BARRIERS AND FACILITATORS FOR AN ORAL CANCER SCREENING PROGRAM IN A HIGH-RISK COMMUNITY IN THE DOWNTOWN EASTSIDE OF VANCOUVER

by

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ABSTRACT

Oral squamous cell carcinoma (SCC) is the 6th most common cancer in the world and is believed to progress through sequential stages of premalignancies. It is a deadly disease combining both high mortality (5-year survival rate of just over 50%) and morbidity, largely due to late diagnosis. Multiple factors contribute to this late diagnosis, including problems in both clinical and histological identification of high-risk oral premalignant lesions (OPLs) and early SCC and difficulties in reaching some of the high-risk populations, notably the marginalized poor.

The BC Oral Cancer Prevention Program (BC OCPP), a leading research team in the study of early high-risk oral lesions, has developed a number of molecular, histological and clinical tools to help identify high-risk OPLs and early SCC. However, research to date has been confined to high-risk dysplasia clinics. There is an urgent need to expand this research into the community for two reasons: first, tools developed in the high-risk clinics need to be validated in community settings; and second, we need to find ways to reach high-risk populations, who frequently do not access medical/dental care. This thesis focuses on the expansion of BCOCPP research into communities and involves two phases.

The objectives of the Phase I were: (1) to establish an oral cancer screening clinic in the Vancouver Downtown Eastside (DTES), where a high concentration of the marginalized poor reside; (2) to determine characteristics of
persons attending the clinic as compared to the broader community; (3) to
determine the frequency and pattern of oral diseases in patients in the clinic; and
(4) to identify potential challenges to screening in the clinic.

In the Phase I, an oral cancer screening service was established in the
existing Portland Community Dental Clinic (which provides dental services with
free or reduced rate for the marginalized poor in the area, approximately 3500
people). The approaches and tools used to screening included: (1)
questionnaires, (2) conventional oral and head and neck examinations, (3) the
use of visual tools (toluidine blue staining and fluorescence visualization device),
with (4) biopsy and follow-up whenever required.

A total of 200 dental patients were screened over a 2-year period. The
results showed the following: (1) patients were characterized by the presence of
high-risk attributes including lifestyle (86% were smokers, 83% were drinkers and
most were drug users), compromised immunity (30% with hepatitis, 27% with
diabetes, and 12% HIV infection) and low-income, with associated poor nutrition
and limited access to care; (2) disease (oral cancer) prevalence was high in this
group, with 2 SCC found in the 200 patients compared to 1/10,000 in the general
population (in addition, 8 dysplasia and 2 atypia were found); and (3) most DTES
residents did not attend the clinic during the study period, identified as a
significant challenge to screening in this community.

Based on the findings and challenges from phase I, the objectives of the
phase II were (1) to characterize the knowledge and beliefs about oral cancer
and the attitudes towards oral cancer screening in this community, (2) to identify
the barriers and facilitators for an oral cancer screening intervention, (3) to provide a basis for development of strategies for the implementation of an oral cancer-screening program in this high-risk, hard-to-reach community.

This was carried out through focus group discussions (questionnaires and open-ended questions) in the DTES to assess the participants' knowledge of oral cancer, feelings of susceptibility to developing oral cancer, and perceived barriers and facilitators to oral cancer screening. All conversations were audio recorded and transcribed verbatim. Major themes were identified from the narrative data and analyzed accordingly.

Six focus group discussions were completed during the course of a six-month period. A total of 38 individuals participated in the focus group discussions. The results showed that participants demonstrated a lack of awareness and knowledge about oral cancer and a lack of feeling of vulnerability for developing the disease. They were not aware of what oral cancer is nor were they aware of the early signs of the disease. Most were unaware of the risk factors, especially the association of alcohol with oral cancer. Participants said they would be willing to attend regular oral cancer screenings if they were free, accessible, painless and quick and if they were offered incentives for participating. In addition, they indicated their need and desire for education about oral cancer, especially the early signs of disease and its risk factors.

Results from these two studies highlight the need for improving oral health in this high-risk population by enabling access for all to an oral cancer-screening program and the importance of focusing on educating high-risk communities.
about oral cancer. To maximize results and positive health behavior change, the promotion of tobacco and alcohol cessation should be encouraged. Results from this study will provide the basis for planning strategies and approaches for the development of an effective, sustainable community oral cancer-screening program in this high-risk population.
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I. INTRODUCTION

Globally, we have a burgeoning major health concern to confront: Oral cancer. Oral squamous cell carcinoma (SCC) is the 6th most common human cancer, more common than leukemia, melanoma and cancer of the brain, liver, kidney, thyroid, stomach, ovary or cervix (Boring, 1994). It is believed to progress through sequential stages of premalignancies. Once oral SCC is formed, the prognosis is dismal, with 5-year survival rates remaining just above 50% for the last 3 to 4 decades. Those who survive frequently have to endure severe functional and cosmetic compromise. The following sections include a general review of oral premalignant lesions (OPLs) and SCC and a description of problems in early diagnosis, outreach to high-risk populations, and in community oral cancer screening. In addition, a brief review of work by the BC Oral Cancer Prevention Program (BCOCPP) is presented. The objective of this review is to demonstrate the need for community oral cancer screening initiatives with a specific focus on the marginalized poor, the central theme of this thesis.

1.1. Oral cancer – epidemiology

The term “oral cancer” refers to malignancies arising in the lip, tongue, floor of the mouth, gingivae, palate, buccal mucosa/vestibule and salivary glands. Most oral cancer is oral squamous cell carcinoma (SCC), which is believed to be preceded by an oral premalignant lesion (OPL) that later progresses into a malignancy (Rosin et al., 2000). The OPL is often visible and can be recognized early. This progression from
OPL to SCC occurs over many years, thus allowing the opportunity for detecting early changes and intervening in the process.

Worldwide, over 300,000 new cases are diagnosed each year. The incidence of oral cancer varies greatly geographically. Within Europe (Black et al., 1997) and the world (Franceschi et al., 2000), there are differences in incidence and prevalence of oral cancer. In India, oral cancer accounts for 40% of all cancer (Day et al., 2003). The incidence of oral cancer is highest amongst men in Northern France (49.4/100,000 men) and Southern India (more than 20/100,000 men) and some areas of Eastern Europe and Latin America. It is estimated that each year in Canada, 3200 new cases of oral cancer will be diagnosed and 1100 will die from the disease (Canadian Cancer Statistics 2005). Approximately 30,000 new cases of oral cancer are diagnosed each year in the United States resulting in 8000 deaths (Patton, 2003) while in the United Kingdom there are over 2,500 cases of oral cancer each year with approximately 50% dying of the disease (Warnakulsuriya et al., 1999).

The incidence of oral cancer in men is 2.6 times that of women (14.8 compared with 5.8) and blacks have a higher rate than whites (12.4 compared with 9.7) (National Cancer Institutes SEER 1994-1998). In the United States, the highest rate reported is among black men, with 20.5 cases per 100,000 people. Among women, rates for blacks and whites were similar (6.1 compared with 5.8) (Ries, LA National Cancer Institute SEER 2001). Although the incidence of oral cancer has remained higher in men than in women, the gender gap is closing slightly. Currently the male: female ratio for oral cancer is reported at 1.8:1, slightly lower than the previously reported ratio of 2.6:1.
(Ries, 2001). This may be due to the increased use and more prolonged use of tobacco products by women.

The lateral and ventral aspects of the tongue remain the most common site of oral cancer with 2.5 cases per 100,000 people for the 1994-1998 periods. A comparison of data from between 1973 and 1984 with data from 1985 and 1996 reveals that the prevalence of tongue cancer has actually increased from 26 percent to 30 percent of all oral cancers (Shiboski, 2000). The floor of the mouth follows the tongue as the next most common site of oral cancer.

Recently, the World Health Organization (WHO) provided a comprehensive global examination of all cancer sites to date through the publication of the World Cancer Report (WCR) on the Burden of Cancer and estimated that cancer rates in general are set to increase at an alarming rate from 10 million globally in 2000, to 15 million in 2020, a 50% increase (Mignona. 2004). This will cause a global cancer crisis unless a preventive approach is taken by health care professionals. In summary, intervention to prevent development of oral SCC is not only critical but also feasible since the disease develops over several decades and frequently have clinically visible preceding oral premalignant lesions.

1.2. Oral premalignant lesions (OPLs)

A premalignant or precancerous lesion has been defined by the World Health Organization as a morphologically altered tissue in which cancer is more likely to occur than in its apparently normal counterpart (Pindborg et al., WHO, 1997). Some OPLs progress into oral SCC. Clinically OPLs are classified according to their clinical
appearance. They most frequently present as leukoplakia and occasionally as erythroplakia.

### 1.2.1. Leukoplakia

Leukoplakia is defined by the World Health Organization (1978) as a “white patch or plaque that does not rub off and cannot be characterized clinically or pathologically as any other disease, and has increased cancer risk”. Since most OPLs are leukoplakia, the term leukoplakia has been used interchangeably in the literature with OPL. White lesions of reactive nature that have no premalignant potential, however, are common in the oral cavity (for instance, traumatic hyperkeratosis) and can be very hard to differentiate from leukoplakia. Some believe that the term leukoplakia should only be used after a histological confirmation of presence of dysplasia, the gold standard for assessing cancer or cancer risk. A diagnostic biopsy should be considered for any mucosal lesions that persist for more than 14 days after obvious irritants are removed.

