# A RETROSPECTIVE ANALYSIS OF REFERRAL PATTERNS TO A UNIVERSITY

### ORAL MEDICINE CLINIC

by

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Friesen ii

#### Abstract

**Objectives:** To assess, characterize and analyze, referral patterns to an Oral Medicine Clinic at the University of Alberta. Emphasis was placed on assessing the types of referrals made by dental and medical practitioners, as well as access to care issues that patients face when receiving Oral Medicine specialty care. Materials and Methods: A retrospective chart review of all Oral Medicine/Oral Pathology specialists at the University of Alberta for the year 2015 was performed. Method analysis: Proportions for data points were collected using a 95% Wilson Score Confidence Interval. Two-sided Fisher's Exact tests were performed to assess for statistical differences between data when relevant. Results: 924 patients were included in the analysis. Dental practitioners referred cases most frequently (81.4%) with general dentists representing the largest total proportion (74.5%). White/red lesions were the most common reason for referrals (38.0%), with the tongue (21.8%) and gingiva (17.6%) representing the most common locations of issues. There was no significant difference between the accuracy of provisional diagnoses between physicians and dentists, although dentists referred cases urgently more frequently (16.9% of dentist vs 7.0% of physician cases). The experience of dentists did not have any effect on accuracy of provisional diagnoses, however it did affect the type of conditions referred. Immune mediated conditions were the most common final diagnosis, which were 28.7% of cases. The average wait time for patients was 105.5 days. The average distance travelled by patients was 55.44 km. 18.7% of urgent referrals were seen within 2 weeks. Conclusions: Patients often travel long distances and experience extended wait times after referral. There are small differences between the referral patterns of dental and medical practitioners, but increased training and continuing professional development would benefit both groups. This data can be used to develop future curricula for dental students and can aid in

developing CE courses for graduated dentists. In summary, this research highlights the need for improvement of access to Oral Medicine care by patients in Edmonton, Alberta.

### Preface

This thesis is an original work by Reid Tyler Friesen. The research project received ethics approval from the University of Alberta Research ethics board for the following application:

 "A Retrospective Analysis of Referral Patterns to a University Oral Medicine Clinic" Pro00065171 on July 12, 2016

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## **Table of Contents**

1. Int	roduction and Literature Review	1
1.1.	What is Oral Medicine?	1
1.2.	Prevalence of Lesions/Disease and Disease Impact	3
1.3.	Referral Patterns in Other Countries	6
1.4.	Dentists' Knowledge and Opinions of Oral Medicine	9
1.5.	Experience of Dentists and Effect on Referrals	13
1.6.	Physicians' Knowledge of Oral Medicine	15
1.7.	Access to Oral Medicine Care for Patients	19
1.7	7.1. Access to Care – Distance to Appointment	20
1.7	7.2. Access to Care – Delay in Referral time	21
1.7	7.3. Access to Care – Associated Costs	24
1.8.	Summary of Literature Review	26
1.9.	Objectives and Hypotheses	28
1.9	0.1. Statement of Problem	28
1.9	0.2. Primary Objectives	29
1.9	0.3. Secondary Objectives	29
1.10.	Hypotheses	29
1.11.	Materials and Methods	30
1.1	1.1. Study Population	30
1.1	1.2. Subject Materials:	30
1.1	1.3. Methods	33
1.1	1.4. Data Collection	33

	1.11	.5. Data Analysis	4
2.	Resi	ults and Data Analysis	4
2	.1.	Patient Age and Gender	4
2	.2.	Source of Referral	5
2	.3.	Reasons for Referral	8
2	.4.	Location of Lesion	9
2	.5.	Urgency of Referrals	1
2	.6.	Final Diagnosis 4	5
2	.7.	Accuracy of Referrals 4	9
2	.8.	Distance Traveled by Patients	4
2	.9.	Time Waited by Patients	7
3.	Disc	pussion	9
3	.1.	Patient Age and Gender	1
3	.2.	Source of Referral	1
3	.3.	Reasons for Referral	4
3	.4.	Location of Referral	6
3	.5.	Experience of Dentists: Years since graduation	8
3	.6.	Urgency of Referrals	1
3	.7.	Final Diagnosis – Diagnostic Groupings 7	2
3	.8.	Accuracy of Referrals7	5
3	.9.	Distance Traveled by Patients7	7
3	.10.	Time Waited by Patients7	8
4.	Con	clusions	0

4.1.	Limitations of Study	80
4.2.	Future Research	83
4.3.	Conclusion	83
Referen	ces	85
Appe	ndix 1: Ethics Approval for Retrospective Chart Review	96
Apper	ndix 2: Referral Form	98

## List of Tables

Table 1 - Summary of Review	. 26
Table 2 - Percentage and Type of Clinicians Providing Referrals	. 37
Table 3 - Reasons for Referral Frequency	. 39
Table 4 - Location of Lesion	. 40
Table 5 - Location of Lesions and Type of Referring Clinician	. 41
Table 6 - Urgent and Routine Cases from Medical and Dental Referrals	. 42
Table 7 - Urgent and Routine Cases and Years of Experience	. 43
Table 8 : Type of Lesions in Relation to Routine and Urgent Referrals	. 44
Table 9 - Location of Lesion and Urgent Cases	. 45
Table 10 - Final Diagnosis – Number of Cases	. 47
Table 11 - Final Diagnosis and Urgent or Routine Referral	. 48
Table 12 - Final Diagnosis and Practitioner Years of Experience	. 49
Table 13 - Accuracy of Provisional Diagnosis and Dental Clinician Type	. 50
Table 14 - Accuracy of Provisional Diagnosis and Medical Clinician Type	. 51
Table 15 - Accuracy of Provisional Diagnosis - Medical and Dental	. 51
Table 16 - Accuracy of Referrals for Different Experience Groupings	. 52
Table 17 - Accuracy of Referrals for Different Diagnostic Groupings	. 53
Table 18 - Distance Traveled by Patients	. 54
Table 19 - Distance to Clinic and Rate of Urgency	. 55
Table 20 - Distance to Clinic and Relative Population	. 56
Table 21 - Distance to Clinic and Oral Cancer Cases	. 56
Table 22 - Wait Time Between Referral and First Appointment	. 57

### Friesen x

Table 23 - Patient Wait Times	58
Table 24 - Wait time and Routine and Urgent Referrals	50
Table 24 - Walt time and Routine and Orgent Referrals	

# List of Figures

Figure 1 - Distribution of Patients by Age and Gender	35
Figure 2 - Urgent and Routine Cases as Identified by Referral	42

#### 1. Introduction and Literature Review

#### 1.1. What is Oral Medicine?

Oral Medicine, in conjunction with oral pathology, is defined by the Royal College of Dentists of Canada (RCDC) as "the branch and specialty of dentistry concerned with the diagnosis, nature and primarily nonsurgical management of oral, maxillofacial, and temporomandibular diseases and disorders, including dental management of patients with medical complications"<sup>1</sup>. The exact definition of Oral Medicine, however, differs between various countries. In the United States, Oral Medicine is defined by the American Academy of Oral Medicine as "the discipline of dentistry concerned with the oral health care of medically complex patients - including the diagnosis and management of medical conditions that affect the oral and maxillofacial region" ("The American Academy of Oral Medicine")<sup>2</sup>. In contrast, the British Society of Oral Medicine defines Oral Medicine as "the specialty of dentistry concerned with the oral health of patients with chronic, recurrent and medically related disorders of the oral and maxillofacial region, and with their diagnosis and nonsurgical management" (BSOM)<sup>3</sup>. In Canada, along with thirty-two out of thirty-six polled countries, Oral Medicine is recognized as a distinct specialty within dentistry<sup>4</sup>. Ultimately, the scope of practice of Oral Medicine can best be assessed based on the graduate training competencies as well as the clinical practice patterns. The clinical practice patterns can best be clarified by analyzing the patients seen in an Oral Medicine Clinic.

Oral Medicine graduates possess knowledge in a variety of specific skills to best manage patients. The basic medical sciences competencies, as put forth by the RCDC, include the following: anatomy, physiology, pathology, immunology, microbiology, general medicine and biostatistics. Additionally, relevant tissue-based diseases include: developmental conditions,

benign and malignant neoplasms, immunological conditions, infectious diseases, diseases of bones and joints, diseases of salivary glands, physical and chemical injuries and their sequelae, metabolic and hormonal disease, orofacial disorders and dental management of patients with medically complex conditions and orofacial pain and neurosensory disorders. Collectively, using these competencies to address the relevant tissue-based diseases forms the basis for much of Oral Medicine.

Clinical Oral Medicine is comprised of three major, separate domains including: 1) oral mucosal and salivary gland disorders 2) temporomandibular, orofacial pain and neurosensory disorders and 3) management of the medically complex patient <sup>5</sup>. Within each of these broad domains, there are several competencies that Oral Medicine specialists possess. These competencies can be broken down into: 1) appropriate examination of the patient 2) proper diagnosis of the patient and 3) appropriate management of the condition. A recent survey revealed that >95% of Oral Medicine specialists routinely manage oral lesions and salivary gland dysfunction, while >70% of Oral Medicine specialists routinely managed patients with orofacial pain, chemosensory disorders and oral manifestations of systemic disease <sup>6</sup>.

Despite the wide range of conditions managed by Oral Medicine specialists, the general public, as well as other health care providers, have limited knowledge of Oral Medicine <sup>3</sup>. Ongoing changes in the demographics of our population have resulted in an increased need for specialty Oral Medicine care. For example, with an increasingly elderly population, there is an ever-increasing population of patients with chronic medical conditions, which highlights the importance of raising the profile of Oral Medicine and improving patient care <sup>7</sup>.

#### 1.2. Prevalence of Lesions/Disease and Disease Impact

To appreciate why Oral Medicine specialists serve a critical role in the health care continuum, it is important to understand the prevalence of the conditions they treat. For instance, in Alberta, Canada, there were 378 cases of oral cancer diagnosed in 2012, representing 2% of all cancers <sup>8</sup>. Said differently, males have a 1 in 204 chance of dying from oral cancer in Alberta, while women have a 1 in 368 lifetime probability <sup>8</sup>. Oral Medicine specialists play an important role in providing early diagnosis and management of premalignant and malignant oral conditions. A variety of countries (e.g., Sweden, Brazil, USA, China, Germany, Chile, Cambodia, Slovenia) have performed prevalence assessments of different oral mucosal lesions <sup>9</sup> <sup>10, 11, 12, 13, 14</sup>. To date, however, there has been limited research in Canada of a similar size or scope.

Sweden provides a relevant example of important research in the field. For example, in a landmark study, Axéll found a 21% prevalence of recurrent intraoral aphthous stomatitis, and a 15.8% prevalence of recurrent herpes labialis, two painful and recurrent conditions <sup>9</sup>. Shulman found that the point prevalence of aphthous stomatitis was 1.51%, while the annual prevalence was 19.84% and the lifetime prevalence was 40.18%. Another study from Sweden found the prevalence of oral lesions to be significantly higher in patients who utilize tobacco (either smokeless or cigarettes) <sup>12</sup>. Moreover, a Chinese study found only 64% of elderly patients exhibited no mucosal lesions <sup>15</sup>, which read another way, indicates that 36% of all patients exhibited some mucosal pathology. Another Chinese study <sup>16</sup> found the prevalence of oral setting, 6% in city-dwelling women and 5% for women in a rural setting. These differences were mainly attributed to varying smoking rates between the sexes.

Different aspects of oral health have been researched in many countries. A German study, for instance, found that the spectrum and incidence of oral mucosal disease changes with age, indicating the need for increasing assessment in the elderly population  $^{17}$ . This study also found that age related lesions tended to be: denture stomatitis, traumatic lesions, and plicated tongue. This study found that men are more commonly affected by oral lesions than women. Reichart and Kohn found the prevalence of leukoplakia to be 1.6% in men and 0.2% in women, with an association with alcohol and tobacco consumption <sup>18</sup>. A Slovenian study found a 61.6% prevalence of one or more mucosal lesions in the 25-75-year-old population<sup>14</sup>. This included some benign pathology, such as Fordyce granules, which many clinicians would consider variations of normal anatomy and not a true pathologic process. In a different context, an American study found that smokeless tobacco was the strongest risk factor for oral lesions, with removable dentures being the second most common <sup>19</sup>. This study also found that the odds of having oral mucosal disease increased with age. The point prevalence of some significant lesions in patients over the age of 17 are as follows: homogenous leukoplakia (0.38%), nonhomogeneous leukoplakia (0.04%), geographic tongue (1.85%), amalgam tattoo (3.30%), frictional keratosis (2.67%), lichen planus (0.1%), raised lesions (including papillomas, fibromas) (2.14%).

The prevalence and incidence of oral lesions have also been assessed in children. A British study found that tooth pathology represented 22.1% of all lesions seen in histology cases. Nearly 10% of all specimens sent to this oral pathology service were of patients under the age of 16. This study also found that certain rare tumours such as adenomatoid odontogenic tumours and ameloblastic fibroma are seen most frequently in children, compared to adults <sup>10</sup>. A study in the United States found that 4% of children had one or more oral mucosal lesions at the time of

examination, with almost one-third of affected patients reporting a history of recurrent herpes labialis and recurrent aphthous stomatitis <sup>20</sup>. An American study found that lip bites and aphthous stomatitis, recurrent herpes labialis and geographic tongue are the most common conditions found in American children between the ages of 2-17 years <sup>15</sup>. Therefore, it is especially important to note that the types and nature of oral diseases change with different age demographics.

The impact of oral disease can be quite significant for patients. An Irish study found four main themes regarding the effects of chronic oral disease <sup>21</sup>. The first theme included the contemporary biopsychosocial issues involved in managed chronic oral conditions. Patients often exhibited higher levels of stress and depression secondary to their diagnoses. Another one of the issues that patients frequently reported is the limitations of their treatment and possible side effects of prescribed medications. Thirdly, patients reported distress due to the unpredictable nature of their conditions, as well as the potential risk of malignant transformation, which ties in with the first theme of increased biopsychosocial stress. Finally, patients reported issues with the health care professionals. Patients described anger at the health care professionals regarding delays in diagnosis, as well as difficulties patients suffered with their pharmacists when trying to obtain necessary medications that were deemed to be off-label.

In summation, the above has shown a broad array of studies that have been conducted around the world. Seeing the variance above, one begins to recognize the vast scope of Oral Medicine, as well as the various ways the field can be explored.

#### **1.3. Referral Patterns in Other Countries**

As previously outlined, there are a wide variety of complex conditions that occur in the oral and maxillofacial complex. As such, appropriate and timely referral and triage of these patients is necessary to provide the proper treatment.

To understand what type of patients the University of Alberta Oral Medicine Clinic would be expected to see, it is critical to assess the referral patterns of other Oral Medicine clinics. There have been studies that have addressed the referral patterns in the following countries: Cambodia, China, Netherlands, Italy, USA, Malaysia, Germany, Spain, Slovenia, Chile and Brazil <sup>12</sup>, <sup>22</sup>, <sup>23</sup>, <sup>24</sup>, <sup>25</sup>, <sup>26</sup>, <sup>15</sup>, <sup>20</sup>, <sup>13</sup>, <sup>18</sup>, <sup>7</sup>, <sup>27</sup>, <sup>28</sup>, <sup>29</sup>, <sup>30</sup>, <sup>14</sup>, <sup>17</sup>, <sup>16</sup>, <sup>31</sup>, <sup>11</sup>, <sup>32</sup>, <sup>33</sup>, <sup>34</sup>, <sup>10</sup>, <sup>35</sup>, <sup>36</sup>, <sup>37</sup>, <sup>38</sup>, <sup>39</sup>. A Canadian study, looking at referrals to an oral and maxillofacial radiology clinic found that general dentists were the most likely practitioners to refer cases to oral radiologists, however all referring clinicians could benefit from further radiologic training <sup>40</sup>.

