamling av demografiske opplysninger i spørreskjema). Prosjektet er dermed meldepliktig, jf. personopplysningsloven § 31. I e-post fra studenten 30.05.2018 ble Personvernombudet gjort oppmerksom på at prosjektet var igangsatt før det ble meldt inn til personvernombudet. Vi finner dette uheldig, og minner om at prosjekter som omfattes av meldeplikten skal meldes senest 30 dager før oppstart, samt at studentene skal avvente tilbakemelding fra personvernombudet før datainnsamling igangsettes. I det følgende har vi gjort en vurdering av prosjektet slik det er innmeldt:

**INFORMASJON OG SAMTYKKE**

Dere har opplyst i meldeskjema at utvalget vil motta skriftlig informasjon om prosjektet, og samtykke skriftlig til å delta. Vår vurdering er at informasjonsskrivet til utvalget er mangelfullt utformet. Vi ber dere om å ende/tilføye følgende opplysninger i informasjonsskrivet

- dato for prosjektslutt
- hva som vil skje med datamaterialet etter prosjektslutt
- kontaktopplysningene deres, og deres veileders kontaktopplysninger
- informere om at studien er helt frivillig, og det er mulig å trekke seg når som helst uten oppgi noen grunn.

Videre er det klart at enkelte av formuleringene har til hensikt å overtale utvalget til å svare på undersøkelsen. Vi viser til at det ble kommunisert at dere var "avhengige av at så mange som mulig av dere svarer", og på forhånd takker for hjelpen. Slike formuleringer kan påvirke utvalgets frivillighet, og disse formuleringer må derfor fjernes.

De nye personvernreglene fra EU, som trer i kraft i august, stiller strengere krav til at behandlingsansvarlig institusjon kan dokumentere at det er avgitt et gyldig samtykke. Vi har foretatt en vurdering på bakgrunn av dagens lovverk, men anbefaler at veilederen og studentene setter seg inn i hvilke krav som stilles til informasjon etter det nye regelverket. For mer informasjon om det nye regelverket, og en veileder om samtykke, viser vi til Datatilsynets hjemmesider:

<https://www.datatilsynet.no/samfunnsomrader/overordnet-om-rettigheter-ogplikter/samtykke/>

Vi legger til grunn at studentene foretar endringene skissert ovenfor, og sørger for å gi supplerende informasjon til informanter som har mottatt mangelfull informasjon.

### INFORMASJONSSIKKERHET

Personvernombudet forutsetter at dere behandler alle data i tråd med UiT Norges arktiske universitet sine retningslinjer for datahåndtering og informasjonssikkerhet. Vi legger til grunn at bruk av skylagring er i samsvar med institusjonens retningslinjer.

### EKSTERN DATABEHANDLER

Dere har opplyst i meldeskjema at det tas i bruk en transkriberingsassistent/den online surveytjenesten

Nettskjema som databehandler i prosjektet. Dersom det ikke allerede eksisterer en databehandleravtale mellom UiT Norges arktiske universitet og databehandleren, skal det inngås en skriftlig avtale om hvordan personopplysninger skal behandles, jf. personopplysningsloven § 15. For råd om hva databehandleravtalen bør inneholde, se Datatilsynets veileder: <https://www.datatilsynet.no/regelverk-ogskjema/veiledere/databehandleravtale/>

### PROSJEKTSLUTT OG ANONYMISERING

Prosjektslutt er oppgitt til 30.06.2019. Det fremgår av meldeskjema/informasjonskriv at dere vil anonymisere datamaterialet ved prosjektslutt. Anonymisering innebærer vanligvis å:

- slette direkte identifiserbare opplysninger som navn, fødselsnummer, koblingsnøkkel
- slette eller omskrive/gruppere indirekte identifiserbare opplysninger som bosted/arbeidssted, alder, kjønn

For en utdypende beskrivelse av anonymisering av personopplysninger, se Datatilsynets veileder:

<https://www.datatilsynet.no/globalassets/global/regelverk-skjema/veiledere/anonymisering-veileder-041115.pdf>

Personvernombudet gjør oppmerksom på at også databehandler må slette personopplysninger tilknyttet prosjektet i sine systemer. Det inkluderer eksempelvis transkripsjoner, filer, logger og koblingsnøkkel mellom IP-/epostadresser og besvarelsene.