### 1.2.2. Erythroplakia

Erythroplakia is a red lesion that cannot be classified as another entity and is the red counterpart of leukoplakia. The red appearance of erythroplakia is due to thinning of the epithelium, allowing the underlying vascular tissue to be more visible. The presence of a persistent red area within a lesion is usually the most significant sign of carcinoma in situ or early SCC. The red component of the lesion is the area exhibiting the most cellular change (Mashberg, 2000). Although it is not common, it has a much
greater chance (91%) of showing signs of dysplasia or malignancy at the time of
diagnosis (Shafer & Waldron, 1975). These lesions often have a flat, macular, velvety
appearance and may be speckled with white spots representing foci of keratosis.

I.2.3. Assessment of cancer risk of OPLs

Currently the cancer risk of OPLs is judged by morphological changes clinically
and histologically. When a lesion is judged clinically as suspicious of OPLs or cancer,
the lesion is biopsied and then judged histologically for cancer risk.

I.2.3.1. Clinical risk of OPLs

Currently a number of clinical risk factors are used by clinicians to judge cancer
risk of leukoplakia. The most important ones are: location on the floor of mouth, and
ventrolateral tongue (termed high-risk sites); large size; a nonhomogeneous clinical
appearance, and a prior or family history of oral cancer.

I.2.3.2. Histological risk of OPLs

Currently, histological diagnosis is the gold standard for determining the cancer
risk for premalignant lesions. This gold criterion requires that the clinician take a biopsy
from a suspicious premalignant lesion to be microscopically evaluated for the presence
and degree of histological changes called “dysplasia”, the histological sign of cancer risk
(WHO, 1978). Dysplasia, meaning disordered or abnormal growth, is graded based on
numerous changes that can occur in the structure of the epithelium or in the individual
cells of the tissue. The followings are features of dysplasia:
- Loss of basal cell polarity
- Parabasilar hyperplasia
- Increased nuclear/cytoplasmic ratio
- Drop shaped rete ridges
- Abnormal epithelial maturation
- Increased mitotic activity
- Cellular pleomorphism
- Nuclear hyperchromacity
- Enlarged nucleoli
- Loss of cellular cohesiveness
- Individual cell keratinization in the spinous cell layer.

Depending on the amount and severity of these changes the pathologist grades the dysplasia as mild, moderate, or severe. A diagnosis of mild dysplasia is made when the changes involve the lower third of the epithelium, the basal and parabasal cell layers. When the changes occur in the lower half of the epithelial cell layers, a diagnosis of moderate dysplasia is given. Severe dysplasia occurs when two thirds of the cell layers are altered. When the cell and architectural changes comprise the whole width of the epithelial layer it is graded as carcinoma in situ (CIS). Once the changes break through the basement membrane the lesion is considered an invasive cancer. The existence and grade of dysplasia is the current gold standard for predicting the malignant risk of OPLs. Studies have shown that leukoplakias with dysplasia have significantly higher cancer risk than leukoplakias without dysplasia, and that leukoplakias with high-grade dysplasia (severe dysplasia and CIS) have significantly higher cancer risk than leukoplakias with low-grade (mild/moderate) dysplasia. A histological progression model has been established for oral cancer based on above
criteria and studies. In this model, oral cancers progress through hyperplasia and increasing degree of dysplasia, mild, moderate and severe, to carcinoma in situ (CIS), and finally break through the basement membrane and become SCCs (Axéll et al., 1984).

1.3. Poor oral SCC prognosis and source of this problem

1.3.1. Relationship between early diagnosis and prognosis of oral SCC

Oral SCC has one of the worst prognoses among major human cancers. The five-year survival rate for oral SCC has remained virtually unchanged over the last 3 to 4 decades, just over 50%. The major reason for this poor prognosis is the late diagnosis of oral SCC. In developing countries such as India, the majority of oral SCCs are diagnosed at late stages (stages III or IV). Even in Western countries, a significant percentage of oral SCCs are diagnosed at late stages. For example, in BC, around 40% of oral SCCs are still diagnosed at stages III or IV. Studies have shown that early diagnosis is the most important factor for better prognosis of oral SCC. Late diagnosis results in markedly increased mortality: those oral SCCs diagnosed at late stages have only around 20 to 30% of 5-year survival rate; whereas those diagnosed at early stages have a 5-year survival rate around 80%. Late diagnosis also results in severe morbidity, as oral SCC diagnosed at late stages has to be treated much more aggressively, causing more functional and cosmetic compromises. The aggressive treatment and lengthy hospital stay associated with late stage oral SCC also pose a much heavier burden for our medical system.
1.3.2. Problems in early diagnosis

It may be surprising that oral SCC are still diagnosed late, considering that oral SCC develops slowly over several decades, that the premalignant stages of oral SCC have known clinical changes, and the oral cavity is readily visible for identifying these premalignant or early cancer changes. However, a number of problems contribute to the late diagnosis, including difficulties in both clinical and histological identification of high-risk OPLs and early SCC, and problems in reaching some of the high-risk populations, notably those marginalized poor.

1.3.2.1. Problems in clinical diagnosis

There are a number of problems in the clinical identification of high-risk OPLs and early SCC. They may not be clinically visible. When they are clinically visible, they are not readily differentiated from benign reactive changes such as frictional hyperplasia (white) or inflammation (red). In addition, most OPLs do not become cancer, and frequently it is hard to separate those with a high risk of transformation from those without. Tools that could help the identification of high-risk OPLs and early SCC are needed.

1.3.2.2. Problems in histological diagnosis

There are also problems associated with the gold standard, histology, that is used for cancer risk assessment of OPLs. The histological progression model has a better predictive value for high-grade lesions (severe dysplasia and CIS) than low-grade dysplasia or OPLs without dysplasia (Banoczy and Csiba, 1976; Schepman et al.,
Severe dysplasia and CIS are believed to have a high probability of progression into cancer if left untreated (Hayward, 1977). As a result, high-grade preinvasive lesions are generally treated aggressively, and the histological diagnosis serves as the stimulus for that aggressive treatment. On the other hand, only a small percentage of OPLs with low-grade dysplasia or without dysplasia progress into cancer. Histology cannot separate OPLs with low-grade dysplasia or without dysplasia that will later progress into cancer from those that will not progress. Again, tools or makers that could help to identify the progressing OPLs are needed.

I.3.2.3. Problems in reaching some of population at high risk of oral SCC

The diagnosis of high risk OPLs and early SCC clinically and histologically is only possible if the patient has sought medical/dental care. However, many people at high-risk of oral SCC do not seek the care.
1.4. High-risk populations and risk factors

Oral SCCs generally develop slowly with long-term exposure to carcinogens; hence, most oral SCCs occur in people over 50 years old because of the time needed for the SCC to develop. Many etiological or risk factors have been identified, together with their high-risk groups.

1.4.1. Long-term heavy tobacco and alcohol consumption

Long-term heavy smokers and drinkers are the foremost high-risk population since the use of tobacco products and excessive alcohol consumption are responsible for about 75% of the oral cancers in the western world (Mashberg et al., 1993). Both tobacco and alcohol exhibit a dose-response association with oral cancer and have a synergistic effect when combined. Good evidence from case control and cohort studies demonstrates this association between alcohol and tobacco use and the development of oral cancers (Kato et al., 1992). (Silverman & Gorsky, 1990). Additionally, VanderWaal (1998) reported that the risk of developing oral cancer for smokers who are heavy drinkers is six to fifteen times more than those who are non-smokers and non-drinkers. Population studies also strongly support the connection. For example, results from a large population study in Sweden (Rosenquest, 2005) indicated that both smoking tobacco and alcohol consumption are risk factors for oral and oropharyngeal SCC. More than 350 g of alcohol per week (OR 2.6; 95% CI 1.3-5.4) and 11-20 cigarettes per day (OR 2.4; 95% CI 1.3-4.1) were dose-dependent risk factors.
results showed a tendency for women to have a greater risk (OR 1.8) than men at any given level of tobacco consumption.

I.4.1.1. Tobacco and oral cancer

In 1997 the World Health Organization (WHO) published a monograph entitled “Tobacco or Health: a global status report.” In this report, the WHO estimated that worldwide from 1990 to 1992 a total number of $6.05 \times 10^{12}$ cigarettes were consumed annually. In China alone a 260% increase in cigarette consumption occurred between 1972 and 1992. Smoking data show that Korean men are the heaviest smokers followed by German men and German women. For industrialized countries there is an estimated daily consumption of 22 cigarettes per person as compared to 14 cigarettes in less developed countries (Europe 18, Africa 10, USA 18, South East Asia 15, Western Pacific 16/cigarettes/day). A heavy smoker is considered to be one that smokes 20-40 cigarettes/day.