In Australia, Farah et al. performed a retrospective analysis of all patients seen over a 5year interval at an Oral Medicine Clinic <sup>36</sup>. This study included patients seen in both a hospital clinic and a private practice clinic and found that the majority of the patients seen were female, with an average age of approximately 51 years. The most common reasons for referrals were soft tissue lumps and leukoplakias (white patch with unknown etiology). The tongue was the most common location of lesions. The most common clinical diagnoses provided were epithelial keratosis and oral lichen planus.

Riordain et al performed a retrospective analysis of clinical records of new patients in an Irish Oral Medicine unit. These researchers found that the majority of referrals were from dental clinicians (73%), with general dentists representing the greatest proportion of that group (84%) <sup>37</sup>. The most common reason for referral being white lesions, with raised soft tissue lesions being second most common. As found in other studies, women in their 4th-6th decade were the most common group referred. Further, very few patients under the age of 20 were present.

Haberland assessed referrals to a private practice oral and maxillofacial pathology (OMFP) clinic in the USA<sup>29</sup>. In this study, 362 referrals to a private clinic were assessed. This study included phone consults with patients to provide information regarding costs incurred, the number of health care practitioners seen and patient satisfaction. The average patient age was 51.3, and again, most of the patients were female (62%). 55% of referrals came from dentists and 45% came from physicians. The most common diagnostic groupings included allergic/immunologic diseases (17%) and mucocutaneous diseases (16%). The diseases most commonly found were: candidiasis, burning mouth syndrome and lichen planus. The mean time spent between initial symptoms and specialty evaluation was 15 months +- 28.5 days. The average amount of money spent by these patients on treatment before having specialty care, was \$349, while patients only paid about \$94 for a specialty Oral Medicine consult and required medications. A critical finding of this author showed that patients saw, on average, 2.2 health care practitioners before seeing a specialist in Oral Medicine/Oral Pathology. These additional health care visits often resulted in increased time before diagnosis and higher health care costs for the patient and the medical system.

Villa et al. performed a comprehensive assessment of all the patients seen for Oral Medicine assessment over a 3-year period in a large hospital-based setting <sup>38</sup>. In this study, 66% of all referrals came from physicians. 25% of all patients had a provisional diagnosis provided before being seen and 69% of these provisional diagnoses were correct. The most frequent diagnoses were: immune mediated mucosal conditions (27.2%), orofacial pain disorders (25.1%) and benign tumors or neoplasms (10.3%). They found that patients had to travel roughly three to

four times as far to receive specialty Oral Medicine care as compared to the distance to their primary care providers. This is particularly relevant as most specialists are located in major metropolitan regions. Patients living in a rural setting will often have to travel longer distances to receive this specialty care.

Comparing referrals in Australia to Canada is particularly appropriate, not only as Oral Medicine is a recognized specialty in both countries, but also because the demographics and rural/urban spread is similar between these countries. Kaing et al. assessed oral squamous cell carcinoma (OSCC) cases in an Australian centre <sup>39</sup>. The author found a larger number of male patients (almost 2:1male to female ratio) with an average age of 63, and the tongue was the most common location for OSCC. Only 4% of all cases of OSCC were asymptomatic or incidental findings. This small percentage is a crucial finding, as OSCC typically starts off as asymptomatic tissue changes, and this reflects a failure of the screening system to identify many of these patients early in their disease. The author found that initial introduction of OSCC patients to the health care stream was more often through the general practitioners (subsequently referred to as GP (general practitioner) throughout this paper) and not dentists. Patients were most often referred to oral surgeons in both the dental and medical groups. GPs also frequently referred to other medical specialists. General dentists often referred patients to dental specialists (Oral Medicine/periodontist) other than oral surgeons, and never referred patients to a medical specialty. Based on this study, it appears there is a tendency for practitioners to refer within their community, be it medical or dental. This trend indicates a potential need for increased communication and teamwork between these communities.

#### 1.4. Dentists' Knowledge and Opinions of Oral Medicine

Screening and initial diagnosis of oral lesions fall within the scope of dental practitioners and, as such, it is imperative that they have a high level of confidence in diagnosing patients and referring patients, when required. There can be grave consequences to the patient when diagnosis and treatment are delayed, particularly in patients with premalignant or malignant conditions. Appropriate management involves an appropriate clinical exam, radiographic assessment and biopsy with microscopic assessment to confirm the diagnosis. Dentists, as opposed to physicians, are the clinicians best equipped with the appropriate knowledge and instruments to perform these thorough examinations. Lodi found in a survey that most dentists perform complete oral examinations on new patients, as would be expected <sup>41</sup>. Studies have been conducted assessing the adequacy of referrals, as well as the ability of dental practitioners to detect and appropriately manage oral conditions. Of importance, there is a greater chance of a dentist seeing a patient with OSCC due to routine oral examinations; however, only a portion of OSCC patients even consult with dentists. This lack of consultation may be due to the misconception that dentists are only involved in the treatment of teeth and gums, and not the rest of the oral cavity <sup>42</sup>. An increased financial barrier also exists when it comes to seeing dentists as compared to GPs. Accordingly, increasing the public awareness of the scope of practice of dentists may provide long term benefits in early diagnosis of OSCC.

In the United Kingdom, researchers assessed the opinions and attitudes of dentists concerning oral cancer prevention and oral mucosal screening <sup>43</sup>. This study showed that while the majority of dentists perform screening procedures, upwards of 16% did not perform a full mouth examination. Also, only approximately half of respondents reported asking patients about habits involved in oral cancer etiology (alcohol and tobacco). The author found that 21% of

dentists would biopsy suspicious lesions in their clinic, with the majority preferring to refer to a dental specialist. At present, no similar studies in Canada are available for comparison.

One of the most critical steps in appropriate management of oral disease is an accurate diagnosis, which is often predicated on obtaining tissue with a biopsy. Bacci found that there was a high rate of incorrect clinical diagnoses (diagnosis based on clinical examination as opposed to histopathological assessment) amongst dentists and oral surgeons, showing that clinical exam alone leads to an approximate 33% rate of misdiagnosis <sup>44</sup>. Dentists were found in this study to diagnose precancerous conditions more accurately, but malignant conditions were erroneously diagnosed approximately 80% of the time. Bacci reaffirms the need for biopsy and histopathologic assessment of lesions, as merely examining the patient leads to a high misdiagnosis rate and inadequate treatments. Kondori et al. performed a study and found that 43% of clinical diagnoses made by dentists were deemed incorrect after definitive histopathologic diagnosis by a specialist <sup>45</sup>. Of note, there was no difference in the accuracy of clinical diagnosis between general dentists and dental specialists (diagnoses made only based on clinical exam and not including a biopsy). This underpins the importance for both general dentists and dental specialists alike to utilize biopsy procedures to obtain a final diagnosis. Kondori reported that malignant lesions (cancers) were infrequently misdiagnosed only 5.6% of the time, while benign conditions were misdiagnosed more frequently. This is a promising finding, as misdiagnosis of a malignant condition is associated with significantly more concerns than misdiagnosis of a benign condition. Kondori also indicated that dentists are more likely to adopt a "wait and watch " approach to lesions, which represents the obvious risk of an undiagnosed malignant lesion progressing before re-assessment. Malignant lesions are often large and associated with symptoms such as pain and dysphagia, by the time they are diagnosed,

making the diagnosis easier. This study shows the significance of dentists ensuring that all lesions are biopsied and sent for appropriate analysis. If practitioners are uncomfortable performing these biopsy procedures themselves, referrals should be initiated.

A critical step in the referral process is the letter sent from the referring clinician to the specialist outlining the reason for the referral. Adequate referral letters are important in that they help the Oral Medicine specialist triage the referrals, as well as providing relevant background information in regard to the evolution and progression of any disease. Often, when a patient presents for their appointment, the lesion does not present in the same fashion as it did when they were initially seen. Sardella discovered that only 45% of referral letters sent to an Oral Medicine clinic included a clinical provisional diagnosis <sup>35</sup>. The author speculated that this low rate of provisional diagnoses might represent a problem in the knowledge of Oral Medicine amongst physicians and dentists. The author found that younger dentists may have received better training in Oral Medicine and were thus more confident in their ability to provide a provisional diagnosis, as reflected by their higher provisional diagnosis rate. A similar study by Navarro showed that 80% of referral letters lacked appropriate descriptions of oral lesions <sup>46</sup>. In particular, they failed to include symptoms, previous clinical diagnoses, and progression of the disease. Failure to provide any or all of this supplementary information leads to decreased information for the specialist to utilize in a diagnosis and results in poorer patient outcomes.

Brocklehurst et al. found that dental hygienists performed at the same level as primary care dentists regarding detecting oral cancer <sup>47</sup>. This is an interesting finding, however, with the referral system at the University of Alberta Oral Medicine Clinic, only referrals from dentists or physicians are accepted. This could perhaps justify a future change in practice whereby dental hygienists may provide referrals.

Kujan et al. found that dental specialists (Oral Medicine specialists and oral surgeons) have a better appreciation of the etiology of oral cancer and possible risk factors as compared to general dentists <sup>48</sup>. Kujan indicated that there were several gaps in the knowledge of general dentists in regard to oral cancer factors. Only a small fraction of dentists (<5%) had referred more than ten patients to specialists for assessment of suspicious lesions over a period of 12 months. Almost 40% of respondents had not referred any patients to have suspicious lesions assessed. It is plausible that these dentists are performing appropriate biopsies and therapy in their clinic; however, perhaps these clinics are not appropriately diagnosing oral lesions. Possibly instrumental in these dismaying results is that 41% of all dentists reported their training in oral lesion recognition/management was insufficient. Kujan showed that general dentists referred suspicious lesions to oral surgeons approximately 80% of the time, to Oral Medicine specialists 20%, and to ENT or dermatology less than 1% of the cases. These numbers may reflect how the dentists were trained and natural professional networks, as the first line of referral in any dental school is to another dental speciality.

Adequate communication between the referring clinician and the specialist is key to efficient and, more importantly, effective patient care, and several exercises have been developed to improve this communication flow. Navarro found that Brazilian dentists failed to provide a location in 64% of referral letters and size of lesion in 99% of them<sup>46</sup>. A provisional diagnosis was only provided in 16% of the referrals. It is well understood in the Oral Medicine community that the location of the lesion has clinical significance, particularly relating to risk of malignancy. Lesions involving the lateral tongue or floor of mouth are a greater concern than lesions involving the gingiva or buccal mucosa. Less than 5% of referrals included information about previous consultations or any laboratory investigations. This can lead to duplicate tests being

performed, particularly in patients who are unable to provide an adequate history. The time of evolution of the lesion was infrequently provided. These are all important parameters for an Oral Medicine clinic to assess when triaging patients as well as being potentially valuable when making diagnoses. It was found that most referral letters fail to meet the minimum requirements of what constitutes an adequate referral. Djemal explained that using a standardized referral form, which needed to be completed in full before being accepted as a valid referral, improved the quality of referrals and allowed appropriate triaging <sup>49</sup>. Navarro performed a follow-up study a year after his initial study and found that standardized letters provide significant differences in the rate that the chief complaint and site of lesion was provided <sup>50</sup>. The standardized forms were more commonly adequately completed. This may be something that Oral Medicine specialists in Alberta may want to consider adopting in the future.

#### **1.5. Experience of Dentists and Effect on Referrals**

With increasing experience, it is expected that health professionals will expand and consolidate their knowledge in their respective fields, which would then be reflected in the referrals provided to specialists. On the one hand, less experienced dentists may be expected to not only refer more frequently, but it is also likely they will be less accurate in their provisional diagnosis of lesions due to lack of experience. Alternatively, newly graduated dentists are less removed from their undergraduate Oral Medicine and Oral Pathology didactic training, where most of their knowledge is attained. It is plausible that as dentists age, although they gain more clinical experience, their understanding of the fundamentals of Oral Medicine may lessen. This would be particularly true if there are no continued training courses provided to these clinicians. Another aspect that can affect referrals is the degree of confidence in the referring clinician. Inexperienced dentists may exhibit less confidence in their diagnostic skills and would rather

have a second opinion. The author postulates this may result in dentists with less experience referring lower risk or normal anatomy conditions more frequently than more experienced clinicians.

In the field of dentistry, there have been several studies that have assessed how the experience of referring dentists has affected the referral patterns to specialists. Perschbacher et al. looked at referral patterns to an oral and maxillofacial radiology practice <sup>40</sup>. That author thought that previous exposure to a lesion would provide the clinician better diagnostic capabilities when they come across the same lesion at a subsequent time, thus decreasing the frequency and need for referrals amongst more seasoned clinicians. Perschbacher hypothesized that dentists with more experience would be less likely to refer films for radiographic interpretation. However, they found that experience level played no part in the referral patterns for radiograph assessment. It is probable that dentists may benefit from ongoing training in radiographic interpretation regardless of experience. Goldstein et al. found that dental students were more likely to identify a false positive finding (the student thought there was actual pathology, but no actual pathology was present) than they were to miss identifying a true positive (actual pathology was present) <sup>51</sup>. This indicates that dental students, and by extension, less experienced dentists, may be more likely to refer innocuous findings more frequently.

A German study by Reissmann et al. assessed how the number of years since dentists' graduation affected their diagnosis and treatment of temporomandibular disorders (TMD) <sup>52</sup>. These authors found that younger clinicians estimated that a greater percentage of their patients required TMD therapy. They also found that less experienced dentists (under ten years' experience) provided lower quality of treatment and were more likely to refer patients for specialist care. It is plausible that dentists are not being taught TMD management appropriately

in their dental school curriculums in Germany, and dentists' knowledge of the adequate diagnosis and management of TMDs increases with experience. No other studies, to date, have assessed the impact of the dentists' years of experience on the quantity and quality of Oral Medicine referrals, and as such, is one of the research questions addressed in this paper.

#### 1.6. Physicians' Knowledge of Oral Medicine

Patients generally must see an initial clinician, either a general dentist or a family physician (GP), before being seen by an Oral Medicine specialist. As the current funding for health care is structured, medical doctors must be expected to see some of the patients, presenting with oral concerns, who cannot afford to be seen by dentists. Allison et al. found that only 33.5% of oral cancer patients first presented to a dentist, indicating that GPs are also at the front line in oral cancer diagnosis <sup>53</sup>. Carter and Ogden found that patients with oral diseases often present first to their GP <sup>54</sup>. This applies, in particular, to patients who are at high risk of oral cancer, as these high-risk groups often represent a lower socioeconomic demographic <sup>55,56</sup>.

A positive attitude amongst primary physicians is a crucial step in integrating them into the diagnostic and treatment algorithm for patients suffering from oral diseases. Simply put, if physicians do not appreciate the value, or fail to accept their role in oral disease, patients will suffer. Ramirez et al. put forth five reasons for physicians to increase their knowledge of oral diseases: 1) the link between periodontal disease and systemic health 2) the variety of systemic diseases that exhibit oral manifestations, including HIV-AIDs, diabetes, hematological malignancies, and autoimmune diseases 3) physicians do not examine the mouth and are inadequately trained 4) physicians could help guide oral public health policies in the future and 5) early detection and appropriate referral will have positive patient outcomes and reduce costs

associated with oral diseases <sup>57</sup>. Improving the Oral Medicine exposure in medical school can elicit positive long-term patient results.

Several studies have shown significant self-reported deficiencies in oral and dental training of medical students and physicians <sup>58, 59</sup>. It has also been shown that physicians are more likely to perform oral examinations if they feel they have adequate knowledge of what they are assessing <sup>60</sup>. Patton et al. assessed the self-reported adequacy in oral cancer screening amongst physicians, nurse practitioners and dental health practitioners <sup>61</sup>. Physicians reported significantly more confidence in palpating neck nodes and providing appropriate tobacco and alcohol cessation recommendations, while dentists were more confident in intraoral examination. It is likely that these differences in skill sets correlate to their educational preparation and the types of diseases these clinicians refer for assessment. It may be expected that since physicians do not have confidence with intraoral lesions, they may more frequently refer intraoral findings. Alternatively, it is possible that physicians will routinely ignore intraoral assessments, and as such, most of their referrals will be related to visible areas such as the lips and tongue, which do not require a thorough intraoral examination to visualize. Dental health practitioners would benefit from improved cancer prevention strategies such as smoking and alcohol cessation to be aligned with their medical colleagues.