## Appendix two: Questionnaire

### Spørreskjema om cøliaki og tannhelse.

Side 1

Vi er 2 tannlegestudenter ved UiT som skal skrive en masteroppgave om tannlegers og tannpleieres kunnskap om cøliaki. I den forbindelse har vi behov for hjelp fra dere som arbeider som tannleger og tannpleiere i den offentlige tannhelsetjenesten i Nordland og Troms.

Spørreundersøkelsen er anonym. Den er tredelt og det er totalt 20 spørsmål. Det vil ta omtrent 5-10 minutter å svare på den.

Del 1 er generelle spørsmål om behandleren som svarer på spørreundersøkelsen.

Del 2 er et egenrapporterings skjema, og her er veldig viktig at man svarer ærlig. Vi minner om at besvarelsene er anonyme.

Del 3 er spørsmål om cøliaki. Den består av flervalgsoppgaver der det er ett riktig svaralternativ. Denne delen av spørreundersøkelsen skal gjennomføres uten hjelpemidler, med andre ord ingen bruk av internett eller andre kilder.

Der svarboksene er firkantet er det mulig å oppgi flere svar, der de er runde er det kun mulig å huke av ett svaralternativ.

Lykke til.

## Del 1

- 1. Alder \*
- 2. Hvor mange år er det siden du avsluttet din utdanning?
- 3. Ved hvilken utdanningsinstitusjon tok du din utdanning?
  - Oslo
  - Bergen
  - Tromsø
  - Elverum
  - Utenfor Norge
- 4. Hvilken utdanning har du? \*
  - Tannlege
  - Tannpleier
- 5. Hvilket fylke jobber du i? \*
  - Nordland
  - Troms

## Del 2 Rapporterings skjema

- 6. Hvor har du fått kunnskapen om cøliaki og tannhelse? \*
  - Gjennom grunnutdanningen
  - Kurs
  - Klinisk erfaring
  - Videreutdanning

- Annet
- 7. Påstand: Grunnutdanningen ga meg tilstrekkelig kunnskap om cøliaki og tannhelse. \*
  - Ja, enig
  - Delvis enig
  - Delvis uenig
  - Nei, uenig
- 8. Påstand: Jeg føler jeg har god nok kunnskap om cøliaki og tannhelse. \*
  - Ja, enig
  - Delvis enig
  - Delvis uenig
  - Nei, uenig
- 9. Har du personlig merket en endring i antall pasienter med cøliaki de seneste fem årene? \*
  - Ja, det har blitt flere med cøliaki
  - Nei, det er uendret
  - Ja, det har blitt færre med cøliaki
  - Vet ikke
- 10. Omtrent hvor mange pasienter med cøliaki har du hatt det seneste fem årene? \*
- 11. Vet du hvilke trygderefusjoner/støtteordninger pasienter med cøliaki har krav på? \*
  - Ja
  - Nei
  - 
  - Usikker      Vet hvor jeg slår det opp/finner det

### Del 3 Spørsmål om cøliaki

- 12. Er cøliaki og glutenintoleranse det samme? \*
  - Ja
  - Nei



- Vet ikke
- 13. Hva er cøliaki? \*
  - Autoimmun systemisk sykdom hvor de røde blodcellene brytes ned på grunn av at man reagerer på proteinet gluten.
  - Autoimmun tynntarmsbetennelse hvor man reagerer på proteinet gluten.
  - Autoimmun muskelsykdom der muskelfibrene brytes ned på grunn av at man reagerer på proteinet gluten.
  - Autoimmun skjelettsykdom hvor bein brytes ned på grunn av at man reagerer på proteinet gluten.
  - Vet ikke
- 14. Hvilken del av tannen påvirkes ved cøliaki? \*
  - Emalje
  - Dentin
  - Pulpa
  - Cement
  - Vet ikke
- 15. Hvordan kan cøliaki påvirke kjevebeinet? \*  Cøliaki kan føre til periodontale sykdommer
  - Symptomene ved cøliaki kan spre seg til kjevebeinet slik at det brytes ned
  - Cøliaki kan påvirke peridontalligamentene (PDL) slik at tanna felles, og det fører til resorpsjon av kjevebeinet.
  - Cøliaki kan føre til beinskjørhet i kjevebeinet
  - Vet ikke
- 16. Hva kan skje i munnhulen ved ubehandlet cøliaki før fylte 6 år? \*
  - Hypermineralisering av emalje
  - Hypomineralisering av emalje
  - Nedbryting av kjevebeinet
  - Gingivitt
  - Vet ikke