Tobacco use is considered to be the most important risk factor for oral cancer. The risk of developing an oral pre-cancer or invasive cancer increases with amount smoked and the duration of use. The risk is 16 times higher for developing oral cancer in a smoker as compared to a non-smoker (Silverman, 2003). Furthermore, oral cancer patients who continue to smoke have a greater risk of a second oral malignancy (Reichart, 2001).

It is estimated that 4 million people die worldwide every year as a result of tobacco use (Silverman, 2003). In the United States, about 95% of cases of oral cancer
have been attributed to smoking (US Surgeon General Ann. Rep. 1995). Worldwide, various smoking and tobacco chewing habits exist with differing risk as to the induction of oral cancer and precancer.

Tobacco products differ worldwide due to varying methods of preparation and in the way it is used. Tobacco is available in many forms and can be smoked, chewed or used as snuff resulting in geographic variation in the reported oral cancer risk associated with its use. For example, in parts of India and Asia, where chewing tobacco and betel nut is very common, the incidence of oral cancer is 3 times higher than in the US. The location of oral cancer in the mouth also varies geographically. In the western world tobacco is most commonly associated with cancer of the floor of mouth, while in India the buccal mucosa is the most common site of tobacco related oral cancer due to the use of smokeless tobacco (Silverman, 2003).

The most common form of tobacco use is cigarette smoking where there is a strong dose-response relationship between the use of tobacco and the development of oral cancer. Jaber et al. (1999) found that patients who smoked more than 20 cigarettes a day, particularly unfiltered, were at a much higher risk of developing pre-cancer than nonsmoking individuals. Accordingly, the risk of oral cancer decreases for former smokers as the time since they last smoked increases. For former smokers, the risk of oral cancer is considered to be on par with never smokers when smoking cessation reaches 10 years (La Vecchia et al. 1999).

Studies have also correlated the use of tobacco with risk of a second oral malignancy, whereby the risk has been shown to increase with the duration and amount smoked. Silverman (2003) stated that oral cancer patients who do not quit smoking or
drinking are at a much greater risk of developing a second oral malignancy (SOM). Day et al. (1994a) examined the smoking and alcohol habits of patients who developed a second cancer of the upper aero digestive tract and found that the length of time since the patient quit smoking was inversely proportional to the risk of the second malignancy. A study on a cohort of 25,000 Swedish men (Carstensen et al., 1987) reported a recurrence rate of 1.3 in former smokers, as compared to never smokers (death rate 4.3/100,000 person years). In current smokers the recurrence rate was 1.1 for 1–7 g/day of tobacco, 2.5 for 8–15 g/day and 5.4 for >15 g/day.

A number of the products intrinsic to smoking have been identified as toxic, tumorogenic and carcinogenic, with the most important carcinogens including polycyclic hydrocarbons such as benzo(a)pyrene. The presence of nicotine has been shown to significantly increase the permeability of the oral mucosa to tobacco-associated nitrosamines and other carcinogens. Additionally, there is an early suggestion that the use of marijuana may also increase the risk of squamous cell carcinoma of the head and neck with a strong dose-response pattern by interacting with other risk factors (Zhang et al., 1999).

In 1982, the Surgeon General issued the following statement: “Long term use of snuff appears to be a factor in the development of cancers of the oral cavity, particularly cancers of the cheek and gum.” A study by Winn and Blot (1981) provided strong evidence for a causal relationship between smokeless tobacco use and oral cancer, particularly on the buccal mucosa and gingiva. Results from this study (n = 255 women) found a four fold increased risk of oral cancer among non-smokers who dipped snuff. For long term users (> 50 yrs) there was a 50-fold increased risk. Subsequent studies
corroborated these results and in 1985 the International Agency for Research on Cancer (IARC) concluded that, "In aggregate, there is sufficient evidence that oral use of smokeless tobacco is carcinogenic to humans."

Smokeless tobacco can be used in the form of snuff or chewing tobacco. There is a dose-response relationship between exposure and risk of developing a lesion. Lesions generally form at the site where the tobacco is placed. The lesion is typically white, wrinkled and thickened. Tobacco-specific N-nitrosamines are believed to be the main carcinogen found in smokeless tobacco (Scully, 1995; Reichart et al., 2001). Snuff is available in various forms, dry, moist or in sachets. Dry snuff is typically inhaled through the nose. Snuff use is common in the western world, especially in Scandinavia and the USA. There is a rise in the USA in the use of smokeless tobacco, moist snuff and loose leaf chewing tobacco amongst mostly male young adults and children (Glover and Glover, 1992). A reported 6% of the adult male population is said to be regular users of smokeless tobacco. This increase in use has led to an increase of oral premalignant and malignant lesions, particularly of the buccal mucosa, in young Americans (Lippman and Hong, 1989). In South and South-East Asia, smokeless tobacco includes betel quid, nass, naswar, mawa, mishri and gudakhu.

The primary cause of the high incidence of oral cancer in South Asia is the widespread habit of chewing betel nut or paan and related areca nut use. Chewing betel is thought to date back at least 2000 years and worldwide an estimated 200-400 million people practice the habit (Gupta, 2002). In India, oral cancer is a major health problem due to the chewing of the betel nut. The prevalence of tobacco chewing increases with age, especially among women. The components of the betel quid vary
between different populations, but the main ingredients are the leaf of the vine, Piper betel, areca nut, slaked lime (calcium hydroxide) and spices (Warnakulasuriya, 2002). The areca nut is considered carcinogenic to humans and the risk of oral cancer is increased with chewing paan without tobacco, although the risk is higher for paan containing tobacco. It is much more common to have the tobacco included (Gupta P.C. 1996). As with smoking tobacco, risk is dependent on dose and duration of use. Betel quid has recently been categorized as a Group 1 carcinogen, carcinogenic to humans, by the International Agency for Research on Cancer (Jacobs et al, 2004).

1.4.1.2. Alcohol and oral cancer

Alcohol is the second major risk factor for oral cancer, with 75-80% of patients frequently consuming alcohol (Rodriguez, 2004). For non-smokers it is the most important risk factor. Above 30 grams of alcohol per day, risk increases linearly with amount of alcohol consumed (Rodriguwyz, 2004). People who both drink and smoke have a much higher risk of oral cancer than those using only alcohol or tobacco (Blot, 1992).

Alcohol consumption has always been considered a factor in the etiology of oral cancer, and in fact excessive alcohol consumption is considered the second most important risk factor behind tobacco use (Moreno-Lopez, 2000). The rising trends in oral cancer mortality in Europe have been related to increasing levels of alcohol consumption. For example, in Denmark the increase in oral cancer has been attributed predominantly to greater alcohol consumption (Moller, 1989). An exception to this rise
in alcohol consumption is seen in France, where a decrease in alcohol consumption has
been linked to the fall in oral cancer mortality rates in the 1980s (Blot, 1994).

It has been suggested in the research that substances other than ethyl alcohol in
alcoholic beverages may play a role in oral carcinogenesis. Although research has not
been able to experimentally induce oral cancer in animal models with ethyl alcohol
alone (Tuyns, 1979), it should be noted that ethyl alcohol is the only component
common to beer, wine and distilled spirits.

Several possibilities have been suggested for the role of alcoholic beverages in
the etiology of oral cancer. One theory suggests that alcoholic beverages may act as a
promoter, or co-carcinogen, rather than an initiator of cancer. Alcohol may also act as a
solvent enhancing the penetration of oral epithelium by organic carcinogens such as
tobacco smoke (Silverman, 2003). Or, alcohol may induce the induction of microsomal
enzymes that catalyze the activation of carcinogens in tobacco products. Another
possible mechanism is that alcohol may decrease immuno-competency via liver injury
resulting in deficient detoxification of potential carcinogens. Alternatively, increased risk
may involve nutritional deficiencies that often develop in alcoholics leading to
morphologic or metabolic changes in oral epithelium and in the liver (Blot, 1988).

All three forms of alcohol (beer, hard liquor, and wine) have been associated in
some way with oral cancer although some studies report that hard liquor and beer have
a higher associated risk (Merletti, F 1989). For example, a study by Keller (1981)
reported that whiskey carried three times the risk of beer or wine; as well, Blot et al.
(1988) found whiskey or beer to be more damaging than wine. In contrast however,
Mashberg et al (1981) implicated beer and wine over whiskey. The amount of
consumption of alcohol appears to be important for risk. Heavy drinkers and smokers have 38 times the risk of abstainers from both products. It has been suggested that it is the total amount of ethanol ingested rather than the type of product (beer, wine, spirits) which is important (Boyle, 2003). One study found an elevated risk only if greater than 56 glasses of wine per week were consumed (Ng, 1993). Another study showed a significant increase in risk only if the average daily consumption of alcohol exceeded 120 grams (Merletti, 1989).