Macpherson investigated gaps in the training of GPs and dentists in Scotland <sup>62</sup>. GPs tended only to examine the mouth if there was a complaint of pain or discomfort, while dentists routinely incorporated examinations as a screening tool. This is of clinical significance, as early cancerous lesions are asymptomatic and only elicit symptoms later in its clinical course. Based on these authors, it is plausible that GPs may miss these early cases. Almost two-thirds of physicians reported that they believe they have a significant role to play in oral cancer diagnosis.

Physicians also waited longer before referring patients (4-5 weeks instead of 2-3 weeks for dentists). Of importance, dentists reportedly did not ask about risk factors such as alcohol use, due to feeling uncomfortable asking such questions of patients <sup>62</sup>. This is an area that could be improved in undergraduate dental training, to provide dentists with the skills and confidence to ask these important questions. A study by Morgan et al found that, although physicians appreciated the importance of oral exams on routine physicals, only 19% of general physicians performed them <sup>63</sup>. More so, 56% of general physicians did not feel confident performing an intraoral examination, mainly due to inadequate training. These authors found that detection of early squamous cell carcinoma was only achieved by 20% of physicians. Shimpi et al found that only one-third of medical providers from an American city would frequently refer patients to dentists. Of this referring population, only 16% reported good coverage of oral/dental health topics in their medical school training. Their competency levels in diagnosis of basic oral pathology, as obtained via a questionnaire, was <30% and reflected this perceived poor training <sup>59</sup>.

A critical step in the management of oral disease is the appropriate first referral from the primary clinician. Sarumathi found that despite their self-reported lack of knowledge in oral conditions, general physicians more frequently refer patients with oral disease to other medical specialists, as opposed to dentists or dental specialists <sup>60</sup>. Improving collegial networks between dentists and physicians would likely contribute to improving patient outcomes, as patients are currently often not being referred to appropriate providers. McCready et al found that American 4th-year medical students reported that oral cancer diagnosis was the responsibility of both physicians and dentists <sup>64</sup>. ENT surgeons were the most likely referral source for suspected oral cancer cases from these physicians, while Oral Medicine specialists and oral surgeons were

significantly less frequently used as a referral option <sup>64</sup>. Another study by Ramirez-Amadr supported this finding and found that medical practitioners often referred oral lesions to other medical specialists, often dermatologists, because some oral diseases were viewed as manifestations of cutaneous disease <sup>57</sup>.

An Australian study by Barnett, which looked at rural patients, found that these patients faced several barriers to seeing dental specialists. These barriers included oral health being a low priority and the high cost of seeing the dentist <sup>65</sup>. Physicians in this study reported that there was a "one-way" flow of communication between dentists and physicians, as dentists frequently failed to communicate back to the physicians adequately. In many cases, there was no coordination or communication between dentists and physicians. This may be a key aspect of why physicians are less likely to refer to dentists, as general physicians like to be informed about the patient's condition and management.

There are deficiencies in continuing professional development (CPD) courses, in relation to Oral Medicine topics, available for physicians once they have graduated. This underscores the importance of increased Oral Medicine education in the undergraduate medical curriculum. Alami assessed the knowledge of oral cancer in newly graduated medical and dental professionals. While there were felt to be some deficiencies in the dental graduates' knowledge, they nevertheless exhibited significantly better knowledge of oral cancer (including aspects such as risk factors, high-risk locations and appropriate management) than their medical counterpart <sup>66</sup>.

McCann assessed the accuracy of medical students and physicians in diagnosing various oral pathologies. Compared to dentists who were correct 89% of the time, the physicians were only accurate 28% of the time <sup>67</sup>. Wee et al found that minimal continued professional

development for GPs through online courses can significantly increase not only the clinician's confidence but also the rate at which they perform oral exams <sup>68</sup>. A greater focus should be placed on continued training and keeping physicians current to provide ideal diagnosis and treatment.

#### 1.7. Access to Oral Medicine Care for Patients

Access to care is defined as "the timely use of personal health services to achieve the best health outcomes"<sup>69</sup>. Adequate access to care involves three separate steps: 1) entry into the health care system 2) gaining access to sites of care where patients can receive services and 3) finding providers who work well with the patient and can develop an appropriate patient-clinician communication. There are several considerations when assessing patients' access to care including financial costs, a usual primary care provider and patients' perceptions of need, which can create barriers to care <sup>69</sup>. Patients must consider financial costs, not only from the examination and treatment itself, but related to travel expenses and time away from work. Inadequate access to care often results in significantly higher hospital costs and morbidity in the long term if patients are unable to see the appropriate clinician early in their disease process <sup>69</sup>.

Weissman et al looked at different reasons for referral delay before patient hospitalizations. A primary issue, as it relates to patients following through on recommended referrals, was the thought that their problem would go away on its own. This led to one of the most common reasons for delayed care, i.e. the belief that the problem was not severe enough to warrant seeing a specialist <sup>70</sup>. Of importance, patients who were uninsured, poor or lacked a regular GP were likely to experience the longest delays in treatment. It was also found in the Weissman et al study, that patients who had delays in obtaining care subsequently experienced longer hospital stays. In an Oral Medicine Clinic, hospital stays are not a primary outcome.

However, long delays in accessing care can lead to increased morbidity regarding painful and malignant, or potentially malignant, conditions. This is an important aspect to consider for referring clinicians, who need to reinforce to patients the importance of seeing the specialist.

Andersen et al conducted an extensive assessment of the different factors contributing to access to care issues. Travel time was found to be a significantly greater factor than even travel cost <sup>71</sup>. Based upon this study, patients would rather pay more money if it meant traveling less distance, although this does vary. Access to care issues represents a complex and important aspect of medical care. For this study, two fundamental issues of access to care (distance traveled to the appointment and time between referral and first appointment) were examined.

1.7.1. Access to Care – Distance to Appointment

As the distance from the patient's home to the specialty clinic increases, the burden on the patient and their family increases, in terms of both time commitment and costs. This is compounded if the patient is required to have follow-up appointments. There is also an increase in health care resources used to serve the patient in the case of required follow-up <sup>72, 73, 74</sup>. A study by Welch et al found that in hospital patients, disease severity was increased in those who had to travel a further distance <sup>74</sup>. This finding was also found by Jordan et al who found that patients located further from appropriate care exhibited higher rates of limiting long term illness <sup>75</sup>. There are different reasons why this may be the case. On the one hand, patients may not desire to travel further for their appointments initially, so by the time they present, their disease has worsened. Alternatively, the referring clinicians may exhibit a different threshold for what constitutes a referral compared to clinicians in more urban/centrally located areas where access challenges may be less. Although Welch et al looked at hospital visits, it is likely that a similar situation can be applied to an Oral Medicine Clinic. Younger, healthy patients who are currently

employed are prepared to travel further to access healthcare, which may be indicative of their higher mobility <sup>76</sup>. However, the majority of patients seen in Oral Medicine practice are not young, healthy patients and likely face higher degrees of difficulty transporting themselves.

Shook performed a comprehensive look at transportation barriers to patients accessing specialty care <sup>77</sup>. 9% of patients over the age of 65 were unable to access specialty care due to transportation problems. Patients have been shown to miss appointments for cancer therapy because of difficulties with transportation. If patients have issues accessing transportation for necessary cancer treatment, it is likely that many patients are missing appointments to obtain a diagnosis for undiagnosed oral disease. This can affect patients who are not only traveling long distances but also patients located within proximity to the center but do not have access to a car, or someone to drive them.

Similar studies have been performed in Canada looking at access to specialty care, however not specifically Oral Medicine specialty care. Barisic et al found inter provincial differences in access to necessary cancer diagnostic services <sup>78</sup>. Patients in British Columbia wait significantly longer for access to colonoscopy compared to patients in Ontario. A study by Loree et al found that access to rectal cancer management showed no urban-rural differences, but the outcomes were worse in patients who traveled further <sup>79</sup>. Karunanayake et al looked at access to specialist medical care in rural Saskatchewan, which exhibits similar demographics to Alberta, and found that approximately 25% of patients requiring specialist care reported difficulty in accessing that care <sup>80</sup>. This reported difficulty increased with further distances traveled.

1.7.2. Access to Care – Delay in Referral time.

The traditional way of triaging patients is urgent vs. non-urgent referrals <sup>81</sup>. An issue with this system is that there is an artificially created delay for most patients to accommodate the

urgent patients. Along the referral pathway, patients are faced with several periods of delay. Delays can be categorized as patient delay and professional and/or system delay. The patient delay is the time between first noticing signs/symptoms and seeing a health care provider. A professional delay is between the first examination and a final diagnosis (histologically confirmed). Integrated into the professional delay is the "system delay," which involves accessibility and availability of the appropriate clinician. There are 4 specific delays involved in the referral process: 1) delay between first sign/symptom and initial visit 2) delay between initial visit and patient referral 3) delay between referral and patient seeing specialist 4) delay between final visit to definitive diagnosis <sup>82</sup>. The cumulative delay is critical to the patient and limiting each individual delay is important for timely care for patients.

Previous studies have repeatedly shown that wait times are longer than preferred by patients and clinicians alike. Elwood and Gallagher looked at major factors that influenced cancer diagnosis in oral cancer patients in Canada <sup>83</sup>. Early diagnosis was more common in patients with low alcohol consumption and regular dental visits, highlighting the importance of routine dental care. Of importance, increasing professional delay is correlated with late stage disease. Many oral cancers present to a health care provider at an early stage, but the professional delay is leading to a significant portion of these cases turning into late stage cancer <sup>53</sup>. Patients with oral cancer who exhibit a professional delay >1 month have a higher rate of late stage disease as compared to patients with shorter professional delays.

Jafari et al assessed common causes of delays in diagnosis of oral cancer <sup>84</sup>. This is particularly relevant, as early diagnosis and treatment can achieve high survival rates (~70%), while delayed diagnosis leads to significantly lower cure rates. These authors found that men were significantly more likely to delay their appointment, which lead to later diagnosis. Women

were considered to pay more attention and have greater concern of lesions in their mouths than men. This study found that, although there are often long delays for patients after seeing the first clinician (professional delay), the critical delay is observed between patients first noticing oral symptoms and subsequently seeking care (patient delay). Allen and Farah asked patients for input on their referrals <sup>85</sup>. Not only was it expected by patients that dentists perform an oral cancer screening (98.8%), the majority of patients expected physicians also to perform oral cancer screening (82.1%). This study was critical in that it revealed approximately half of all patients were aware of their lesion before it was noticed by their health care provider. The greatest delay in patient care was the delay patients imposed on themselves before seeing a health professional, which was also a finding in a study by Hollows et al <sup>86</sup>. The second longest delay in treatment was the time between the referral being issued and the first specialist appointment (professional delay). The time between the first appointment with a health care provider which initiated the referral and the subsequent specialist appointment was very short (81.1% of the time it was less than two weeks), but it was the time gap waiting to be seen by the specialist that constituted the longest delay. Kerdpon et al found that patient delays are responsible for twice the wait as compared to professional delays <sup>42</sup>. 20% of patients had patient delays over three months, which means that these patients were aware of a lesion for over three months before seeking any care. Güneri and Epstein found that both the "patient delay" and the "professional delay" are important to reduce to make a significant impact on patient prognosis <sup>82</sup>.

San Martin et al looked at determinants of waiting time for specialized services in Canada <sup>87</sup>. The authors found that 17-29% of patients reported that their wait for specialty care was unacceptable. Most patients waited less than three months, with a majority waiting less than one month. Wait times under one month were generally acceptable, however those who had

between 1-3 month wait had a much higher rate of dissatisfaction, while waits over three months had significant dissatisfaction, many times greater than the dissatisfaction of 1-3 months. Up to 20% of patients reported that the wait for care greatly affected their lives. The younger the patient, the more likely they were to deem their wait times unacceptable. A recent Canadian study by Liddy et al. looked at appropriate wait times for chronic pain patients and found that 83% of patients reported that a wait-time less than 3 months was ideal<sup>88</sup>. Liddy looked specifically at chronic pain patients, which is slightly different than a typical Oral Medicine demographic, however many patients in an Oral Medicine clinic suffer from significant discomfort. Patients suffered both psychologically and physically when waiting for appointments, although psychological effects were found to be more common than physical effects. In addition to personal effects, family and friends were frequently affected by patient wait times. Patients were more likely to be understanding with waiting for nonemergency surgery than they are waiting for a specialist appointment or diagnostic service. This was likely due to the concern of life threatening diagnoses and not knowing the outcome of the diagnosis. This would be the case in most Oral Medicine clinics, which primarily provide a diagnostic service, as opposed to non-emergency surgery.

#### 1.7.3. Access to Care – Associated Costs

The related expenses of Oral Medicine treatment to both patients and the greater health care system must be considered when assessing referral patterns. A significant amount of the research on health care costs, as it relates to Oral Medicine, has examined oral cancer. Funk et al found that early diagnosis is the single most important aspect of reducing costs. Early diagnosis of patients can often be managed with a single modality of treatment (surgery) as opposed to requiring multi-modality treatment (chemotherapy and radiation) <sup>89</sup>. Shariff and Zavras found

similar findings in a Greek study, with higher stage cancer being correlated with higher costs <sup>90</sup>. These increased costs are due to increased treatment modalities as well as longer hospital stays and more required follow-up. It is plausible that improving the initial early diagnosis of these patients will not only improve patient outcomes and decreased mortality rates, but it may also provide diminished health care costs for the province.
# **1.8. Summary of Literature Review**

The following table provides a review of the relevant literature used in this study.

Table 1 - Summary of Review

Area of Literature	Key findings	
What Is Oral Medicine?	<ul> <li>A dental specialty involved in the diagnosis and non-surgical management of medical conditions affecting the oral and maxillofacial region</li> <li>Three major competencies of Oral Medicine practice: <ul> <li>Oral mucosal and salivary gland disorders</li> <li>TMD, orofacial pain and neurosensory disorders</li> <li>Management of medically complex patients</li> </ul> </li> </ul>	
Oral Lesion Prevalence and Oral Disease Impact	<ul> <li>Oral and maxillofacial disease, excluding dental caries, is evident across the population, affecting both young and old</li> <li>Oral lesions tend to increase with age, and are frequently associated with reversible factors such as tobacco, alcohol and UV radiation</li> <li>Oral disease affects patients in several ways, including physical and psychological suffering, as well as financial strain</li> </ul>	
Referral Patterns in Other Countries	<ul> <li>Studies have looked at referral patterns to Oral Medicine clinics around the world, however there have been no studies performed in Canada</li> <li>Referral patterns amongst countries in the Western world are similar</li> <li>Oral Medicine practices primarily manage: immune-mediated oral conditions, orofacial pain conditions and benign growths of the oral cavity. Diagnosis of malignant conditions is an important aspect of Oral Medicine practice</li> </ul>	

Dentists' Knowledge of Oral Medicine and Effect of Dentist Experience	<ul> <li>Screening and diagnosis of oral lesions often relies upon general dental practitioners</li> <li>Studies have shown self-reported deficiencies amongst dentists in their Oral Medicine knowledge, as the result of suboptimal dental school exposure to Oral Medicine topics</li> <li>Increased awareness and education in the generation of optimal referral letters, as well as appropriate clinical communications, would pay dividends for patients and clinicians alike</li> <li>The experience of dental practitioners has been shown to have implications in the types of procedures performed for, as well as confidence in diagnosis of, Oral Medicine conditions</li> <li>General dentists and dental specialists of all experience levels would likely benefit from continued exposure and training in Oral Medicine topics</li> </ul>
Physicians' Knowledge of Oral Medicine	<ul> <li>GPs report a high level of appreciation of the need for an adequate oral examination and many would consider incorporating it into routine physical examinations</li> <li>GPs are considered front line in the diagnosis and appropriate referral of patients with a variety of oral conditions, including oral cancer</li> <li>GPs often report a lack of exposure in medical school to managing oral conditions</li> <li>GPs tend to refer cases to medical specialists, while dentists tend to refer to other dental specialists</li> </ul>

Access to Care Issues	• Receiving adequate care is often difficult for patients for a variety of reasons, including: financial issues, travel distances to appointments, limited number of specialists and resultant long wait times
	• Access to care issues increase patient morbidity and mortality
	• Patient outcomes are poorer when they are required to travel long distances to specialist appointments
	• Long wait times can result from different steps along the referral process. Patients may suffer delays until the initial referral, but also between the referral and the first appointment
	• Patient imposed delays (patient failing to seek care on their own accord) is often the longest delay in patient care
	• Long wait times, generally considered to be over 3 months, result in increased patient stress and physical pain

## **1.9.** Objectives and Hypotheses

## 1.9.1. Statement of Problem

Currently, both the general public and health care professionals have limited knowledge of Oral Medicine. The demand for Oral Medicine specialty treatment in Canada, and in particular Alberta, as well as how the medical community at large uses these clinics is not known at this time. Increased insights into the referral patterns to an Oral Medicine clinic will provide opportunities for improving the delivery of care and will also influence future training of clinicians. The goal of this study was to systematically characterize the referral patterns to a university-based Oral Medicine clinic, with a focus on highlighting the referral patterns, clinical diagnoses and access-to-care issues for patients. The objectives established were as follows:

#### 1.9.2. Primary Objectives

- What types of clinicians are referring patients to the Oral Medicine clinic (dentists, dental specialists, GPs, medical specialists)?
- How do different diagnostic groupings correlate with referring clinician type?
- What percentage of presumptive diagnoses match the definitive diagnosis?
- How do different diagnostic groupings correlate with the designated urgency of referral?