- 17. Ubehandlet cøliaki forårsaker malabsorpsjon i tynntarmen. Hvilke stoffer er viktig for utvikling av emalje? \*
  - Kalsium og jern
  - Kalsium og vitamin B2
  - Kalsium og vitamin D
  - Vitamin B2 og vitamin D
  - Vet ikke
- 18. Hvordan diagnostiserer man cøliaki? \*
  - Blodprøve
  - Avføringsprøve
  - Biopsi av tynntarmen
  - Kostholdsending til glutenfri kost
  - Vet ikke
- 19. Hvor stor andel av de som har sykdommen cøliaki, antar man har blitt diagnostisert? \*
  - 1 av 8
  - 1 av 10
  - 1 av 4
  - 1 av 5
  - Vet ikke
- 20. Ved oppdagelse av emaljedefekter (Hypomineralisering) – Vurderer du cøliaki som en mulig årsak? \*
  - Ja
  - Nei

## **Appendix three: Information letter to participants**

### **Informasjon om behandling av personopplysninger.**

## **”Cøliaki og tannhelse”**

### **Bakgrunn og formål**

Denne masteroppgaven skal undersøke tannlegers og tannpleieres kunnskap om cøliaki og dens eventuelle relevans for tannhelse.

Du mottar spørreskjemaet og dette informasjonsskrivet fordi du arbeider i den offentlige tannhelsetjenesten i Nordland eller Troms.

Den ansvarlige institusjonen for denne masteroppgaven er IKO, ved UiT Norges arktiske universitet.

### **Kontaktinformasjon:**

Studenter:

- Erlend Storvolleng, epost: est084@uit.no
- Lene Blix Christensen, epost: lbl001@uit.no

Veileder:

- Arne Christer Ullbro, epost: christer.ullbro@uit.no

### **Hva innebærer deltakelse i studien?**

Deltagelse i denne studien innebærer å svare på et spørreskjema. Dette skjemaet sendes per epost, men svaret blir ikke koblet til denne eposten når svaret blir sendt inn.

Skjemaet samler inn noen personopplysninger som indirekte kan brukes til å identifisere en deltager. Disse opplysningene er alder, utdanningssted, yrke, yrkesaktive år og hvilket fylke du arbeider i.

### **Hva skjer med informasjonen om deg?**

Alle personopplysninger vil bli behandlet konfidensielt. Det er kun studentene som skriver masteroppgaven, samt veilederen til masteroppgaven, som har tilgang til disse.

Alle opplysninger anonymiseres slik at ingen (dette inkluderer studentene og veilederen) direkte kan koble epostadresser og svar sammen.

Ingen deltagere vil kunne identifiseres i publikasjonen av masteroppgaven.

Prosjektet skal etter planen avsluttes i juni 2019, alle data som har blitt innsamlet vil da slettes.

### **Frivillig deltakelse**

Det er frivillig å delta i studien. Alle besvarelser blir anonymisert, og det ikke er mulig å direkte koble svar og epost sammen. Dersom du ønsker det, og det er mulig å identifisere deg entydig ut fra de generelle innsamlede persondataene, kan du trekke ditt samtykke til å delta i studien. Dette vil bli vurdert individuelt. Det betyr at dersom det er flere besvarelser med like opplysninger vil det ikke være mulig å slette en besvarelse. Du trenger ikke oppgi noen grunn for at du ikke ønsker å delta i studien.

Studien er meldt til, og godkjent av, Personvernombudet for forskning, NSD - Norsk senter for forskningsdata AS.

## **Samtykke til deltakelse i studien**

Ved å svare på spørreundersøkelsen, blir dette ansett som samtykke til å delta i studien.