Given the fact that there are different types of alcoholic beverages, standardization has been made based on the amount of alcohol in each. For example, 1 oz of distilled spirit, 4 oz of dry wine and 12 oz of beer are considered equivalent. The reported relative risk for developing oral cancer from consumption of alcoholic beverages alone is calculated at 2.7 for 2 whiskey equivalents per day, increasing to a range of 4.1-15.2 for seven or more equivalents per day (Mashberg, et al., 1981). In contrast, in a study by Blot (1988), the relative risk was based on the number of drinks per day, where a consumption of 30 or more drinks per week (4.3 drinks per day) translated into a relative risk that ranged from 6.0 to 12.3 varying with site and gender.

While it is accepted that excessive alcohol consumption is considered an important risk factor for oral cancer and precancer, there are several problems that make it difficult to identify alcohol as an independent risk factor for oral cancer. One problem is that heavy drinkers tend to be users of tobacco products as well, making it difficult to single out alcohol as the primary carcinogen. Another problem is that the consumption of alcohol combined with a poor diet might affect the risk for oral cancer, as alcoholics are frequently malnourished. Additionally, the assessment of alcohol
intake may not be accurate because of a tendency toward underreporting and the often-episodic nature of usage, thus making it hard for the patient to estimate “average use”.

Studies have found that most patients with oropharyngeal cancer drink alcohol. A study by Blot, (1988) found alcohol consumption rates as high as 94% in men and 82% in women. Furthermore, Hindle et al. (2000) suggested that rising alcohol consumption since the 1950s may be more closely related to increasing oral cancer incidence and mortality than smoking.

While the risk associated with alcohol consumption and oral cancer is not as clearly understood as that of tobacco and oral cancer, it may be reasonable to assume that any form of alcohol consumed in excess may help promote the development of oral cancer.

1.4.1.3. Tobacco, alcohol and oral cancer – a synergistic effect

The use of tobacco and alcohol together contributed to almost 75% of oral and oropharyngeal cancers. The odds ratio for developing oral cancer for young heavy smokers and drinkers in one study was greater than 48 times that of non-smokers and drinkers. The odds of developing oral cancer increase with the frequency and duration of the use of tobacco and alcohol and with the combined use of the two (Blot, 1992). A study by Jaber et al. (1999) also reported that heavy users of tobacco and alcohol were found to have the highest risk for developing dysplasia.

A combination of heavy tobacco use and heavy alcohol consumption has been shown to result in odds ratios (ORs) for developing oral cancer of up to 38 for men and 100 for women (Blot, 1988). A study by Van der Waal, (1998) demonstrated that
smokers who do not drink have a two- to four-fold risk of developing oral cancer as compared to non-smokers and non-drinkers, while the risk of smokers who are heavy drinkers increased six to 15 times, compared to non-smokers and non-drinkers. Talamini et al. (1998) studied the risk of oral and pharyngeal cancer in nonsmoking heavy drinkers and nondrinking heavy smokers and found that both groups had an increased risk of disease. Nonsmoking drinkers who consumed 35 - 55 drinks per week had an OR of 5.0 while those who drank more than 56 drinks per week had an OR of 5.3. The OR for never drinking heavy smokers (> 25 cigarettes per day) was 7.2. It is thought that the combined use of nicotine and alcohol significantly increases the penetration of the nitrosamines into the oral tissue with the alcohol acting as the solvent (Du, 2000).

I.4.2. Marginalized poor and other risk factors

Marginalized poor are regarded one of the highest risk populations because not only are they frequently heavy smokers and drinkers, but they also are exposed to multiple other independent etiological or risk factors for oral SCC, including poor oral hygiene, poor access to care, poor nutrition, and exposure to high-risk lifestyle with resulting increased compromised immunity and infection.

I.4.2.1. Infections and oral cancer

The potential role of host infection with a virus is reviewed below, specifically that of the human papilloma virus. Viruses influence many molecular events that govern the control of the cell cycles. The virus most commonly implicated in oral cancer
transformation is the human papilloma virus (HPV), especially HPV type 16 (HPV-16). It is possible that HPV 16 transfectants play a significant role in oral cancer development by mutating the cellular defense mechanisms acting against cancer development (Gimenez-Conti, 1993). It is important to understand the role of infection in the development of oral cancer in order to develop effective strategies for prevention.

1.4.2.1.1. Human papilloma viruses infection and oral cancer

The human papilloma viruses (HPV) are a large group of viruses, associated with cervical cancer as well as with cancers of other mucosal surfaces. As well, HPV is associated with a variety of oral and skin pathology including warts, condylomas, papillomas and cancers in a number of other organs (Silverman, 2003). These associations have prompted the investigation into the relationship between HPV and oral cancer. HPV infection, specifically HPV-16 is believed to be involved in the carcinogenesis of anogenital epithelial cancers and are also suspected of causing epithelial oral cancers (Mork, 2001).

HPV, specifically HPV types 16 and 18, is considered to play a primary role in cervical epithelial transformation (zurHausen, 1991). Oncogenic HPVs have also been detected in oral squamous cell carcinoma (SCC) and are present in up to 22% of cases, either alone or in combination with other HPV types (Sugerman, 1997). The genotypes most often found in oral carcinoma are HPV 16 and 18 (Palefsky, 1995). HPV 18 is present in up to 14% of cases, while HPV types 16 and 18 are present together in approximately 6% of cases. However, HPV 16 and 18 have also been detected in normal mucosa (10% and 11% respectively). This suggests that HPV infection may be a
co-factor in oral carcinogenesis and that latent HPV infection of the oral mucosa is common (Sugerman, 1997).

More than 100 different types of HPV types have been isolated from benign and malignant cancers. HPV has been detected in biopsies of oral cancer and precancer. HPV has also been identified in nodal metastases from oral, head and neck cancers. A study by Bouda et al. (2000) found that high-risk types of HPV (HPV 16, 18, 33) were detected in oral precancer and cancer but not in normal oral mucosa. These results were supported in another study that showed that the odds ratio for squamous cell carcinoma of the head and neck in patients that were seropositive for HPV-16 was 2.2 (95% confidence interval, 1.4 to 3.4). No increased risk was observed for other HPV types. Fifty percent of the oropharyngeal and 14% of the tongue cancers contained HPV-16 DNA according to the PCR analysis and these authors concluded that HPV-16 might be a risk factor for head and neck cancer (Mork, 2001).

There are several possible theories linking HPV to oral SCC. Infection of oral keratinocytes with high-risk HPV (16/18) may (1) deactivate the tumor suppressor proteins by viral oncoproteins, (2) block tumor suppressor gene transcription as a result of HPV oncogene insertion or (3) stimulate cellular oncogene transcription (Sugerman, 1997).

The precise role of HPV in the etiology of oral cancer needs to be examined further to determine whether the virus acts independently of other etiological agents or whether there is a synergistic relationship between this virus and exogenous agents such as tobacco or alcohol to promote malignancies.
1.4.2.1.2. Candida albicans infection and oral cancer

A possible role for Candida albicans in the development of oral cancer is based on reports of its presence in a high percentage of oral leukoplakias with morphologic signs associated with malignant transformation. Precancerous lesions such as oral leukoplakia, with Candida infection, may carry an increased risk for transformation to a cancerous lesion, although this is still somewhat controversial. The leukoplakias with Candida are often erosive or speckled leukoplakias, a clinical type with a high rate of malignant transformation. It may be that the high incidence in these lesions is due to the fact that these lesions merely provide a fertile ground, thus Candida may be just a passenger as opposed to acting on its own (Gerson, 1990). Of interest, Candida has been found to generate nitrosamines, a carcinogen, although the association between this activity and oral cancer has not been demonstrated (Silverman and Sugerman, 2000).

1.4.2.1.3. HIV infection and oral cancer

Oral cancer does not appear to be a common consequence of systemic immunosuppression, even though, among HIV-positive immunocompromised individuals, HIV-associated oral malignancies have been reported, the most common being Kaposi’s sarcoma (KS) and non-Hodgkin’s lymphomas (NHL)(Epstein, 1992). KS is a malignant reactive lesion that stems from cytokines that induce the formation of tumors in tissues and organs. The most prominent lesion of KS is the characteristic appearance of a vascular lesion on the skin. While the skin is the most common site for lesions, half of the patients will have oral manifestations. KS can afflict any oral
mucosal site, the palate being the most common and the gingiva the second. The occurrence of non-Hodgkin's lymphoma in HIV individuals increasing as the number of HIV cases grows and their longevity extends. Frequently these lymphomas are extranodal and can involve the mouth.

As the population ages and the number of HIV-infected patients increase, the number of immunocompromised individuals also increases. Patients with immunodeficiency acquired by medication are reported to have an increased rate of lip cancer, but not intraoral cancer (Scully, 1983). It has been reported that young adult males with AIDS or AIDS related complex and thus immune deficient, have a higher rate of oral cancer than controls in the same age range (Silverman, 1986). However, more recent studies have shown that oral squamous cell carcinoma in patients with HIV-infection or AIDS is generally rare (Langford, 1995).

1.4.2.2. Immunocompromised patients and oral cancer

Host diseases are the result of the interactions between external factors and the host whereby the ability of the host to resist certain diseases such as oral cancer may be tempered by factors such as immune deficiency, poor diet and nutrition. Age and external factors such as the use of tobacco and alcohol have also been shown to reduce the efficacy of the immune system (Newbill, 1983).