## 1.9.3. Secondary Objectives

- What is the average distance travelled by patients to their Oral Medicine appointment?
- What is the patient waiting time between initial referral and first appointment?

## 1.10. Hypotheses

Given that this study is providing baseline descriptive information, a hypothesis was not provided for all of the objectives. GPs and newly graduated dentists were hypothesized to be the most likely groups to refer cases that receive a low-risk diagnosis, such as normal anatomy. In 50% of cases the referring clinician's presumptive diagnosis will match the definitive diagnosis. Diagnoses of dysplasia or cancerous conditions will correlate most closely with referrals designated as urgent referrals.

Acquisition of this information will be beneficial in several ways. Primarily, and most importantly, this study will reveal what types of obstacles patients face in acquiring timely Oral Medicine specialty care. Additionally, the study results can help inform the education curriculum for undergraduate and graduate dental practitioners. There may also be a benefit in guiding continued professional development (CPD) courses for graduated dentists. This

information can also be used as an initial assessment of the competency of different medical practitioners in referring to an Oral Medicine clinic and indicate possible gaps in their Oral Medicine knowledge. Ultimately, this will improve the accuracy and timeliness of referrals and facilitate improved treatment for patients. To our knowledge, this is the first study to assess and quantify the delivery of Oral Medicine services in Canada.

#### 1.11. Materials and Methods

This study was a retrospective descriptive correlational study, with the aims of describing some of the relationships between different aspects of the referral process to an Oral Medicine clinic.

1.11.1. Study Population

Patient records from all 3 of the Oral Medicine/Oral Pathology specialists at the University of Alberta were included in this study. Patient records from all new patients seen in 2015 (January 1, 2015-December 31, 2015) were evaluated. All three specialists were involved in the initial development of this study and agreed with the use of patient records.

Inclusion criteria: any patient referred to and seen in the Oral Medicine clinic over the specified period. Referrals to the separate TMD/Orofacial Pain clinic were not included in the analysis. Patients were only included in the analysis if a written referral was received.

Exclusion criteria: Patient charts that did not contain a referral form were excluded. Charts with incomplete referral forms were also excluded. Patients who were completely lost to follow-up before a final diagnosis was established were also excluded.

1.11.2. Subject Materials:

The materials obtained were the patient records from the Oral Medicine specialists. Included in the charts were: referral letters sent to the specialist by referring clinician, patient medical history, daily treatment notes and the correspondence letter from the specialist to the referring clinician. The data collected included:

- 1. Patients' age
- 2. Patients' gender
- 3. Type of practitioner
- 4. Years since graduating (of referring dentists)
- 5. Date of referral
- 6. Date of the first appointment
- 7. Time between referral and first appointment
- 8. Distance traveled by patients for appointments
- 9. Reason for referral
- 10. Location of lesion
- 11. Category of referral (based on reason for referral)
- 12. Presumptive diagnosis (if provided)
- 13. Nature of referral (urgent or routine)
- 14. Final diagnosis and,
- 15. Category of final diagnosis (based on final diagnosis).

Information regarding the type of practitioner and years since graduating was obtained from publicly available records including the University of Alberta records. The clinician type (dentist, dental specialist, physician, medical specialist) of the referring doctor was obtained through the referral letter. Determination of the reason for referral and the provisional diagnosis were obtained from the referral letter. The distance traveled by the patient was calculated using the patient's postal code and Google Maps. The distance to drive to Kaye Edmonton Clinic (T6G 1Z1) was calculated.

The final diagnosis of each patient was obtained from the patient records and the correspondence letter back to the referring clinician. The categories for referral and final diagnosis were based on prior studies performed <sup>37,38</sup>. The specific referral categories used were:

- 1. Altered sensation
- 2. Pain
- 3. Pigmented lesions
- 4. Raised soft tissue lesion
- 5. Ulceration
- 6. Red and/or white lesion
- 7. Specific diagnosis
- 8. Other

The specific diagnosis categories used were:

- 1. Benign tumours/neoplasms
- 2. Dysplasia and cancerous lesions
- 3. Immune-mediated conditions
- 4. Infections
- 5. Orofacial pain disorders
- 6. Osteonecrosis of the jaw
- 7. Reactive keratosis
- 8. Salivary gland disorders

#### 9. Other - pathology

10. Other – normal anatomy

Diagnoses were placed only in one referral or diagnostic category.

Within the data set, there are approximately 1,000 records. Using a confidence level of 95% (or 19 times out of 20), the exact number required to have a representative sample size is 375, with a margin of error of  $\pm 2\%$ . That said, the intention was to investigate all available records, improving both the confidence level as well as the margin of error.

1.11.3. Methods

The methodology laid out by Vassar and Holzmann, regarding performing a retrospective chart review was followed <sup>91</sup>. Any time a retrospective chart review is performed, several important details are required. For this study, clear, well-defined research questions were proposed, and all the essential variables were calculated before initiating the chart review. A standardized data input format was used for all charts. There was explicit criterion for the inclusion of different data points. A pilot test was initially performed before acquiring all the data. The study was approved by the Research Ethics Board of the University of Alberta (Pro00065171 on July 11, 2016).

1.11.4. Data Collection

Data were entered into a password encrypted spreadsheet using a de-identified form by the principal investigator. The data set was captured in Microsoft Excel (Microsoft, Redwood, WA). All data was maintained on a password encrypted USB key, which was locked at all times. The fields were given pre-arranged sub categories to ensure the data input was systematic. These fields allowed more homogenous and efficient use of the acquired data. Data about the referring practitioners, other than the type of practitioner and years since graduation, was not

included so as to maintain clinician confidentiality. Patients were provided with numeric codes to protect their identity. The primary investigator was the only individual with access to the collected data. Data accuracy was verified by duplicating data input on 50 randomly selected cases to assess for consistency. There were no mismatches noted.

#### 1.11.5. Data Analysis

Data points were recorded using Microsoft Excel. A PivotTable was used to perform descriptive statistical analysis on all the required parameters. The analysis included descriptive measures of proportions of referring clinicians, the category of referral, the category of diagnosis, location of lesion and rates of urgency. Mean, median and mode were calculated for patient's age, distance traveled and time waited. OpenEpi online software <sup>92</sup> was used to calculate proportions using 95% confidence intervals and the Wilson score interval. When indicated, Fisher's Exact test was used to defend significance from the proportions <sup>93,94</sup>.

#### 2. Results and Data Analysis

In total, there were 932 charts accessed, of which 924 were included in the analysis. Eight patient records were excluded after collection as there was no final diagnosis obtained therefore they did not meet all the initial criteria. The following sections assess individual parameters determined in the study.

#### 2.1. Patient Age and Gender

The patient demographics of all the referrals were determined based on the patient intake forms. The patient's ages were calculated based on their age at the time of the first appointment. Of all 924 patients seen, 361 (39%) were male, and 563 (61%) were female. The average age of

patients seen was 56.6 years old, standard deviation 16.4, with a median age of 59, a maximum of 101 and a minimum of 4. Presentation of the patient demographics is in Figure 1. Figure 1 - Distribution of Patients by Age and Gender



## 2.2. Source of Referral

In the analysis of the source of referrals, practitioners were considered as referring clinicians if they submitted at least one case to the Oral Medicine clinic. In the current referral system, only practitioners with a Practice ID (PracID), as provided by the Government of Alberta, are able to refer cases. Due to this, there are no referrals from hygienists or nurses. In the data set, there were 752 referrals from 483 unique dentists. Of these 483 dentists, 42 were dental specialists and 441 were general dentists. In 2015 Alberta Dental Statistics <sup>95</sup>, there were 2300 general dentists in Alberta and 290 dental specialists. Approximately 19% of all general dentists in Alberta (442/2300), referred at least one case to the Oral Medicine clinic. These

statistics are noteworthy because, in Southern Alberta most of these cases would be seen by specialists in Calgary or Lethbridge who exhibit clinical overlap with Oral Medicine specialists (such as oral surgeons or periodontists). Edmonton is the only city with board certified Oral Medicine specialists, where there are only similarly trained clinicians in Calgary. There are no other such specialists in Alberta, indicating that only Edmonton or Calgary can be plausibly seen as referral locations. There is no data available to confirm the referral patterns within Alberta. In Alberta, there were 290 dental specialists. Within the data set, 14% of all dental specialists referred at least one case to the Oral Medicine clinic. Periodontists (1.9%), endodontists (1.6%) and oral surgeons (1.5%) represented the most frequent source of referrals from dental specialists (Table 2).

A total of 124 separate GPs referred to our clinic. There were 4883 GPs in Alberta in 2015 (117/100,000) (2015 CMA Survey). This statistic indicates that approximately 2.5% of all GPs referred to the Oral Medicine clinic. In addition to GPs, dermatologists (1.7%), ENT specialists (0.9%) and rheumatologists (0.2%) referred cases to the clinic (Table 2).

Type of Clinician	Total number of Referrals	Total % (out of 924)
General Dentist	688	74.5%
Endodontist	15	1.6%
Oral Surgeon	14	1.5%
Orthodontist	5	0.5%
Periodontist	18	1.9%
Prosthodontist	10	1.1%
Oral Medicine specialist	2	0.2%
Dental Total	752	81.4%
Family physician (GP)	146	15.8%
Dermatologist	16	1.7%
ENT specialist	8	0.9%
Rheumatologist	2	0.2%
Medical Total	172	18.6%

Table 2 - Percentage and Type of Clinicians Providing Referrals

## 2.3. Reasons for Referral

The reason for referral indicated by the referring practitioner in the referral letter was documented. This data was collected directly from the referral note to the clinic. The reason for referral was classified into one of 8 categories, following the groups developed by Riordain et al <sup>37</sup>. Cases were classified as: altered sensation, pain, pigmented lesions, raised soft tissue lesion, ulceration, white/or red lesion, specific diagnosis or other. The primary reason as indicated by the referring clinician was included. In cases where more than one reason for referral was provided, the primary or first one listed was used. In cases for which no clinical descriptors were provided, and only the name of the suspected lesion, a categorization of specific diagnosis was provided. The "other" category included anything that could not be easily categorized into the other groupings. This included: radiographic findings without any soft tissue lesions and referrals that only provided a location but no actual pathologic description. As seen in Table 3, red and/or white lesions were the most regularly referred finding to the clinic, representing 38% of all referrals.

Referral Category	Number of Cases	Percentage (%)
Altered sensation	36	3.9
Pain	100	10.8
Pigmented lesions	32	3.5
Raised soft tissue lesion	219	23.7
Specific diagnosis	44	4.8
Ulceration	104	11.3
White and/or red lesion	351	38.0
Other	38	4.1
Grand Total	924	100

Table 3 - Reasons for Referral Frequency

#### **2.4.** Location of Lesion

The site of the lesion/diagnosis in question is often included in the referral request. However, it is not a mandatory field. The oral cavity was divided into well-known, commonly acknowledged structures of the mouth and documented for each referral, seen in table 4. Cases where no location was given, such as cases of generalized pain, were also included in the analysis as "none provided". The tongue was the most common area referred, with 21.8% of all referrals. The second most common were cases where no location was provided (20.0%). The gingiva and buccal mucosa (17.6% and 16.9%) were the 3rd and 4th most common sites respectively. Referrals which received a location of "other" included: nose, tooth, outside cheek and parotid.

Location	Number of Cases	Percentage (%)
Tongue	201	21.8
None provided	185	20.0
Gingiva	163	17.6
Buccal mucosa	156	16.9
Palate	69	7.5
Lip	57	6.1
Oropharynx	50	5.4
Floor of mouth	26	2.8
Other	11	1.2
Mandible	6	0.6
Grand Total	924	100

Table 4 - Location of Lesion

The correlation between referral location and type of clinician (dentist or physician) was also characterized in Table 5. These figures provide insight into what areas of the oral and maxillofacial complex were a focus by different clinicians. It was found that the physicians in this study most frequently referred cases involving the tongue and the lips (31.6% and 13.5% respectively) in the cases where a location was provided. Alternatively, dentists were most likely to refer cases involving the tongue, gingiva and buccal mucosa (19.5%, 20.1 and 17.5%).

Lesion Location	Physician Proportion*	Dentist Proportion*
Buccal Mucosa	14% (9.6-20.0%)	17.5% (15.0-20.4%)
Floor of Mouth	1.8% (0.6-5.0%)	3.1% (2.0-4.5%)
Gingiva	7.0% (4.1-11.9%)	20.1% (17.4%-23.1%)
Lips	13.5% (8.9-19.7%)	4.5% (3.2-6.2%)
Mandible	0% (0.0-2.7%)	0.8% (0.3-1.8%)
Oropharynx	6.4% (3.4-11.5%)	5.2% (3.8-7.1%)
Other	0% (0.0-2.7%)	1.5% (0.8-2.6%)
Palate	7.6% (4.5-12.6%)	7.4% (5.7-9.5%)
Tongue	31.6% (25.1-38.9%)	19.5% (16.9-22.5%)
None provided	18.7% (13.3-25.5%)	20.3% (17.6-23.3%)

Table 5 - Location of Lesions and Type of Referring Clinician

\*95% CI (Wilson score)

## **2.5. Urgency of Referrals**

Every referral form provided to the Oral Medicine clinic requires the referring clinician to mark the referral as urgent or routine. In cases where neither was marked, the referral was considered routine. Urgent referrals are of particular importance, as it is assumed by the referring clinician that there is special significance to that case that requires immediate action. Of the 924 cases, 785 were considered routine (85.0%) and 139 referrals were identified as urgent (15.0%) (Figure 2).



Figure 2 - Urgent and Routine Cases as Identified by Referral

Part of the evaluation looked at how the rate of urgent referrals correlated with the type of clinician, the experience of the clinician, reason for referral, the location of referral and final diagnosis. The data showed that dentists (general dentists and dental specialists) referred cases urgently approximately 16.9% of the time (127/752 cases), while physicians referred cases urgently 7.0% of the time (12/172 cases) (Table 6).

Table 6 - Urgent and Routine Cases from Medical and Dental Referrals

Clinician	Routine Referrals	Urgent Referrals	Proportion of Cases Designated as Urgent*
Dental	625	127	16.9% (14.3-19.8%)
Medical	160	12	7.0% (4.0-11.8%)

\*95% CI (Wilson Score)

The experience of the referring clinician was predicted to play a role in how frequently cases were referred urgently, as it was hypothesized that less experienced clinicians would refer cases more urgently. Table 7 shows the number of cases referred urgently and routinely by

clinicians with different experience levels. The years of experience were calculated based upon the graduating year of the clinician, which was available through the University of Alberta. The graduation year of 25 of the dentists could not be retrieved, and they were subsequently not included in this part of the analysis. 95% confidence limits for the proportion of urgent referrals were calculated using the Wilson score.