Transplantation is becoming an increasingly common procedure. It is currently used as a standard procedure in the treatment of leukemia and to replace dysfunctional organs. An immunocompromised status is necessary in order to prevent rejection of the transplant. As a consequence of the immunosuppression, other diseases such as the
development of other cancers and graft versus host disease may occur. Patients who
develop graft-versus-host disease as a result of transplantation, have been shown to
have an increased risk for developing oral cancer as a result (Otsubo, 1997). Zhang et
al. (2002) suggest that such patients should be monitored very closely. Patients who
are immunosuppressed after organ transplantation have a higher incidence of
subsequent cancer development, particularly of the lower lip, supporting a role for
immunosuppression whether it is viral or transplant-induced (De Visscher, 1997).

I.4.2.3. Diet and oral cancer

Poor nutrition was considered to be the third most important factor in oral cancer
according to Rodriguez et al. (2004), after tobacco and alcohol, together accounting for
85% of oral cancers. Nutritional factors, particularly the consumption of fresh fruit and
vegetables, the primary sources of beta-carotene, appear to be associated with a
decreased risk of developing oral cancer. Studies on the role of dietary influences on
the development of oral cancer have generally confirmed that a healthy diet rich in
antioxidants like vitamins A, C and E may be protective for cancer by scavenging free
radicals from damaged cells. Patients who ingest high levels of vitamin C and fiber
have been shown to have half the risk of oral cancer as compared with those with the
for oral cancer in association with an increased intake of vitamins A and C. In another
study by Marshall (1992) results showed that an intake of more fruit and vegetables,
vitamin C and fibers reduced the risk for cancer of the upper digestive tract.
A deficiency of iron is also associated with an increased risk for oral cancer. Patients with Plummer Vinson syndrome, in which there is often iron-deficient anemia and mucosal atrophy, have a higher than expected rate of oral cancer. Binnie et al. (1983) proposed several theories on how iron deficiency might factor in the etiology of oral cancer. One possibility is that iron deficiency may cause a thinning of the epithelium thereby rendering it more permeable to carcinogens; or, it may stimulate an increased epithelial turnover, increasing the chances of chemical carcinogens altering DNA; and finally, iron deficiency may cause an impairment of the immune system.

There is some evidence that patients with oral cancer have decreased levels of serum zinc and copper (Varghese, 1987). Zinc deficiency has been reported in association with esophageal cancer (McClain, 1983). Esophageal epithelium is morphologically and functionally similar to the noncornified epithelium of the oral mucosa.

I.4.2.4. Lichen planus and oral cancer

Oral lichen planus (OLP) is a common dermatological disorder with oral manifestations sometimes occurring prior to skin involvement (Mattsson, 2002). It is a chronic inflammatory disease of the immune system of unknown etiology with a prevalence rate as high as 1–1.2 % of the general population (Zhang et al., 2000), more common in females than males. OLP can have various presentations, including reticular, erosive, and plaque-like. The presence of reticular white striations and or white papules distinguishes OLP from other diseases of the oral mucosa. Plaque-type, atrophic, ulcerative and bullous lesions may be present at the time of diagnosis or may
occur during the course of the disease. Biopsy is required for diagnosis especially at high-risk sites such as the lateral and ventral tongue and sites with an erosive or red component to the lesion (Silverman, 2003).

The malignant potential of oral lichen planus (OLP) has been a matter of ongoing debate, although it is considered a premalignant lesion by the World Health Organization (1978). Reported transformation rates on lichen planus followed over time vary between 0 and 9%, indicating a possible higher-than-expected rate of malignant transformation (Mattsson, 2002). However, controversy exists as to whether reported cases of OLP developing oral cancer were actually not OLP but rather dysplastic lesions with lichenoid features (Krutchkoff and Eisenberg 1985, 1986). This implies that patients with lichenoid dysplasia may represent a distinguishable risk group for oral cancer that can be identified with appropriate diagnostic methods, as compared to patients with OLP showing no dysplasia-related increased risk of development of oral cancer (Mattsson, 2002). Zhang et al. (1997) suggested that either oral lichen planus has a very small malignant potential or that oral lichen planus should only be considered premalignant if accompanied by dysplasia. A review by Zhang et al., (2000) also suggests that the presence of any degree of dysplasia should not be discounted by the presence of oral lichen planus but considered a proper dysplasia.

The separation of oral lichen planus without dysplasia from lichenoid dysplasia (dysplastic lesions with lichenoid features) makes management difficult and may prove to significantly reduce the reported malignant potential of oral lichen planus. For example, some lichenoid lesions may in fact be lichenoid contact reactions caused by components leaking from amalgam fillings. Histologically, these lesions are difficult to
distinguish from OLP. These lesions are not been known to be associated with malignant transformation; however, their inclusion may result in a decrease in the rate of the malignant potential of OLP (Bolewska et al., 1990, Bratel et al., 1996).

Patients who fulfill the commonly used criteria for OLP do appear to have an increased risk of developing oral cancer, although the observed incidence is low. Since OLP is considered to have pre-malignant potential by many researchers, it has been recommended by some that in order to facilitate the early diagnosis of oral cancer, patients with OLP should be followed closely and have regular follow-up examinations two to four times annually (Scully et al., 1998). However, at this point, there is no evidence to show that intensive follow-up of OLP will reduce the morbidity and mortality of oral cancer related to OLP (Mattsson, 2002). It may be appropriate however, to biopsy lesions at high-risk sites during the initial visit to confirm diagnosis and monitor them thereafter for clinical changes indicative of premalignant or malignant change.

I.4.2.5. Poor dentition

There is little evidence to suggest that poor oral hygiene, improperly fitted dental prosthesis, defective dental restorations, or misaligned sharp teeth promotes oral cancer (Silverman, 1990). In a study by Silverman and Gorsky (1984), 400 patients with oral cancer were studied to determine whether dentures were a risk factor. Results found no correlation between the wearing or dentures and the patients' cancers. In contrast, however, poor oral hygiene has been implicated as a risk for oral cancer in more recent studies (Lissowska et al., 2003; Sudbø et al., 2001). Further studies in this
regard will be necessary to determine the exact etiologic role of poor oral hygiene in the development of oral cancer

1.4.3. Genetic factors and oral cancer

The activation of certain oncogene proteins have been associated with the development of human oral cancer. In an analysis of 23 human oral cancers, six different oncogenes showed amplification with more extensive amplification associated with more advanced clinical stages of the cancer (Saranth, 1989). Oncogenes regulate cell cycle growth and differentiation. When a mutation occurs to the proto-oncogene it becomes an oncogene, a gene that is constantly "on", leading to uncontrolled cell growth. Tumor suppressor genes inhibit the cell cycle or activate pathways that lead to cell death (apoptosis). Loss or mutation of the tumor suppressor gene is associated with changes to cell proliferation and increased malignancy. For example, mutation of the \( p53 \) tumor suppressor gene may represent the most common genetic change in human cancers (Greenblatt et al., 1994). These proteins can be detected in tissues by molecular and immunohistochemical analysis.

Research is currently ongoing to define how oncogenes and tumor suppressor genes fit into the multi-step carcinogenetic process for oral cancer and to determine their role as prognostic factors for disease-free or overall survival.

Loss of genetic material in one pair of chromosomes is designated loss of heterozygosity (LOH). LOH at chromosomal regions that are supposed to contain tumor suppressor genes might be related to the process of malignant development (Renan, 1993). LOH in oral pre-malignant lesions and its possible positive predictive
value were recently reviewed (Zhang and Rosin, 2001). LOH, in particular at chromosome arms 3p and 9p, was shown to be associated with a greater possibility of malignant development of premalignant lesions (Lee et al., 200, Califano et al., 2000, Rosin et al., 2000). Other chromosomal losses in addition to 3p and 9p increased the possibility of malignant development (Rosin et al., 2000). Studies on chromosomes show that mutations (allelic loss) occur in over 70% of head and neck tumors; this was also found to be true for pre-invasive lesions (Nawroz, 1994). A loss of genetic information on chromosome 9p is an early event in head and neck squamous cell carcinogenesis. Those lesions with LOH limited to 3p and 9p showed a 3.8-fold increased risk, while those with loss at any of the chromosomes 4q, 8p, 11q, 13q, and 17p in addition to loss at 3p and 9p had a 33-fold increased risk for progression to cancer compared with lesions that retained those arms.

The use of molecular biologic markers for predicting malignant transformation of oral premalignant lesions is showing great promise for use as future diagnostic tools.

1.5. BC Oral Cancer Prevention Program (BC OCPP)

The BC OCPP is a leading research team that is leading worldwide efforts in the study of early high-risk oral lesions. The vision of the British Columbia Oral Cancer Prevention Program is to reduce the incidence and mortality of oral cancer through the development, validation and adoption of new techniques for early detection, risk assessment and management of premalignant oral disease and cancers. An integrated management structure links community health professionals in a step-wise referral
pathway, to ensure seamless management of the disease from early dysplasia to frank malignancy. The initial focus is a province-wide strategy for BC. Its chief objectives are:

- To prevent the development of oral cancer, or to detect it at the earliest possible stage.
- To achieve a greater cancer cure rate through more clinically effective treatment.
- To improve the early detection of local and regional recurrences.

On a global scale, there is universal recognition that a new strategy for management of oral cancer is needed. The BC OCPP will answer this call by developing universal models for transferring the BC vision to the international community.

The BC OCPP has identified and focused on the major reasons for late diagnosis of high-risk lesions: (1) problems in the clinical diagnosis of high-risk lesions; (2) problems in the histological diagnosis of high-risk lesions; and (3) difficulty in accessing the high-risk population, the marginalized poor. To solve the above problems, the BC OCPP has developed a number of molecular, histological and clinical tools to help the identification of the high-risk OPLs and early SCC. However, to date, this research had been confined to high-risk dysplasia clinics and tools developed in these clinics have not been validated in the community settings. Also, access to high-risk population in the community such as the marginalized poor has been limited.
1.6. **Oral cancer screening**

1.6.1. Concept of screening

In general, screening refers to methods used to detect treatable diseases in the least invasive, most economic and most patient friendly manner, with the least possible false-positive results (specificity) and the highest possible rate of true positivity (sensitivity) in an at-risk population (Sanduleanu, 2003). Screening for oral cancer is the examination of asymptomatic people for the detection of oral pre-cancer and early cancer. Specifically, it should include a thorough head, neck and intra-oral examination, with palpation of the cervical lymph nodes and visual examination and palpation of the oral mucosal surfaces, especially the lateral borders of the tongue and the floor of the mouth. The social, family and medical history should be reviewed along with the documentation of any risk behaviors (tobacco and alcohol usage). Screening for OPLs and early-stage oral cancer in high-risk populations may be the most effective approach in reducing the mortality, morbidity and the economic burden of treatment associated with advanced SCC.

It is recognized that early detection, through screening, in a high-risk population may provide the most effective strategy for controlling oral cancer. Early diagnosis and treatment improves quality of life of the patient by reducing the physical, functional and psychosocial disabilities attributable to the disease, and at the same time reduces the economic burden associated with the costs of treatment.
1.6.2. Adjunctive tools for screening

Verifying the premalignant status of an oral lesion requires a biopsy. However, there are non-invasive adjunctive aids available to aid in the diagnosis of early premalignant lesions. One of the more common adjunctive tools available for the clinical detection of oral SCC and OPL is toluidine blue (TB). Research supports the use of diagnostic aids to facilitate a clinical decision.

Toluidine blue (TB), also known as Tolonium Chloride, is a metachromatic, acidophilic vital thiazine dye that is soluble in water and alcohol (Dunipace et al., 1992) and is used by clinicians to help in the identification of primary SCC, SOMs and dysplasias. The topical application of toluidine blue to a suspicious area helps to identify the presence of dysplastic or carcinomatous lesions (Silverman, 1984). Toluidine blue stain is believed to bind selectively with the RNA and DNA in cells, showing a propensity for cells with increased nuclear content. Another mechanism of action proposed for TB is that it is taken up by the mitochondria of malignant and premalignant cells. Mitochondria are the energy sources of a cell and become more numerous and acquire a negative charge as the cell progresses along the cancer pathway. This mechanism, however, has not been confirmed in the research as of yet.

Toluidine Blue can be applied by direct application or by rinsing. Direct application involves applying a 1% TB solution directly to a lesion with a cotton tip applicator, waiting for 20-30 seconds, and then wiping the stained area with a cotton tip applicator soaked in 1% acetic acid. This method can be preceded with an initial acetic acid wipe of the lesion prior to TB application. With the rinse method, the patient swishes with 1% acetic acid for 20 seconds, followed by a 1% TB rinse for 20 seconds,
another rinse of 1% acetic acid and finally, a water rinse. A stained lesion is considered positive when it retains a dark blue color once the lesion has been wiped with the acetic acid and rinsed with water (Figure 1). If the lesion stains weakly it is called ‘equivocal’, and if no stain remains on the lesion it is considered negative. Mashberg (1980) suggests that equivocal results should be considered positive unless proven otherwise.

Clinicians can use TB to help identify lesions more likely to have premalignant or malignant changes. Used correctly, toluidine blue is believed to yield false positive and false negative rates of less than 10% (Mashberg, Samit, 1995). Additionally, using TB can help determine the appropriate biopsy site, and as well help the surgeon determine the surgical field for the excision of the lesion. Clinical judgment must be exercised in evaluating the results of the TB stain. Whenever there is an unexplained leukoplakia or erythroplakia, a biopsy should be performed to confirm the diagnosis. TB should be considered an adjunct to biopsy, not a replacement.

The use of fluorescence visualization (FV) is another adjunctive approach to clinical examination. A hand-held device that directly measures auto fluorescence, the VELscope, is currently being evaluated for oral cancer screening in the dental office and in community screening programs. FV identifies lesions with alterations in biochemistry and morphology that may be associated with the development of oral cancer (Lane, 2006). Historically, this technology has been used at other body sites such as lung and cervix, facilitating the identification of cancers and premalignant lesions.

This device is a non-invasive, patient/user friendly device that is recently gaining favor in the dental community to visualize tissue fluorescence in the oral cavity (Poh et al., 2006). Fluorescence in the oral cavity can be observed directly by aiming a blue...
light at the surface of the oral mucosa. Normal tissue will retain fluorescence and appear green (FV-R) while abnormal tissue has loss of fluorescence and appears dark brown/black (FV-L) (Figure 1). A pilot study of 44 patients has demonstrated encouraging results with a high sensitivity and specificity (98% and 100% respectively) when comparing normal mucosa with histological confirmation of severe dysplasia or invasive carcinoma (Lane, 2006).

Figure 1. Use of new devices/tools to identify suspect clinical change.
A, An ill-defined red lesion on the left buccal mucosa of a 65 year-old male. B, The same lesion, viewed with a fluorescence visualization (FV) device, showing a well-demarcated dark area of FV loss. C, Lesion after application of vital stain toluidine blue (TB) showing focal uptake of the blue stain. Biopsy from site with TB staining was an invasive squamous cell carcinoma.
1.6.3. The impact on mortality and morbidity

Screening has the potential to have significant impact on oral cancer. The five-year relative survival rate for this disease is low; 54% for whites and 34% for African-Americans and it has remained relatively unchanged for the past three decades despite advances in appropriate treatment. Additionally, those that survive face an increased risk of developing new primary head or neck cancers. This risk appears to be greater among smokers. Early detection of oral cancers reduces the morbidity and decreases the mortality. Those diagnosed with oral cancer at a localized stage have a four times greater five-year survival rate than those diagnosed at a later stage (82% for early stage diagnosis as compared to 21% for late stage diagnosis) (NCI SEER Results, 2001). In addition, late detection requires aggressive treatments such as surgical resection and/or radiation therapy, which increase morbidity and decrease quality of life. Facial appearance may be altered; individuals may experience infections of the oral and dental structures and difficulties with eating, speaking and tasting. As a result of extensive treatment of advanced SCC the patient may suffer significant psychosocial impacts, further reducing quality of life.

Early diagnosis and treatment improves the quality of life of the patient by reducing the physical, functional, and psychosocial disabilities attributable to the disease and the various forms of treatment involved in treating the disease.
1.6.4. Cost effect benefit analysis

The economic burden of cancer can be measured by direct and indirect costs. Direct costs are costs associated with the care provided in hospitals, physician services, drugs and other expenses (including other health professional, public health and research cost). Indirect costs are those related to loss of life due to premature death (mortality costs) and the value of activity days lost due to disability (morbidity costs). A report from Health Canada in 2002 entitled “Economic Burden of Illness in Canada, 1998” (Health Canada, 2001) showed that cancer, for all sites accounted for $2.5 billion in direct costs with hospital care accounting for $1.8 billion or 74% of the total costs. Physician costs were $333 million, or 14% of direct costs of cancer treatment. This represents 3% of the total costs in Canada of all medical services provided by physicians. Clearly, cancer does have a significant economic impact in Canada.

For oral cancer, a study in the Netherlands, Van Agthoven et al, reported an average cost of US $22,080 on the basis of 306 patients with a primary oral cancer tumor. In the United States, Funk et al reported an average cost of $US$ 32,500 after evaluating 73 patients with a primary oral cancer tumor. A study in Greece by Zavras et al, (2002) demonstrated the stratified direct costs of oral cancer across the various stages. Stage I cancer treatment costs were reported as US$3,662, Stage II at US$5,867, Stage III at US$ 10,316 and Stage IV direct costs at US$11,467. While these costs are considerably lower than reported in other studies, they demonstrate that the costs of oral cancer treatment increase significantly with later stage of diagnosis.

Additional or extended surgical therapy and/or combined treatment modalities (radiation therapy and/or chemotherapy) for the late-stage oral cancer will significantly
increase the cost to the healthcare system. Early diagnosis and treatment may positively affect the economic burden associated with cancer treatment by reducing the overall costs associated per patient.