Years' Experience of Dentist	Routine Referrals	Urgent Referrals	Proportion of Cases Designated as Urgent*
0-9	153	31	16.8% (12.1-22.9%)
10-19	173	27	13.5% (9.5-18.9%)
20-29	170	33	16.3% (11.8-22.0%)
30+	114	26	18.6% (13.0-25.8%)

Table 7 - Urgent and Routine Cases and	Years of Experience
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95% CI (Wilson Score)

The reason for the referral and rate of urgency can be found in Table 8. Overall, most cases were referred an average of 15.0% urgent. Ulceration was found to be the most common urgent reason for referral (28.8%), while white and/or red lesions were least frequently urgently referred (9.4%).

Referral Category	Routine	Urgent	Total	Proportion of Cases Designated as
	Referrals	Referrals	Referrals	Urgent*
Ulceration	74	30	104	28.8% (21.0-38.2%)
Other	30	8	38	21.0% (11.1-36.3%)
Altered sensation	29	7	36	19.4% (9.8-35.0%)
Pain	83	17	100	17.0% (10.9-26.1%)
Pigmented lesions	27	5	32	15.6% (6.9-31.8%)
Raised soft tissue	186	33	219	15.1% (10.9-20.4%)
lesion				
Specific diagnosis	38	6	44	13.6% (6.4-26.7%)
White and/or red	318	33	351	9.4% (6.8-12.9%)
lesion				
*95% CI (Wilson Score)	785	139	924	15.0% (12.8-17.6%)

Table 8 : Type of Lesions in Relation to Routine and Urgent Referrals

\*95% CI (Wilson Score)

Consideration was also given to the location of the lesion, and how it correlated with the urgency of referral. Table 9 shows the rate of urgency as related to the site of referral. Locations documented as other (nose, TMJ, tooth, cheek, parotid or maxilla) represented the most frequently urgently referred locations; however, they represent a small portion of the overall referrals. Overall, most lesions were referred at approximately the same rate of urgency (~15%).

Location of lesion	Urgent Referrals	Total Referrals	Proportion of Cases Designated as Urgent*
Other	3	11	27.3% (9.7-56.6%)
Tongue	34	201	16.9% (12.4-22.7%)
Mandible	1	6	16.7% (3.0-56.4%)
None provided	30	185	16.2% (11.6-22.2%)
Gingiva	26	163	16.0% (11.1-22.4%)
Lip	9	57	15.8% (8.5-27.4%)
Floor of mouth	4	26	15.4% (6.2-33.5%)
Palate	10	69	14.5% (8.1-24.7%)
Oropharynx	6	50	12.0% (5.6-23.8%)
Buccal mucosa	16	156	10.3% (6.4-16.0%)
*95% CI (Wilson Score)	139	924	15.0% (12.9-17.5%)

Table 9 -	Location	of Lesion a	nd Urgent Cases
1 4010 7	Locution	or Lesion u	

\*95% CI (Wilson Score)

The rate of urgent referral and final diagnosis correlation will be discussed in the next subsection.

## 2.6. Final Diagnosis

While collecting the data, each diagnosis was classified into one of 10 diagnostic groupings, using the taxonomy outlined by Villa et al <sup>38</sup>. The categories, with examples of each, can be seen in Table 10. Every case (924) included in the analysis had a final diagnosis. For each case, only one final diagnosis was provided. In some cases, such as lichen planus, there is occasionally a superimposed candida infection. In these patients, the final diagnosis was considered immune-mediated (lichen planus), as the candidiasis was superimposed. A diagnosis

of an infection was only provided if that was the sole reason for the pathology. One difference in the groupings of this study from the Villa et al. study, is the introduction of a separate category called: Other – normal anatomy. This group is particularly insightful, as referrals for cases that turn out to be normal anatomy reflect a lack of knowledge on the part of the referring clinician, and as such, indicate a potential opportunity for teaching. Immune-mediated conditions were the most frequently referred cases to the clinic with 28.7% of all patients having one of these conditions. Benign tumours and neoplasms represented the second most commonly referred grouping with 18.2% of all referrals. Of relevance, 13.0% (120) of all cases seen represented dysplasia or cancerous lesions. Dysplasia is a well-recognized precursor to oral cancer and requires close monitoring and follow-up.

The rate that each diagnostic grouping was referred urgently can be found in Table 11. As would be expected, normal anatomy was referred urgently least frequently. Osteonecrosis and infections represented the most commonly urgently referred diagnoses, with 28.6% and 24.3% urgency rates respectively. Table 12 correlates the final diagnosis and the years' experience of the referring dentist.

Diagnosis Category	Common Examples	Number of Cases	Proportion of Total Cases
Immune-mediated	Lichen planus, aphthous ulcer	265	28.7%
Benign Tumours/Neoplasms	Fibroma, papilloma	168	18.2%
Dysplasia/Cancerous Lesions	Leukoplakia, oral carcinoma	120	13.0%
Other	Glossitis, amalgam tattoo	80	8.7%
Reactive Keratosis	Hairy tongue, benign keratosis	79	8.6%
Orofacial Pain Disorders	Burning mouth syndrome, TMD	77	8.3%
Other - normal anatomy	Mandibular torus, palatal tonsil	50	5.4%
Salivary Gland Disorders	Xerostomia, Sjögrens syndrome	41	4.4%
Infections	Candidiasis, herpes, fungal	37	4.0%
Osteonecrosis of the jaw	Medication related, spontaneous.	7	0.8%

Table 10 - Final Diagnosis - Number of Cases

Diagnosis Category	Routine	Urgent	Total Referrals	Proportion of Cases Designated as Urgent*
Osteonecrosis of the jaw	5	2	7	28.6% (8.2-64.1%)
Infections	28	9	37	24.3% (13.4-40.1%)
Orofacial Pain Disorders	61	16	77	20.8% (13.2 - 31.1%)
Other	64	16	80	20.0% (12.7-30.1%)
Dysplasia/Cancerous Lesions	97	23	120	19.2% (13.1-27.1%)
Benign Tumours/Neoplasms	142	26	168	15.5% (10.8-21.7%)
Reactive Keratosis	69	10	79	12.7% (7.0-21.8%)
Salivary Gland Disorders	36	5	41	12.2% (5.3-25.5%)
Immune-mediated	236	29	265	10.9% (7.7-15.3%)
Other - normal anatomy	47	3	50	6.0% (2.1-16.2%)
Total	785	139	924	15.0% (12.9-17.5%)

Table 11 - Final Diagnosis and Urgent or Routine Referral

\*95% CI (Wilson Score)

Diagnostic Category	0-9 Years Experience*	10-19 Years Experience*	20-29 Years Experience*	30+Years Experience*
Benign Tumours	26.% (20.3- 32.9%)	15.5% (11.1- 21.2%)	20.2% (15.3- 26.3%)	10.7% (6.6- 17.3%)
Dysplasia Lesions	11.4% (7.6- 16.8%)	13.5% (9.2-19.2%)	14.8% (10.6- 20.3%)	12.9% (8.3- 19.4%)
Immune mediated	21.2% (15.9- 27.7%)	26.5%(20.9- 33.3%)	29.6% (23.7- 36.2%)	40.0% (32.3- 48.3%)
Infections	1.6% (0.6-4.7%)	4.0% (2.0-7.7%)	5.4% (3.0-9.4%)	4.3% (2.0-9.0%)
Orofacial pain	5.4% (3.0-9.7%)	11.5% (7.6-17.0%)	7.9% (4.9-12.4%)	7.9% (4.4-13.5%)
Osteonecrosis	0.0% (0.0-2.5%)	2.0% (0.8-5.0%)	0.0% (0.0-1.9%)	2.1% (0.7-6.11%)
Other	12.5% (8.5- 18.0%)	7.0% (4.2-11.7%)	5.4% (3.0-9.4%)	8.6% (5.0-14.8%)
Normal anatomy	7.0% (4.2-11.7%)	3.5% (1.7-7.4%)	4.4% (2.4-8.2%)	3.6% (1.5-8.1%)
Reactive Keratosis	10.9% (7.1- 16.1%)	12.0% (8.0-17.5%)	6.4% (3.8-10.9%)	8.6% (5.0-14.8%)
Salivary gland	3.8% (1.9-7.6%)	4.5% (2.4-8.6%)	5.9% (3.4-10.5%)	1.4% (0.4-5.1%)
Total	100%	100%	100%	100%

Table 12 - Final Diagnosis and Practitioner Years of Experience

\*95% CI (Wilson Score)

## 2.7. Accuracy of Referrals

For every referral, the referring clinician has the option to provide their clinical interpretation. The referring clinicians are not, however, required to provide their own opinion, which is referred to as provisional diagnosis. The presence of a provisional diagnosis does not necessarily indicate that the referring clinician knows precisely what is occurring in the patient,

but it does often provide useful information to the specialty clinic in regard to the presentation of the lesion at the time it was first noticed. The accuracy of the provisional diagnoses can also be used to give a sense of the confidence of the referring clinicians. This data can help provide insight into knowledge gaps of the referring clinicians.

The accuracy of referrals of different types of clinicians was determined. Each medical and dental subspecialty was assessed and a comparison between dentists and physicians was made. This information can be seen in Tables 13, 14 and 15.

Clinician Type	Incorrect Provisional Diagnosis	Correct Provisional Diagnosis	Total Provisionals Provided	Total Referrals Provided	Proportion Correct*
Oral Surgeon	1	5	6	14	83.3%
Prosthodontist	1	2	3	10	66.7%
General Dentist	70	102	172	688	59.3%
Periodontist	4	4	8	18	50.0%
Endodontist	2	0	2	15	0.0%
Orthodontist	0	0	0	5	-
Oral Medicine	0	0	0	2	-
Dental Total	78	113	191	752	59.2%

Table 13 - Accuracy of Provisional Diagnosis and Dental Clinician Type

\*of all provisional diagnoses provided

Clinician Type	Incorrect Provisional Diagnosis	Correct Provisional Diagnosis	Total Provisionals Provided	Total Referrals Provided	Proportion Correct*
GP	11	23	34	146	67.6%
Dermatologist	1	8	9	16	88.9%
ENT specialist	1	2	3	8	66.7%
Rheumatologist	1	0	1	2	0.0%
Medical Total	14	33	47	172	70.2%

Table 14 - Accuracy of Provisional Diagnosis and Medical Clinician Type

\*of all provisional diagnoses provided

Table 15 - Accuracy of Provisional Diagnosis - Medical and Dental

Clinician Type	Incorrect Provisional Diagnosis	Correct Provisional Diagnosis	Total Provisionals Provided	Proportion Correct*
Dental Total	78	113	191	59.2% (52.1- 65.9%)
Medical Total	14	33	47	70.2% (56.0- 82.2%)

\*95% CI (Wilson Score)

As the Tables indicate, approximately 59.2% of all provisional diagnoses from dentists were accurate, while 70.2% of all provisional diagnoses from physicians were correct. About 25% of all referrals included a provisional diagnosis, with means the majority of referrals did not include a provisional diagnosis.

The accuracy of referrals of dentists based on years of work experience was calculated and is seen in Table 16. The different groupings were categorized into ten-year intervals. The accuracy of referrals between the various groupings showed no clear pattern. Of the least experienced cohort, 64.8% provided accurate diagnoses, while 61.1% of the most experienced cohort provided accurate diagnoses. It is also worth noting that the younger, less experienced group provided a provisional diagnosis more frequently (29%) as compared to the most experienced cohort (26%), although this was not statistically significant.

Experience Grouping (years)	Incorrect Provisional Diagnosis	Correct Provisional Diagnosis	Total Provisionals Provided	Proportion Correct*
0-9	19	35	54	64.8% (51.5- 76.2%)
10-19	21	27	48	56.3% (42.3- 69.3%)
20-29	21	28	49	57.1% (43.3- 70.0%)
30+	14	22	36	61.1% (44.87- 75.2%)

Table 16 - Accuracy of Referrals for Different	t Experience Groupings
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\*of all provisional diagnoses provided

The accuracy of referrals for different final diagnostic groupings was also considered in Table 17. This data can be used to assess what type of disease categories require more attention by the referring clinicians and which types of disease processes referring clinicians are confident with interpreting. Salivary gland disorders, osteonecrosis, and dysplasia were most frequently referred accurately. The immune mediated conditions, as well as reactive keratosis, were referred less accurately. Once a better understanding of which disease processes are referred more frequently, as well as which ones are associated with greater clinician knowledge, training programs can be developed to address the deficiencies.

Table 17 - Accuracy o	f Referrals for Different	Diagnostic	Groupings
5		0	1 0

Diagnostic Groupings	Incorrect Provisional Diagnosis	Correct Provisional Diagnosis	Proportion Correct*	Proportion with No Provisional Provided
Osteonecrosis of the jaw	0	1	100.0% (20.7- 100.0%)	85.7%
Salivary Gland Disorders	1	7	87.5% (52.9- 97.8%)	80.5%
Dysplasia and Cancerous Lesions	8	23	74.2% (56.8- 86.3%)	74.2%
Benign Tumours/Neoplasms	10	25	71.4% (55.0 – 83.7%)	79.2%
Orofacial Pain Disorders	7	15	68.2% (47.3- 83.6%)	71.4%
Immune-mediated	38	66	63.5% (53.9- 72.1%)	60.8%
Other	3	3	50.0% (18.8- 81.2%)	92.5%
Infections	6	5	45.5% (21.3%- 72.0%)	70.3%
Reactive Keratosis	11	3	21.4% (7.8- 47.6%)	82.3%
Other - normal anatomy	6	0	0.0% (0.0- 39.0%)	88.0%

\*95% CI (Wilson Score)

#### 2.8. Distance Traveled by Patients

The distance traveled by patients to the Oral Medicine clinic (located in Kaye Edmonton Clinic, Edmonton, Alberta) was calculated based on the patients' home postal code. The distance was then calculated using GoogleMaps, which calculated the closest distance by car. The average distance traveled by the patients is seen in Table 18.

Table 18 -	Distance	Traveled	by	Patients

Average distance	55.44km
Median distance	16.60km
Maximum distance	2028.00km
Minimum distance	1.40km

After calculating each distance, the distances were categorized into segments. The distances were calculated as 0-15 km (Edmonton proper), 16-50 km (including all of the immediate surrounding area), 51-100 km (catchment area which included: Westlock, Camrose, Wetaskiwin), 101-200 (included as far south as Red Deer and near the Saskatchewan border) and >200km which includes all other locations. The population calculation for >200km was not computed, as it is not possible to assess what population beyond a 200km circumference would be referred to the Oral Medicine clinic in Edmonton. The populations of the areas were calculated using census data (Municipal Affairs: municipal census and population lists) as provided by the Government of Alberta for 2015. Tables 19 and 20 show the number of patients traveling from different regions of the province. The greatest percentage of patients coming into the clinic came from Edmonton proper. The surrounding area, including Fort Saskatchewan, Strathcona County, Leduc, Spruce Grove and Stony Plain accounted for the second largest proportion of referrals.

Distance to Appointment (km)	Routine Referrals	Urgent Referrals	Total Referrals	Proportion of Total Referral (/924)	Proportion Urgent
0-15	361	79	440	47.6%	18.0% (14.7- 21.8%)
16-50	297	41	338	36.6%	12.1% (9.1- 16.0%)
51-100	38	4	42	4.5%	9.5% (3.8- 22.1%)
101-200	31	3	34	3.7%	8.8% (3.0- 23.0%)
>200	58	12	70	7.6%	17.1% (10.1- 27.6%)

Table 19 - Distance to Clinic and Rate of Urgency

\*95% CI Urgent (Wilson Score)

The number of people living in Alberta in the designated distances from Kaye Edmonton Clinic is found in Table 20, as well as the percentage of each population that was seen in the clinic.

Distance to Appointment (km)	Population within this Region	Total Referrals	Proportion of Total Referrals
0-15	877,926	440	47.6% (44.4-50.8%)
16-50	297,041	338	36.6% (33.5-39.7%)
51-100	69,676	42	4.5% (3.4%-6.1%)
101-200	243,437	34	3.7% (2.6-5.1%)
>200	Indeterminate**	70	7.6% (6.0-9.4%)

Table 20 - Distance to Clinic and Relative Population

\*\*This includes all population that extends beyond 200km circumference of Edmonton, AB

Almost half of all of the patients seen in the Oral Medicine Clinic were from within Edmonton proper. 15.8% of the patients seen in the clinic traveled over 50 km. The further distances from Edmonton have smaller percentages of patients seen in the clinic.

Of particular relevance and importance, calculations relating to patients diagnosed with oral dysplasia or oral cancer were calculated and can be seen in Table 21. The majority of oral dysplasia and cancer patients were from within the city of Edmonton. The further distances did not have as many cases of dysplasia and cancer. These findings are critical, as it is well recognized that lesions exhibiting dysplasia have an increased risk of malignant transformation. Table 21 - Distance to Clinic and Oral Cancer Cases

Distance Category (KM)	Count of Dysplasia and Cancer Conditions
0-15	63
16-50	41
51-100	7
101-200	4
>200	5

## 2.9. Time Waited by Patients

The length of wait time for patients was calculated based upon the date the referral was first made, as found in the referral letter, and the date the patient was first seen in the clinic. The average wait times for the patients can be seen in Table 22. The average wait for patients was 105.5 days or approximately 3 and a half months. The maximum wait time was 905 days. However, that particular wait may be a function of access times to clinic and personal access issues of this particular patient.

Table 22 - Wait Time Between Referral and First Appointment

Average	105.5 days
Median	93 days
Maximum	905 days
Minimum	1 day
Std. Deviation	75.3 days

There are several critical wait times that have been implicated in increasing levels of patient physical and psychological stress. Wait periods of one month and three months have been shown to represent important landmarks as relating to patient stress levels, with increasing stress occurring beyond three months <sup>87, 88</sup>. Therefore, patients were categorized into these groups, as seen in Table 23. Most patients (52%) were seen past 90 days.

Table 23 - Patient Wait Times

Days Until First Appointment	Count (number of patients)
0-30	100
31-90	340
>90	484
Grand Total	924

To get a better sense of how timely urgent referrals were seen, the time until the first appointment was also broken down into smaller segments by week. Table 24 shows the rate of urgent referrals. Urgently referred cases were sometimes seen in a timely manner in the clinic and 65% of all the patients seen within 2 weeks were urgent referrals, indicating an effort is made to see urgent referrals quicker. However, of all 139 urgent referrals, only 26 were seen in this critical 2-week period, indicating significant room for improvement.

Days Until First Appointment	Routine Referrals	Urgent Referrals	Total Referrals	Proportion*
0-14 (0-2 weeks)	14	26	40	65.0% (49.5-77.9%)
15-28 (2-4 weeks)	28	24	52	46.2% (33.3-60.0%)
29-56 (4-8 weeks)	89	29	118	24.6% (17.7-33.1%)
57-112 (8-16 weeks)	359	40	399	10.0% (7.5-13.4%)
113-168 (16-24 weeks)	168	12	180	6.7% (3.9-11.3%)
169-336 (24-48 weeks)	113	8	121	6.6% (3.4-13.0%)
>337 (>48 weeks)	14	0	14	0.0% (0-26.8%)
Total	785	139	924	15.0% (12.9- 17.5%)

Table 24 - Wait time and Routine and Urgent Referrals

\*Urgent 95% CI (Wilson Score)

Of note, the average wait time for urgent referrals of all types was 59.0 days, while the average wait time for routine referrals was 113.8 days.

#### 3. Discussion

This study represents a review of 924 patients who were referred for consultation in the Oral Medicine Clinic at the University of Alberta for one full calendar year. Several parameters including the referral source, the diagnosis, the wait time, and distance traveled were considered in the analysis. A two-sided Fisher's exact test was used to test for significance when comparing proportions within the data set. The Fisher's exact test was utilized as the data acquired represents a sample of all of the patients across Alberta who would be referred for the assessment of oral and maxillofacial lesions. Since patients with these conditions are frequently referred to other specialties, such as oral and maxillofacial surgeons and ENT surgeons, this data set is not

representative of all patients and all referrals across the province. For this reason, a Z-score comparing two proportions was not utilized. Fisher's exact test was used instead of a Chi-Square test as some of the data points are small numbers, as Fisher's exact test is more powerful when including numbers below 5.

The adequacy of the referrals, and assessment of clinicians' knowledge, is complicated by the fact that a lesion or condition must be noticed in the first place before a referral can be made. Particularly relevant information would be how frequently lesions are completely missed by clinicians. However, this study cannot quantify or assess this. Even a clinician who refers a patient, who turns out to simply exhibit a variation of normal anatomy, may be performing a more comprehensive oral examination than the clinicians who fail to notice abnormalities completely. This makes application of these conclusions difficult to apply broadly across all dentists and physicians in Alberta. The remainder of analysis only applies to the clinicians who are actively referring patients. To provide a complete analysis of the competency of all clinicians, a different study would need to be undertaken.

It is not possible in this study to assess why a referral was made initially. In addition to the obvious use of referrals to obtain a diagnosis when the referring clinician does not know what is occurring, there can be several other reasons referrals are made. Some clinicians may refer patients at the request of the patient, particularly in patients with a heightened sense of fear of a grave diagnosis, such as oral cancer. Another reason a clinician may refer a patient is to provide additional support in regard to medico-legal situations. A clinician may be confident in their interpretation but fearful of possible implications of a missed diagnosis.

#### 3.1. Patient Age and Gender

The demographics of gender and age of the University of Alberta Oral Medicine Clinic can be compared with that of other countries. This study data shows that 61% of the patients in this clinic were female with a mean age of 56.6 years old. Riordain et al. found similar statistics, as most patients were in their 4th-6th decade <sup>37</sup>. Those authors found a mean age of 46.6, with females being more common than males. The fact that more women than men are referred does not fit with oral lesion prevalence studies, however there may be several reasons why women are seeking care in the first place and that may account for their increased proportion in the referral population <sup>17</sup>. An Australian study <sup>36</sup> had similar statistics, with approximately 60% of all patients being female, with the average age being 51. The study by Villa et al. reported 63.8% women, with a median age of 56 years old  $^{38}$ . Haberland et al. showed an average age of 51.3, with females being more common than males  $(62\%)^{29}$ . Jovanovic found similar results in Netherlands, with a mean age of approximately 50, with a preponderance of women compared to men<sup>26</sup>. This data indicates that the age and gender of patients admitted to the Oral Medicine Clinic at the University of Alberta are similar to, and consistent with, what is reported across different first world countries. It has been shown that men are less likely to seek care for their health concerns <sup>96</sup>. It is plausible that men are less likely to go to their general dentist or GP to have complete assessments completed and, if a referral is initiated, they are less likely to go to the subsequent appointment. Further research could be completed to determine why women more commonly seek Oral Medicine care.

#### **3.2. Source of Referral**

In the study, general dentists were the most frequent referring clinician, accounting for 81.4 % of referrals. This represented approximately 19% of all general dentists in Alberta. This
is a high proportion of dentists, considering a significant number would likely refer to clinicians in Calgary due to proximity. This was an expected finding, as dental professionals are known to refer most frequently to other dental professionals, and general dentists make up the greatest proportion of dental clinicians in Alberta (87%, 2300/2631) <sup>95</sup>. Also of interest, is the fact that 14% of all dental specialists in the province referred cases to the clinic, which is less than general dentists. This could be interpreted as dental specialists having a greater knowledge to manage oral conditions and thus not needing to refer as many cases to the Oral Medicine Clinic. Alternatively, it may indicate that by the time a patient is referred to another specialist, an initial examination has already been performed, and it is likely that the distinct pathologies will have already been referred. Another confounding variable is that patients can sometimes be seen for a less expensive, specific examination in the Oral Medicine Clinic when compared to other dental specialty clinics. This may lead to general dentists referring a wider variety of cases to the Oral Medicine Clinic to aid in the patient's financial situation. This study cannot provide an exact reason for these referral rates, but it is likely that several factors play a role. A further study could examine these reasons and could include a direct survey or assessment of referring clinicians to assess their ability to diagnose standardized cases adequately.

In comparison to the dental cohort, 18.6% of referrals came from physicians. Of all the GPs in Alberta, approximately 2.5% of them referred to the University of Alberta's Oral Medicine Clinic. This may indicate the need for greater awareness amongst the medical profession for this dental specialty. There are many overlap cases and disease processes that can be managed by medical specialties (ENT and dermatology, for example). However, there are many conditions that would best be treated in an Oral Medicine Clinic. The results align with results of an Australian study that found that 18% of their Oral Medicine referrals came from

physicians, with GPs making up 11% of the referrals  $^{36}$ . It is worth noting that Australia has a similar health care system to Canada, wherein the medical care is universal, while dental care is delivered through a private practice, non-universal system. In contrast to these results, a study by Villa, found that two-thirds of all referrals came from physicians <sup>38</sup>. Only 22.2% of referrals came from general dental practitioners. This is an interesting finding, as the University of Alberta Oral Medicine Clinic is also located within a hospital setting, much like the clinic in the Villa study. This relatively small percentage of physician referrals may represent a lack of awareness amongst those clinicians of the Oral Medicine services available to them in Edmonton. It may also reflect a preference for alternative referral sources. A different study out of the USA found 55% of referrals to an oral pathology clinic came from dental professionals, and the remainder coming from physicians <sup>29</sup>. An Irish study found 73.8% of all referrals from dental practitioners, with the remaining coming from physicians <sup>37</sup>. A study out of the Netherlands found an approximately equal number of referrals from dentists and physicians for the evaluation of oral mucosal disease <sup>26</sup>. These significant variations in referrals from physicians, when comparing the University of Alberta clinic to other Oral Medicine clinics, is likely related to a number of factors. It is possible that given the long wait times for patient assessment, physicians are more likely to refer to more expedited routes within the medical community, while dentists are often less confident in referring patients outside the dental community. It is also plausible that some dentists direct their patients with certain oral conditions/lesions to their GPs, who subsequently refer to a medical specialist. This may also indicate a lack of awareness amongst the medical professionals in Alberta as to the resource Oral Medicine specialists can be for their patients. Despite the fact that it is difficult to provide a definitive reason for the trends observed, it is clear that the greatest number of referrals come

from general dentists to the University of Alberta's Oral Medicine Clinic, and physicians contribute a significantly smaller proportion of patients. Increasing awareness amongst medical practitioners of the service that Oral Medicine specialists provide would improve patient access to Oral Medicine specialty care. Increased referrals, however, would potentially lead to further delays in patient care unless there is a concomitant increase in the number of Oral Medicine specialists to care for these patients.

#### **3.3. Reasons for Referral**

The reason provided by the referring clinician on the referral form is generally a clinical descriptor. In this study, these different descriptors were grouped based on past research. The most common reasons for referrals to the University of Alberta's Oral Medicine Clinic were white and/or red lesions (38.0%) and raised soft tissue lesions (10.8%). Pain conditions represented only 10.8% while ulceration represented 11.3% of all referrals. As seen in the Riordain et al. study, white lesions were the most commonly referred lesion (17.2%) with raised soft tissue lesions and ulceration being the second and third most referred conditions <sup>37</sup>. Pain represented 14.3% of their referrals. A critical difference between the Irish study and this study is that there is a separate TMD/Orofacial Pain Clinic that operates in conjunction with the Oral Medicine clinic at the University of Alberta, so the number of pain cases in this study was expected to be significantly lower. Often, referrals made to the Oral Medicine Clinic are directly transferred to the TMD/Orofacial Pain Clinic to expedite appropriate patient management. In an Australian study<sup>36</sup>, which divided referrals based on whether the referral was to a hospital versus a private clinic setting, leukoplakia (a white patch) was the most common reason for referrals to the hospital clinic, while soft tissue lump was the most common reason for

referral to the private clinic. Ulceration was the reason for approximately 10% of the referrals in that study, which is very similar to the data found in this study.

Lin et al assessed referrals in a gate-keeper model of healthcare <sup>97</sup>. A gate-keeper model exists when access to specialty care is designated to primary care providers. This is the case in most Oral Medicine clinics, as patients will not be seen without a referral. The goal of the gate-keeper model is to perform quality control of referrals and to ensure that only the difficult-to-diagnose, or difficult-to-manage cases are seen by specialists. In some cases, it is the patient who desires a specialty referral, even if the primary care clinician does not see a reason to send the referral. There are a variety of reasons patients themselves desire specialty referral, with reassurance of diagnosis or a previous referral to the specialists (the patient has seen the specialist for another concern and would like to see them again) being the most common reasons. This was not taken into consideration in our study, as it is not possible to determine from the referral letter in most cases if the primary concern was that of the clinician or the patient. Some referrals may not represent a clinical concern and subsequent referral by the GP/dentist; rather, it represents a desire of the patient to have a second opinion from a specialist in the area.

Another important aspect to consider is the patients' perception of their referrals. This study did not assess patients' opinions or values. An Australian study found that approximately 50% of all patients knew of their condition before seeking treatment from their first point of health care contact <sup>85</sup>. 91% of these patients had a reason for seeking care, with the most common reasons being: 1) desire for explanation 2) being advised by health care provider and 3) presence of pain. This highlights the importance of patients' attitudes toward initiating their referral process. Allen and Farah also indicated that 92% of their reported patients seen had heard of someone who had oral cancer in the past, which frequently increases the anxiety of

patients. It is useful to the clinician when the patient brings the pathology to their attention, but it is worth noting that Allen and Farah found that approximately 50% of the time the patient was unaware of the pathology <sup>85</sup>. This highlights not only the importance of asking patients at every appointment if they feel any abnormalities in their mouth, but also of routine screening. Sometimes patients will not bring concerns to the awareness of the clinician if they are being seen for something different altogether (for example, a standard dental restorative procedure). It is important to know that the general public has little awareness of the presenting symptoms of oral cancer <sup>98</sup> and, as such, they may miss changes indicative of oral cancer, or conversely may become anxious and obsess over other innocuous changes or variations of normal anatomy. Also, of consequence, is that the group of people who are most likely to present with oral cancer (older men) frequently have the least knowledge of presenting signs/symptoms and risk factors of oral cancer. Articulating the reason for a referral to the patient is a major step in the referral process and must be stressed by all dentists and physicians. Assessing and analyzing patient's opinions and response to referrals in Alberta would be a potential future area of research, to see if Albertans are similar to patients from other countries regarding their opinions and attitudes of referral.

#### **3.4. Location of Referral**

Many referral pads, including the referral pads at the University of Alberta, do not require specific details about the condition in question. Information regarding lesion location and appearance or pertinent medical information is not required. The referral forms to the clinic require patient demographics to be provided and then provide a space for the referring clinician to fill in clinical parameters at their discretion. On a positive note, the majority of the referrals at least provided a location of the lesion to be assessed. The tongue, followed by the gingiva and

buccal mucosa (21.8%, 17.6%, and 16.9% respectively), were the most common sites for the referred lesions in this study. Cases where no location was provided in the referral also represented a large proportion, with 20% of all referrals not having a site listed. There are several reasons that no location may be given. Primarily, there may be a general pain condition in which the entire oral region is involved. Also, lesions may be transient and include multiple locations, so no specific locations are provided. It is likely that in many cases, the referring clinician neglected or forgot to include the location of the lesion. Riordain et al. found the tongue to be the most common area (43.3%) with the gingiva being second (16.3%) and buccal mucosa (14.7%) being the next most common. The floor of the mouth represented the least common location  $(6.1\%)^{37}$ . Farah et al. also found the tongue to be the most common location of lesions, with the buccal mucosa being the second most common site for lesions. The floor of mouth was again the least frequent area or lesion location<sup>36</sup>. Including sections on the referral pads, such as time frame of lesions, the presence of pain, and evolution of the lesion would provide better information to the specialist to help compliment information on location, but it is unclear if it would have any effect on how many patients would be referred, or how much information would be included in the referrals.