1.6.5. Rationale for screening high-risk populations

1.6.5.1. Literature support of screening high-risk populations

Diagnosing oral cancer at an early stage is crucial to reducing morbidity and mortality (Park, 1992). Although currently there is a lack of evidence from randomized clinical trials (considered the 'gold standard' for evaluation of effectiveness) to support the introduction of population-based screening, it has been previously reported that opportunistic and targeted oral cancer screening may produce a health gain of approximately three hundred quality years of life and save fifteen lives for every 100,000 subjects screened (Downer, 1998). Furthermore, the Canadian Task Force on Preventive Health Care has suggested that for patients considered high-risk for oral cancer, an annual screening examination is warranted, as risk factors such as excessive alcohol and tobacco use are known and identifiable. While the overall incidence of oral-cancer is low in the general population, the screening only of high-risk groups would likely increase the yield of the screening programs and therefore be more cost effective.

A consideration for oral cancer screening programs in the general population is the low incidence of oral cancer, especially in the developed countries. This would result in (1) a low yield of oral precancer and squamous cell carcinoma with screening, (2) a high proportion of false positive results, (3) low compliance with organized
screening and hence, (4) poor cost benefit ratio. However, oral cancer is a deadly disease and the improvement in prognosis and morbidity that would result from an earlier stage diagnosis are well documented.

To date, population-based studies of screening programs to identify OPLs have generally found high specificity (98-99%) and a varied sensitivity (56-94%). Positive predictive values have ranged from (15-91%) (Mehta, 1986), depending on the prevalence of the disease. Screening programs that focus on high-risk groups however, may substantially increase the yield for OPLs and SCC and reducing the number of false-positive referrals.

For example, a case control study in Cuba, where oral cancer accounts for 4% of all cancers annually, has shown that regular screening once every three years can reduce late stage diagnosis. Furthermore, in India, where oral cancer has a high incidence accounting for 10-25% of all cancers in men and 8-15% of all cancers in women (Parkin et al. 1992), patients with two or more visual screenings were 2.5 times less likely to have an advanced cancer diagnosis than similar individuals who had not been regularly screened (Sankaranarayanan, et al. 2002).

Encouraging results from a community based oral cancer-screening program have been reported from a longitudinal screening trial of healthy adults in Kerala, India. In this, the first ever-randomized trial, 13 clusters were randomized to an intervention group (N=7 clusters) for visual oral examination by trained lay health workers and a control group (N=6 clusters). There were 95,517 individuals in the intervention group and 95,356 in the control group, all greater than 35 years of age. For 8 years (1996 to 2004), 3 rounds of oral visual screening at 3-year intervals were provided. Screen-
positive cases were referred to physicians for biopsy. Precancer cases were advised to quit tobacco habits and were prescribed chemopreventive medication or surgical excision. Oral cancer cases were treated by surgery or radiation according to the stage at diagnosis.

Data from the first 3-year phase showed a diagnosis of 36 (0.07%) cancers and 1310 (2.7%) oral precancers in the intervention group. The reported sensitivity for detection of oral cancer was 76.6% and the specificity 76.2%; the positive predictive value was 1.0% for oral cancer. The 3-year case fatality rates were 14.9% in the intervention group and 56% in the control group. Study results from screening in the intervention group after a nine year period showed a significant reduction (34%) in oral cancer mortality in this high-risk community among individuals with tobacco/alcohol habit. The authors conclude that there is a potential to prevent 37,000 oral cancer deaths worldwide with oral cancer screening. This is the first data that demonstrates the effectiveness of a periodic screening and intervention program in improving early detection and reducing oral cancer mortality in a high prevalence population. (Sankaranarayanan, et al. 2000).

Some research suggests that oral cancer screenings in low incidences areas might be more cost effective if they target high-risk populations. It is estimated that when based on a high-risk population, only one quarter of the population would need to be screened and 2 to 3 times the number of lives would be saved compared to non-selective screening (Downer et al. 1998, 1997).
1.6.5.2. Vancouver’s Downtown Eastside: a high risk population

The Vancouver Downtown Eastside (DTES) is one of Vancouver’s oldest communities. It is an area bounded by Burrard Inlet (Port of Vancouver) to the north, Hastings Street to the south, Clark Drive to the east and Main Street to the west. There are five distinct neighborhoods and historic areas: Chinatown, Gastown, Victory Square, Strathcona and Oppenheimer. The DTES’s residential area is between Main Street and Heatley Avenue, north of Hastings Street. Most housing is concentrated in the Oppenheimer district. (Downtown Eastside Monitoring Report. 2001, See Fig. 2).

Figure 2. Map of Downtown Eastside Vancouver
(Adapted from Downtown Eastside Monitoring Report, 2001). The insert map shows the location of the DTES within the City of Vancouver. The Portland Hotels are indicated by red dots.

According to Statistics Canada, the 1996 population in the DTES was 16,275 with the 20-44 age group being the most highly represented (6,525). Aboriginals

40
accounted for 9% of the population (1,430), while the Chinese population accounted for 33% (Downtown Eastside Monitoring Report 2001).

The DTES is a unique high-risk population characterized by extreme poverty, excessive use of tobacco and alcohol, a high number of intravenous drug users, persons with mental illness, high rates of HIV and AIDS, Hepatitis A and C, and periodic epidemic outbreaks of tuberculosis and syphilis (Buxton, 2003). Social dysfunction is prevalent and likely the result of a severe shortage of clean, safe, affordable housing, social isolation, marginalization of the injecting drug users, and little employment opportunity (Benoit, 2001).

The demand for housing far exceeds the availability. Many who do have housing however, live in slum, single room occupancy (SRO) hotels that lack most basic amenities and often serve as “shooting galleries” for drug users. The exception to this are the six hotels operated by the Portland Hotel Society, which offer clean, affordable accommodation to approximately 600 residents. Still, many of the Society’s tenants live with alcohol and drug addiction, mental illness, physical disabilities, poverty, and life-threatening diseases, especially HIV/AIDS. Due to the accessibility and as a “step-out” from the current community dental clinic screening, this thesis focused on the Portland Hotel Society as an initial approach to this high-risk population for oral cancer screening.

The study population is approximately six hundred residents in six hotels operated by the Portland Hotel Society (PHS) and two user groups (Latin American men’s group and an all-women’s group) from the Portland Life Skills Center, both in the
DTES of Vancouver, B.C. These groups represent key components of the heterogeneous sub-populations that characterize the DTES.

There are many oral and general health issues and access to care challenges that face this marginalized high-risk population. In his document "Achieving health for all: A framework for health promotion", Epp (1986) suggested that in order to achieve health and equity for all, there must be a focus on reducing the inequities by increasing access to care and prevention, education, and enhancing hope of marginalized populations. Individuals who are at high risk for oral disease are often in the lower socio-economic groups. Due to the different lifestyle and perceptions of this specific population, they are less likely to seek regular visits to dentists as a result of financial constraints, a lack of facilities, the inability to access facilities, or indifference towards their oral health. Two objectives for choosing a high-risk population for this study are firstly to identify the barriers and facilitators of this population with respect to their participation in an oral cancer-screening program, and secondly provide the opportunity to improve oral health through education and awareness of oral cancer and oral cancer risk behaviors.

I.6.6. Public Awareness of Oral Cancer

Several studies have investigated the population awareness of oral cancer and the ability to recognize early signs and symptoms of oral cancer, particularly among high-risk groups. A national survey in the United Kingdom conducted in 1995 reported a low level of awareness, with only 56 percent of the participants having heard of mouth cancer (Warnakulasuriya, 1999). In the United States, a review of studies examining
the awareness of oral cancer also indicated that awareness was low; however, there were only a few studies involved and few had representative samples (Horowitz, 1996). A national survey of adults in the United States in 1990 produced similar results to other studies, showing that adults are ill informed about risk factors for and signs of oral cancer (Howowitz, 1995). Respondents did not know about risk factors for mouth or lip cancer. Only 36 percent correctly responded that excessive sunlight definitely increased the chance of getting lip cancer. Only 13 percent knew that regular alcohol consumption increases the risk of oral cancer. There was also much misinformation across all groups regardless of age, ethnicity or race. As well, findings from a study of veterans in Maryland (Canto, 1998) showed that 84 percent of participants recognized tobacco use as a risk factor for oral cancer but only 39 percent were aware that alcohol was a risk factor. These findings highlight the importance of population education about oral cancer and oral cancer prevention (screening in high-risk populations) in order to detect oral cancer early in an attempt to improve the dismal survival rate.

Preventable diseases such as oral cancers impair lives and impose financial burdens on society. A consequence of communities not being aware of or not having accurate and appropriate information about oral cancer is that people can neither make nor be expected to make informed, intelligent decisions about their own health. They are not able to practice preventive procedures mainly because they have never been taught about them, do not have the skills to seek such information, or do not have access to the information (Green, 1991). Furthermore, educational messages are prevalent about the use of tobacco products and alcohol as contributing factors to mortality and morbidity with regard to heart disease, lung cancer, low birth weight
babies, and liver disease. However, these messages seldom relate alcohol and tobacco use as risk factors for oral cancers.