This study had a particular focus on the difference of referral locations between medical and dental practitioners. It was found that the physician referrals more frequently involved the tongue and lips (statistically significant) as compared to the dentists. Physicians referred cases involving the tongue 54 times out of 171 cases and the lips 23 times out of 171 cases. Dentists referred cases involving the tongue 147 times out of 753 cases and the lips 34 times out of 753 cases. Looking specifically at these two locations, statistical analysis (two-sided Fisher's exact test) confirmed that there is a statistically significant difference in which dentists and physicians

refer cases of the tongue (p = 0.001 Fisher's exact test) and the lips (p < 0.001 Fisher's exact test), with physicians referring cases involving these locations more frequently. This is not an unexpected finding as the tongue and lips are areas that are readily visible with minimal examination and don't involve a thorough intraoral examination as is delivered by dentists. A further evaluation into whether physicians and dentists refer certain locations more frequently because of examination style as opposed to the actual incidence of lesions would be an area of more research. Further, developing intraoral examination skills by GPs, particularly for patients who cannot afford dental care, may help identify and manage oral conditions sooner. Alternatively, dentists may need further training in the evaluation of patient's lips, as this is an area that is easily overlooked when dentists focus solely on intraoral issues.

### 3.5. Experience of Dentists: Years since graduation

Referrals to the Oral Medicine Clinic came from dentists with a broad range of experience, ranging from newly graduated dentists to dentists with over 40 years of experience. The experience of clinicians was anticipated to play a role in the clinical management of patients, as it was expected that more experienced dentists would be less likely to send in referrals for low-risk cases and that more experienced clinicians would be more accurate with their provisional diagnoses. It was expected that less experienced clinicians would likely encounter cases that they have never seen before and would, therefore, refer cases that probably do not require management in an Oral Medicine Clinic. Analogously, experience has been found to lead to more confident treatment of other dental conditions, such as TMD conditions <sup>52</sup>. However, Alami et al. also found that more experienced clinicians did not gain any increased knowledge of oral cancer as they got older <sup>66</sup>. This lack of improved awareness is plausible given the infrequency of which a general dentist will come across a case of oral cancer. Such

infrequent exposure may not allow consolidation of knowledge and experience regarding this condition. There is a paucity of studies directly assessing the clinical judgment and referral patterns of dentists with different levels of experience regarding oral mucosal disease.

Dentists of all experience levels referred cases urgently at similar rates, approximately 15%. This study had hypothesized that younger, less experienced dentists would be more likely to refer cases as urgent due to a higher index of suspicion and lack of exposure to different conditions, but this was not found to be the case.

This study also assessed how accurate the provisional diagnoses were for various clinician experience levels. The accuracy across all groups was similar, approximately 60% correct. The 0-9 years' experience grouping exhibited the highest proportion of accurate referrals (64.8%), but it was not statistically significant different from the 10-19 year experience group, which had the lowest proportion of accurate referrals (56.3%) (p=0.784 Fisher's exact test).

In regard to diagnoses which would be considered low-risk (variations of normal anatomy), the least experienced cohort did refer these more frequently (13 out of 184 cases, 7.0%) than the other groupings, but it was not found to be statistically significant when compared to the group that referred it least commonly, (10-19 years' experience had 7 cases of normal anatomy out of 200 total) (p=0.180 Fisher's exact test).

The most experienced dentists referred benign tumours/masses significantly less frequently (15 out of 140 cases) than the least experienced grouping (48 cases out of 184) (p < 0.001 Fisher's exact test). There are a few possible explanations for this. More experienced dentists may have more experience performing biopsies themselves and are therefore less likely to refer patients for simple nodule removal. This does not conform with the Cottrell et al. study,

which found that younger dentists performed more simple dentoalveolar surgical procedures than older dentists <sup>99</sup>. Although a biopsy is not technically a dentoalveolar procedure, proficiency in basic surgical protocol would allow a dentist to perform a simple biopsy. In the current Alberta dental school curriculum, biopsies are not routinely performed by dental students and the opportunity to do so is quite limited. It is likely that newly graduated dentists would not have a high confidence level to perform biopsies. There was a statistically significant difference in the rate at which immune mediated conditions are referred by the youngest experience cohort and the most experienced cohort (p = 0.002 Fisher's exact test), with the most experienced group referring these cases more frequently. This may be due to the fact younger dentists have more current knowledge of some of these conditions due to their more recent education at dental school. Alternatively, more experienced dentists may be more proficient at identifying slight tissue changes representing immune conditions and therefore refer more of those cases. Further research would be required to assess why these differences in final diagnosis referral patterns exist between different experience levels in clinicians. Unfortunately, the number of dentists across Alberta in each experience category was not available information. This would have been used to compare relative proportions of each experience bracket who referred cases, and as such would provide information on what effect the experience of clinician would have on the likelihood of referring cases.

There are many factors in regard to dentist experience that can affect referrals. The number of patients seen by different practitioners would have a noticeable effect on the number of referrals. Dentists in the prime of their careers who have larger, more established patient bases may see more numbers of patients. Alternatively, a younger dentist may work longer hours and see many patients that way. Also, if the dentist is seeing fewer patients, but providing

more thorough assessment, it is possible that asymptomatic, not clinically obvious lesions may be noticed sooner. Due to these personal and experiential variables, no definitive conclusions can be drawn from this study about the effect of the experience of dentists on their referrals to Oral Medicine specialty practice. All the different groupings showed similar rates of accuracy and types of referrals. It is likely that dentists across the board would benefit from further training and continued education in Oral Medicine topics.

#### **3.6. Urgency of Referrals**

A unique consideration of this study was looking at how frequently cases were referred urgently, and how this correlated with different variables. 15.0% of all referred cases were referred urgently. Of statistical significance was the fact that 16.9% of dental referrals were urgent, while only 7.0% of physician referrals were considered urgent (p<0.001 Fisher's exact test). There are several potential reasons for this finding. Primarily, physicians encounter significant disease, including life threatening conditions more frequently than general dentists. Consequently, different clinical presentations may not evoke the same level of urgency in physicians as it would in dentists. Also, the knowledge of oral conditions and diseases is higher in dental practitioners than medical practitioners and, as a result, dentists may be aware of the potential adverse outcomes of different oral conditions. The index of suspicion may be higher for dentists as a result. Schnetler found that medical practitioners had a better appreciation than dental practitioners of some of the secondary signs and symptoms of oral cancer (lymphadenopathy) and referred tumors quicker than dental professionals in many cases 100. This does not appear consistent with the findings of this study, as it was shown that dentists had a higher index of suspicion in this study. However, given the number of cancer cases seen and

the limited insight into referral patterns of physicians, it is not prudent to provide a definitive interpretation.

The rate of urgency and its correlation to lesion location was addressed. The floor of the mouth, lateral tongue and oropharynx are considered high-risk areas for oral malignancy, so it was expected that these sites would have the highest proportion of urgent referrals. The data showed that no particular location exhibited a statistically significant higher rate of urgent referrals as compared to the other sites. A comparison of urgency rates for "other" referrals, which represented the most common urgently referred location, and buccal mucosa, the least urgently referred, showed no statistical difference. (p=0.229 Fisher's exact test). It is worth noting that there is no distinct grouping for the lateral tongue, so these lesions are likely grouped in with dorsal tongue lesions which rarely present with life-threatening disease processes.

This study was not able to ascertain why a referring clinician may refer something as urgent. Painful lesions or lesions that are considered to present a high risk of malignancy should be referred urgently, but it is not known if that is what the referring clinicians considered. A future study involving interviewing clinicians directly could elucidate reasoning behind decisionmaking related to urgent versus routine referrals.

### **3.7. Final Diagnosis – Diagnostic Groupings**

To aid in appropriate categorization, each final diagnosis was divided into one of 10 diagnostic categories. These groups provided a comprehensive framework to outline oral diseases and provide useful insight into what types of cases are seen by Oral Medicine specialists. This knowledge can be used to help direct graduate training programs to ensure trainees focus on areas that will be significant in clinical practice. Also, of importance, is the ability to compare the lesions seen in the Oral Medicine Clinic and the background rate of

different oral diseases in the general population, as discussed earlier. This information will give us insight into how effectively some medical conditions are being managed and what role this Oral Medicine clinic holds within oral disease management as a whole. Complicating this analysis, however, is the fact that Oral Medicine specialists are not the only specialists who provide management of these disease processes and there is significant overlap with other medical and dental specialties, making it difficult to assess what proportion of people with a certain disease are being managed by the appropriate clinicians.

As seen in a variety of studies, <sup>14,16,17</sup> oral mucosal disease is very common, with numbers as high as 15%-60% of the population exhibiting what would be considered oral pathology. Many of these cases involve benign conditions that do not require management (e.g. Fordyce's granules). Other disease processes such as aphthous ulcers (9.7% of the population) or recurrent oral herpes (16.0% prevalence) are ubiquitous and are managed by generalists due to their frequency or are self-managed by patients with over the counter remedies. More critical diseases such as leukoplakia (0.38% prevalence) and lichen planus (2.3% prevalence) are prevalent and require some intervention or definitive diagnosis. Considering the number of patients seen in the Oral Medicine Clinic as compared to the number of patients expected to be seen in Edmonton with a given condition, the Oral Medicine Clinic only sees a tiny proportion of patients with oral mucosal pathology. Only 265 patients were diagnosed with oral lichen planus. However, approximately 23,000 people within Edmonton would likely have oral lichen planus given past studies on prevalence rates.

In comparison with other studies, there are many similarities with our patient population. Haberland et al. found allergic/immunologic diseases to be the most frequent disease category (16.9%)<sup>29</sup>. Pain was a large diagnostic grouping in the Haberland study, as 14% of all patients

had a pain categorization. Pain is a difficult cluster for comparison, as pain is considered a symptom which may be found across all diagnostic groupings. The most common diagnoses in the Haberland study were candidiasis, burning mouth syndrome and lichen planus. In this study, the individual diagnoses found most commonly were lichen planus/lichenoid mucositis (209), leukoplakia (90), frictional keratosis (58), fibroma/fibrous hyperplasia (58), papilloma (45), burning mouth syndrome (30) and candida (20). For the category of candida, this included only cases where a primary candida infection was the primary diagnosis. In cases where there was a superimposed lichenoid reaction or denture irritation, candida was not documented as the final diagnosis. It is possible that there is some inconsistency between the individual specialists and something that is considered leukoplakia by one clinician may be considered a reactive keratosis by another. It is important to note that not all of the diagnoses were histological (biopsy confirmed). Therefore, some lesions considered lichen planus may have actually represented some other disease process.

It was found that reactive keratosis, immune-mediated conditions and infections were most frequently given an inaccurate provisional diagnosis. This finding is likely due to the similarity in appearance of reactive keratosis and leukoplakia. Infections can often present with a varied presentation, in particular candida, which can show as white or red and which may or may not be removable. This broad clinical presentation makes providing an accurate provisional diagnosis more challenging.

The final diagnostic groupings were correlated with the referring practitioner. The data showed that dentists and physicians refer the same types of cases as there was no significant difference in the rate at which different diagnostic groups were referred. Immune-mediated conditions were the most frequently referred cases in both groups, with benign tumours being the

second most common diagnostic grouping by both. This was not unexpected, as both clinician types have roughly the same pool of patients and, as such, would see similar conditions. Of interest is that even though physicians more frequently referred cases involving the tongue and lips, while dentists referred more cases related to the gingival tissues, the final diagnoses proportions were ultimately approximately the same.

#### 3.8. Accuracy of Referrals

In assessing the disease groupings, patients which ended up exhibiting immune-mediated conditions were most frequently given a provisional diagnosis. The "other" category, as well as other-normal anatomy, were less often given a provisional diagnosis. This finding was expected because if the referring clinician was aware or suspected that something was normal anatomy, it is unlikely that a patient would be referred for assessment in the first place. Reactive keratosis was only given an accurate provisional diagnosis 21.4% of the time, which is quite a low frequency. This is to be expected, however, as the reactive keratosis category is a benign condition, in which some low-grade irritant results in hyperkeratosis. These lesions frequently exhibit clinical features of leukoplakia, which is a premalignant condition. Referring clinicians would have a higher sense of suspicion of a lesion that looks like leukoplakia and would likely treat and refer it as such. Therefore, reactive keratosis is often referred as suspected leukoplakia, only to be found to be a reactive process in the specialty clinic.

Villa et al. found that 25.6% of patients presented with a provisional diagnosis, for which 69% of them were correct <sup>38</sup>. These findings were consistent with what this study found. The provisional diagnostic accuracy of dentists as compared to physicians was also assessed. Dentists provided a provisional diagnosis 25.4% of the time, while physicians did 27.3% of the time. Dentists were correct 59.2% (113 out of 191) of the time while physicians were correct 70.2%

(33 out of 47) of the time, which indicates statistically they were correct the same proportion of the time (p = 0.218 Fisher's exact test). This is in contrast to the findings from other studies in the review of literature, which routinely found that physicians commonly reported low levels of confidence in diagnosing these lesions. This is reportedly primarily due to a lack of exposure during medical school training, as well as lack of confidence to maintain and enhance their skillset for oral examination. There are a variety of other reasons which may explain why dentists are unable to provide more accurate provisional diagnoses as compared to physicians given the expectation that the dentist would have better knowledge of oral lesions. Primarily, dentists may be referring more complicated cases, while the more routine cases are managed at the primary care level. Alternatively, this may also indicate that dentists are not more proficient than physicians in dealing with oral diseases, in which case improvement of dental training should be assessed. Future controlled studies, comparing dentists and physicians could be performed to test this question.

Prior studies have made the argument that lack of provisional diagnoses may indicate a lack of knowledge of oral diseases <sup>35</sup>. However, that is difficult to ascertain as a provisional diagnosis is not required on referrals. There are many reasons why a clinician may not include a provisional diagnosis, one of which is uncertainty, but the referring clinician may simply not take the time, or just doesn't think it would be of any benefit to the Oral Medicine clinic. A study in which a provisional diagnosis was a requirement before referral would provide a better assessment of the relative proficiencies of different clinicians. There are cases where a referring clinician knows what a lesion is, but may refer the patient, not for diagnosis, but rather for appropriate treatment. Consideration of whether referrals are for diagnosis, treatment or both would also provide some important information, and is an area for future research. This would

have obvious implications on dental student training as well, as if it was found that deficiencies were more in disease treatment rather than diagnosis, the curriculum could be altered to help address this area of weakness.

#### 3.9. Distance Traveled by Patients

As seen in Tables 16, 17 and 18, the clear majority of patients (778 out of 924 patients, 84%) come from within Edmonton or the immediate surrounding area (within 50km). This is not unexpected as it is well known that increasing distances reduces the likelihood of patients coming in for specialty care <sup>77</sup>. It is possible that dentists located further away from major urban regions have altered their skill set to manage some Oral Medicine cases better so as to limit the need for their patients to travel as far. It could be that referrals are made to specialists who are closer in proximity to where patients live. It is also possible that these patients simply decide not to come in for an appointment. The data regarding declined referrals is not available.

The total proportion of the population that was seen in the Oral Medicine Clinic in different circumferential areas surrounding Edmonton was also calculated. Approximately 0.050% of all people in Edmonton had gone to the Oral Medicine Clinic. Of particular interest, is the fact that a higher percentage of patients from greater Edmonton and immediate surrounding area are seen in the Oral Medicine Clinic as compared to Edmonton proper (0.11% vs 0.050%). There are several potential reasons for this. This may simply represent various referral patterns of different clinicians. In Edmonton, for example, there are many more oral surgery clinics located throughout the city. For some people in some regions of the city, seeing an oral surgeon is simpler and results in less travel time. Patients traveling from outside of Edmonton proper are required to drive a distance regardless, so it is possible that the referring clinician does not alter their referral based on location within Edmonton, rather they send the

patient to the specialist most likely suited to manage the condition. It would be interesting to determine in a separate study why clinicians refer to a particular type of specialty versus another. There may also be financial differences between people located in Edmonton proper and the surrounding communities, which may alter the frequency which they see dentists. If patients are not routinely seeing their dentist, diseases may be missed. The further distances from Edmonton (>100 km) show a decreasing percentage of the population being seen in the Oral Medicine Clinic, which is reasonable as further distances represent a barrier to access.

Looking specifically at patients diagnosed with squamous cell carcinoma, the majority of the patients were from within the city of Edmonton (7 of 12 cases). The further distance groupings did not contribute any patients with oral cancer. This fact is not surprising as patients with oral cancer are often managed by medical practitioners, particularly GPs. In remote areas, it is possible that patients with complaints that are related to oral cancer (dysphagia, trismus) will likely see their GP before traveling a long distance to see a specialist. We know medical practitioners are more apt to refer to other medical practitioners, so it is possible that these patients were referred to ENT clinicians <sup>64</sup>.

#### **3.10.** Time Waited by Patients

The average wait time in this study was 105.5 days, which would be considered part of the professional delay in treatment as it is out of the patient's control. Broken down into routine and urgent referrals, the average wait time for a routine referral was 113.8 days and the average wait for an urgent referral was 59.0 days. A study out of Australia<sup>85</sup> found that 47.3% of patients with suspicious oral lesions were seen within two weeks of initial referral. In this study, only 26 out of 139 (18.7%) patients who were referred urgently were seen within two weeks. The University of Alberta's Oral Medicine Clinic makes a concerted effort to see urgent cases

promptly. However, it appears that in comparison to other clinics, we are not achieving as ideal wait times. These findings may indicate a deficiency in our systems ability to facilitate urgent cases and see patients in a timely manner. It is difficult to ascertain why there is a delay in seeing these patients and further research could elucidate the reasons for this. It is likely that there is a paucity of available Oral Medicine specialists to handle the case load. There are often scheduling challenges regarding these patients and limited clinic access, which further complicates seeing these patients in a timely fashion. There is not always a lot of flexibility in the bookings which limits the ability to accommodate patients in to the schedule.

One patient waited 905 days, but it cannot be determined why the wait took so long. That waiting period does not accurately reflect how long it usually takes and seems to be an outlier. It is worth noting that there is not a set of clinic criteria for prioritizing patients. In some cases, patients may be seen earlier than average if there is a cancellation and if they are in contact with the clinic at the right time. Additionally, patients traveling from out of town sometimes try to coordinate their appointments with other appointments, which can affect when they will be seen.

As discussed in the literature review, there are 4 delays in the referral process: 1) delay between first sign/symptom and initial visit 2) delay between initial visit and patient referral 3) delay between referral and patient seeing specialist and 4) delay between final visit to definitive diagnosis <sup>82</sup>. This study solely focused on the third step and it is clear that delays can happen due to other issues. Investigation of the other 3 areas of referral delay would be an area of further research.

As seen in the Allen and Farah study, the most critical aspect of timely care for patients who are aware of their lesions, is patient initiated, and that is; the time until first appointment

with the GP or dentist <sup>85</sup>. In patients who were not aware of their lesion (approximately 50% of patients), the longest time contribution to the time until a diagnosis is the time between initial referral and appointment with specialist. If a lesion is referred (and not missed altogether), the health care provider does a good job of referring patients in a timely fashion (81.1% less than two weeks) <sup>85</sup>. It may also be important for the referring clinician to follow-up with patients to ensure that they follow-through on their referrals and are acutely aware of the importance of doing so.

From a clinical perspective, the main aspect of the referral process that can be improved in the Oral Medicine clinic is the rate at which new patients are seen. Broader, public health endeavors designed to improve patient awareness are likely going to yield the most significant improvement in the early diagnosis and management of various severe oral diseases. Until available Oral Medicine resources are increased, the wait times between referral and the initial appointment will continue to grow.

#### 4. Conclusions

#### 4.1. Limitations of Study

The analysis of referral patterns to an Oral Medicine specialty clinic has provided insight into some of the challenges that clinicians and patients face when managing a variety of oral conditions. There are several weaknesses of this study. The primary weakness is the retrospective nature of the study. Looking back at previous referral notes does not always provide adequate insight into exactly why the referral was made. Another weakness is that of assumptions about the adequacy of the knowledge of clinicians based on the presence or absence of a provisional diagnosis. This does not prove to be appropriate because a provisional diagnosis

is not required and many knowledgeable clinicians may just neglect to record it even though they have a good idea of the condition in question. Another consideration is whether referrals are made for diagnosis, treatment or a confirmatory second opinion. These variables could not be assessed in this study. Another limitation is applying these findings of referring clinicians, to the clinicians who do not refer cases. Simply put, a clinician who is aware of, and willing to refer a patient to the Oral Medicine Clinic may exhibit a different proficiency in clinical diagnosis skills than someone who does not refer. It is not possible to assess if the clinicians who refer to the clinic are, on average, less knowledgeable than other clinicians, and that is why they are referring, or if they are more astute clinicians and providing better patient diagnosis and care.

This study focuses on finding the referral patterns of different clinicians, which can be intuited to be related to their particular knowledge on the topic. However, the more critical area to focus on may be the clinicians who never refer patients. What may be considered a weak, or unnecessary, referral may be expected when clinicians are inexperienced or unfamiliar with conditions in the mouth. These referrals indicate that the referring clinician is willing to take time to make the referral and have the best interests of the patient in mind. Of greater concern are the clinicians who are not referring any cases since, based upon prevalence studies, we know that oral disease is ubiquitous and referrals should be made fairly regularly as outlined in many population studies<sup>14</sup>.

To better assess clinician knowledge of oral disease, a well-designed cohort study in which pre-selected patients or patient photographs presented to clinicians in a calibrated examination would be required. A wider variety of clinicians, not only those who refer to Oral Medicine clinics, but those who refer to oral surgeons and medical specialists, would need to be included in this type of study. The study discussed in this thesis, using actual patient cases

submitted for specialist assessment provides a valuable resource as they represent a "real world" clinical context. Data from this study could serve as rationale for deliberate interventions such as clinician education and patient throughput studies in the clinic. Additionally, the results of this study could serve as a baseline to allow future comparison with post intervention or with changes to the population of patients and/or specialists.

Another limitation of this study is the fact that the patient population seen in the Oral Medicine Clinic is also routinely seen in other specialist offices, including oral surgeons, periodontists, otolaryngologists, and dermatologists. A follow-up study could look at comparing the types of referrals these different clinics receive, and if there are significant differences in the utilization of specialist care. This study included all the registered Oral Medicine/Oral Pathology specialists in Alberta and this helps limit bias in that every referral to this type of specialist was included. There is not another population of patients that was not included who were referred to an alternative Oral Medicine specialist. However, the patient population only included people willing and able to attend the clinic in Edmonton. It is unlikely that patient populations differ significantly within Alberta and between provinces, however, it is difficult to apply these findings to Canada where the rural/urban difference is not distributed similarly.

This study provides greater insight into the patterns of referrals to the Oral Medicine Clinic in a large urban center. Information about patients wait times and travel distances will provide concrete information when planning and discussing improved care of these patients in the future. The different diagnostic groupings and location of lesions provide critical awareness into proficiency of the referring clinicians in performing clinical examinations and where improvements could be made. This knowledge will help shape future curriculum changes to ensure the necessary topics are being taught.

#### 4.2. Future Research

This study has laid out a solid baseline of the referral patterns to an Oral Medicine Clinic. To our knowledge, it is the first of its kind in Canada, and as such provides foundational information to help further improve Oral Medicine care.

In addition to some of the further research outlined in the previous section, there are several directions that can be taken to supplement the knowledge gained thus far. Consideration of the impact of the referral process for patients could be achieved by performing a study involving patient interviews or surveys. A well-designed written survey could elucidate a broad range of data, including the psychological and physical impact of being told a referral is required, how the length of the wait affects the patient, and how long travel distances affects the patients and their families. Direct patient input is critical in improving the provision of care.

Another area that could be examined, which wasn't considered in this study, is how effective other dental providers, in particular, dental hygienists, are in assessing patients. It would be interesting to see if dentists differ from dental hygienists in referral patterns. Although dentists generally spend more time during their training focussing on Oral Medicine topics, in clinical practice, hygienists routinely spend more chair time with patients, given the nature of their work. This would be best achieved with a well-controlled clinical simulation testing, or clinical trials as outlined in the limitations section.

#### 4.3. Conclusion

The goal of this study was to analyze referral patterns to an Oral Medicine Clinic to provide insight into the types of referring clinicians, provide baseline information for further improvements including curriculum development and to elucidate some of the access to care issues that patients face. This analysis may lead to consideration of alternate models of service

delivery to patients with oral disease. An example of this might be having more specialists throughout the province, or alternatively, specialists may travel to regions lacking the necessary health professionals. In this instance, bringing the specialists to the patients rather than vice versa would provide a much-needed service for some patients who cannot travel. Another potentially viable solution would be initiating "tele-consults", in which the patient and Oral Medicine Specialist can interact by use of well tested technology. Despite the lack of tactile exam, this method can still allow visual assessment of lesions and more personalized care, without the need for the patient to travel long distances. The results suggest that Oral Medicine specialty clinics could benefit from increased awareness of the clinic amongst physicians, given the relatively small proportion of physician referrals. The complicated process of analyzing referrals has shown that dentists of all levels of experience could benefit from further training. This data will provide support when developing future curricula for dental students as well as direct CE courses for graduated dentists. Improved appreciation of the specialty and better lines of communication will further enhance patient care and outcomes. The key outcome of this study is improved awareness of the discipline and practice of Oral Medicine amongst medical and dental practitioners alike, improved training approaches and hopefully improved patient advocacy with the ultimate result of improved patient care.

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#### Appendix

### **Appendix 1: Ethics Approval for Retrospective Chart Review**

#### Approval Form

Date: July 12, 2016 Study ID: Pro00065171 Principal Investigator: William McGaw

Study Title: A Retrospective Analysis of Referral Patterns to a University Oral Medicine Clinic

Approval Expiry Date: Tuesday, July 11, 2017

Thank you for submitting the above study to the Health Research Ethics Board - Health Panel . Your application, including the following, has been reviewed and approved on behalf of the committee;

- Protocol (6/22/2016)
- Referral Pattern Excel Spreadsheet (6/22/2016)

The Health Research Ethics Board assessed all matters required by section 50(1)(a) of the Health Information Act. It has been determined that the research described in the ethics application is a retrospective chart review for which subject consent for access to personally identifiable health information would not be reasonable, feasible or practical. Subject consent therefore is not required for access to personally identifiable health information described in the ethics application.

In order to comply with the Health Information Act, a copy of the approval form is being sent to the Office of the Information and Privacy Commissioner.

A renewal report must be submitted next year prior to the expiry of this approval if your study still requires ethics approval. If you do not renew on or before the renewal expiry date (Tuesday, July 11, 2017), you will have to re-submit an ethics application.

Approval by the Health Research Ethics Board does not encompass authorization to access the patients, staff or resources of Alberta Health Services or other local health care institutions for the purposes of the research. Enquiries regarding Alberta Health approvals should be directed to (780) 407-6041. Enquiries regarding Covenant Health approvals should be directed to (780) 735-2274.

Sincerely,

Anthony S. Joyce, Ph.D. Chair, Health Research Ethics Board - Health Panel

Note: This correspondence includes an electronic signature (validation and approval via an online system).

Health Research Ethics Board

308 Campus Towne. University of Alberts, Edmonton, AB T6G 1KB p. 780.492 (7724 Roisenshidtal Panel) p. 780.492 (3022 (Heakh Panel) p. 780.492 (MS9 p. 780.492 (MS9 f. 780.492 9429

Notification of Approval (Renewal)

Date:	September 5, 2017
Amendment ID:	Pro00065171_REN1
Principal Investigator:	William McGaw
Study ID:	MS1_Pro00065171
Study Title:	A Retrospective Analysis of Referral Patterns to a University Oral Medicine Clinic
Approval Expiry Date:	Tuesday, September 4, 2018

Thank you for submitting this renewal application. Your application has been reviewed and approved.

This re-approval is valid for another year. If your study continues past the expiration date as noted above, you will be required to complete another renewal request. Beginning at 30 days prior to the expiration date, you will receive notices that the study is about to expire. If you do not renew on or before the renewal expiry date, you will have to re-submit an ethics application.

All study related documents should be retained so as to be available to the Health REB upon request. They should be kept for the duration of the project and for at least 5 years following study completion.

Sincerely,

Anthony S. Joyce, PhD. Chair, Health Research Ethics Board - Health Panel

Note: This correspondence includes an electronic signature (validation and approval via an online system).



## **Appendix 2: Referral Form**

## Oral Medicine/Oral Pathology Clinic

	University of Alberta Kaye Edmonton Clinic, 8 <sup>th</sup> Floor						
		1140	0 University Ave				
Edmonton, AB T6G1Z1							
	Phone 7	80-407	-5561 Fax 780-407-3560				
	Dr. Edmunds Peters		Dr. Seema Ganatra	First Available			
	D.D.S., M.Sc., F.R.C.D(C) Dip. ABOMP Specializing in Oral Pathology/Oral Medicine		D.D.S., MSD, F.R.C.D(C) Dip. ABOMP Specializing in Oral Pathology				
Please check in at Desk #1 or #2 on the 8 <sup>th</sup> floor							
	Patient Name:		C	Date:			
Patient AHC #:							
Patient Home Phone #: Patient cell/work Phone #:							
	Referring Dr.:		Phone				
	#:	_					
	Dr. Address:		City/Province:	P/C:			
	Dr. Fax #:		Dr. AHC Prac ld #:				
0200			* The Prac ld # is NOT the same as t The Prac ld # can be obtained by p				
Referral of patient for evaluation/consultation regarding:							
39							
iii	<u> </u>						
清 33							
建 田 田		E 🗖					
	URGENT ROUTIN		tient 🗖 E-mail 🗖				
		with Pa		:NT:			
	Radiographs: None 🗖	with Pa	TIME OF APPOINTME				



W.T. McGaw DDS, MD, MSc, FRCD(c) Professor – Oral Medicine & Pathology Office: 780.492.5195 Fax: 780.492.7344 Email: wmcgaw@ualberta.ca

# **Consultation Request Form**

Please complete this form then fax to 780-492-7344 for consultation requests with Dr. McGaw

### **Dental / Medical Office Information:**

Clinic Name:	Referred By:				
Address:	Today's Date:				
	Phone Number:				
City / Postal Code:	Fax Number:				
Email Address:	PracID:				
Please Note:	The PracID # is <u>NOT</u> the same as the "Unique Number" used for dental insurance claims. The PracID number can be retrieved by having the referring dentist phone Alberta Health Services at 780-422-1522.				

## Patient Information:

Last Name:	PCN:
First Name:	DOB:
Address:	
87 84	Home Number:
City / Postal Code	Work Number:
Email Address:	Cell Number:
Referral Details:	Yes, Additional Page(s) have been attached

#### **Referral Type:** Fax This Referral AND also phone/email us to explain the reason and to bring Urgent/Emergency Referral? this referral to Dr. McGaw's attention. Note: Do NOT send radiographs by mail or courier. Either EMAIL or give Radiographs Available? radiographs directly to your patient to bring to the appointment. Preferred Location: 01.2016 Earliest Appt. Available - Patient is willing to come to either location (whichever is soonest) **Edmonton Clinic** University Campus Location – Self Parkade is attached / LRT Access Southgate Clinic - N.E. corner of Southgate Centre - Walking distance to Bus / LRT Station

Thank you for your referral. An Adobe PDF fill-in version of this form is available upon request.

Edmonton Clinic Kaye Edmonton Clinic - 8<sup>th</sup> Floor, 11400 University Avenue N.W. Edmonton, Alberta, Canada T6G 1Z1 Southgate Clinic Southgate Dental Centre 10831 51<sup>st</sup> Avenue N.W. Edmonton, Alberta, Canada T6H 5T1