It seems reasonable that morbidity and mortality from oral cancers could be reduced by identifying high-risk patients and increasing their awareness about oral cancer by educating them about (1) the need for, and providing them with oral cancer screening examinations and (2) the signs and symptoms of oral cancer and the risks associated with tobacco and alcohol use.

1.7. Qualitative research

1.7.1. Focus group discussion

Qualitative methodology provides rich in-depth information about a specific topic, and focuses on the participants' perception, and enables the researcher to hear directly from the people participating. This is a method of research that gathers information from the personal first hand experiences of the target population of interest, in their own voice. Focus groups and personal interviews are general approaches of this form of this qualitative research.

According to Carey (1995), the focus group technique is described as “using a semi-structured group session, moderated by a group leader, held in an informal setting, with the purpose of collecting information on a designated topic.

The collection of personal experiences and beliefs related to the designated topic is the purpose of the focus group”. This methodology can avoid the generalizations and stereotyping of the underclass population by professionals who use their own language and filters. First person information also enables the researcher to understand the full
depth of the participant's experiences or concerns and allows for participants to recommend strategies that will be most effective for them. Researchers can obtain a different perspective from first person research as opposed to information obtained from a service agency. It is important to hear first hand from people living the experience. Finally, this qualitative research can help to identify issues that require further study and help shape future research instruments such as quantitative surveys (Graves, 2002).

In focus group discussions, the interview questions are open-ended to encourage participants to respond from their own perspective, thereby giving richness and diversity to the quality of the information obtained. Detailed information is collected and documented from a small group (seven to nine persons), or individual participants. Focus groups generate discussions of similarities and differences among participants.

Focus groups are characterized by the "explicit use of group interaction to produce data and insights that would be less accessible without the interaction found in a group" (Carey, 1995). The focus group discussion, a qualitative methodology, was selected as the approach for this research to gain information about participants' personal feelings and opinions about what would motivate and prevent them from participating in an oral cancer-screening program. This approach gave the participants an opportunity to have their voices heard and to provide rich and diverse information.

Qualitative methods such as focus group discussions are used to explore subjective experiences and allow insight into individuals' understandings, interpretations and beliefs. Therefore, the focus group discussions in this study permitted a discovery investigation into the perceived barriers and facilitators for residents to participate in an oral cancer-screening program in their community. Because this study was exploratory
in nature, the participants were encouraged to discuss other beliefs about oral cancer that were important to them even if it moved away from the focus group discussion questions.
II. STATEMENT OF THE PROBLEM

Oral squamous cell carcinoma (SCC) is the 6th most common cancer in the world and is believed to progress through sequential stages of pre-malignancies. It is a deadly disease combining both high mortality (5-year survival rate just over 50%) and morbidity, largely due to late diagnosis. Multiple factors contribute to this late diagnosis, including problems in both clinical and histological identification of the high-risk oral premalignant lesions (OPLs) and early SCC, and problems in reaching some of the high-risk populations, notably the marginalized poor and medically underserved.

The residents of Vancouver's Downtown Eastside are at high risk for oral cancer because many are heavy smokers and regular consumers of alcohol, known risk factors for developing oral cancer, often with a history of substance abuse. Further aggravating the problem is that many are immunocompromised, have poor nutrition and oral hygiene and a limited access to dental and medical care are found. There is a lack of formalized oral cancer screening initiative in this high-risk community.

In addition, the BC Oral Cancer Prevention Program (BCOCPP), a leading research team in the study of early high-risk oral lesions, has developed a number of molecular, histological and clinical tools to help the identification of the high-risk OPLs and early SCC. However, the research had been confined to high-risk dysplasia clinics, and there is an urgent need to expand the research into community to further its validate their use in the community.
III. OBJECTIVES

The overall objective of this thesis is to develop an infrastructure that will bring screening technologies/devices into the high-risk medically underserved community, Vancouver Downtown Eastside (DTES). There are two phases to this work.

The objectives of the phase I were (1) to establish an oral cancer screening clinic in the Vancouver Downtown Eastside (DTES), where a high concentration of the marginalized poor reside; (2) to determine characteristics of persons attending the Clinic as compared to the broader community; (3) to determine the frequency and pattern of oral diseases of patients at the clinic; and (4) to identify potential challenges to screening in a community dental clinic setting.

Based on the challenges learned from phase I, the objectives of the phase II were (1) to characterize the knowledge and beliefs about oral cancer and the attitudes towards oral cancer screening, (2) to identify the barriers and facilitators for an oral cancer screening intervention, and (3) to provide a basis for development of strategies for the implementation of an oral cancer-screening program in this high-risk, hard-to-reach community.
IV. PHASE I

IV.1. Methods

IV.1.1. Establishment of screening clinic and study group

Screening Clinic: An oral medicine service was established within a pre-existing community dental clinic hosted by the Portland Hotel Society (Figure 1). The service is for all residents of the DTES and involves a multi-disciplinary team led by an oral pathology specialist. This is a drop-in service, operational one morning every 2 weeks.

Study Group: Dental patients were invited by the staff dentist (SS) to receive an oral cancer screening examination. The study group included individuals with current residency in the DTES who were mentally competent, able to speak English or Mandarin and who attended the clinic between September 2004 and April 2006 (48 sessions). Patients requiring multiple tooth extractions or presenting with severe psychological problems or drug or alcohol intoxication were not invited for the screening examination.
IV.1.2. Procedures for screening

**Interview**: Data on patient demographics, known risk factors and medical history were collected by personal interview conducted by trained interviewers. Demographics included gender, age, ethnicity, education, employment status, income, English fluency and residency in a Portland Hotel; known risk factors included tobacco and alcohol consumption; and medical history included specific past infections, prescription drug use and recreational drug use.

Questions on tobacco consumption included: "Have you smoked 100 or more cigarettes in your life? If yes, do you currently smoke? At what age did you begin to smoke? Average number per day? How many years in total did you smoke?" Questions on alcohol consumption were asked separately for beer, wine and spirits/liquor, and included: "Do you now drink or have you ever consumed alcoholic beverages more than once or twice a month? If yes, are you currently consuming? At what age did you begin to consume? Average number per week? How many years in total did you consume?" Similar questions were also asked for current use of prescription drugs (anti-retrovirals, antipsychotics, antidepressants, pain medications, methadone) and for ever use of recreational drugs (marijuana, crack/cocaine, heroin and crystal meth).

Since some infections compromise the immune system, which might increase cancer risk, the specialist or hygienist collected personal history of Human Immunodeficiency Virus (HIV) infection, Hepatitis C virus infection, and Hepatitis B virus carrier status.
Clinical assessment: The oral cancer screening examination included a full head and neck and intra-oral direct visual examination. Clinical findings (presenting symptoms, location and type of oral mucosal lesions, if present) were recorded on a standardized form by the oral pathology specialist (CFP) and the dental hygienist (BC), which then became part of the dental record. Clinical leukoplakia was defined as a white patch on oral mucosa that can neither be scraped off nor classified as any other diagnosable disease (WHO, 1978); it has higher malignant potential compared to its normal counterpart. Suspicious lesions were referred to the staff dentist for biopsy at the time of screening, if possible. The pathology reports for all resulting biopsies were collected and reviewed by an oral pathology specialist in the BC Provincial Oral Biopsy Service.

The study protocol was approved by the University of British Columbia Research Ethics Board and all patients signed informed consent before enrollment in the study.

IV. 1.3. Data analysis

Descriptive statistics were used to summarize demographic characteristics, known risk factors, medical history, and screening results for the study group.

IV. 2. Results

A total of 284 patients attended the dental clinic during the study period, presenting with dental needs, most commonly tooth related (50%), for dentures (24%) or for hygiene (18%). Two hundred and four of these patients were invited by the staff dentist to receive an oral cancer screening examination and 200 (98%) accepted. It was not feasible to screen the remainder for a variety of reasons including the need for
extensive dental treatment, the presence of severe psychological problems, drug and/or alcohol intoxication and lack of willingness to wait for the screening exam.

Table 1 below summarizes the demographic characteristics for these 200 patients. Participants were mostly male, middle-aged (average age, 47.4 years), white, unemployed, with low income (≤ $12,000 annually). Nearly one-quarter had less than grade 10 education. Of interest, only 8 persons were over age 65 years and 11% self-reported as Aboriginal and 3% as Chinese. Only 3% were residents in the Portland Hotels, which host the dental clinic.

Table 1: Demographic characteristics (N=200)

<table>
<thead>
<tr>
<th>Variable</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>152</td>
<td>76%</td>
</tr>
<tr>
<td>Female</td>
<td>48</td>
<td>24%</td>
</tr>
<tr>
<td>Age (yr)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤ 44</td>
<td>78</td>
<td>39%</td>
</tr>
<tr>
<td>45 - 65</td>
<td>114</td>
<td>57%</td>
</tr>
<tr>
<td>&gt; 65</td>
<td>8</td>
<td>4%</td>
</tr>
<tr>
<td>Ethnicity</td>
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</tr>
<tr>
<td>White</td>
<td>154</td>
<td>77%</td>
</tr>
<tr>
<td>Aboriginal</td>
<td>22</td>
<td>11%</td>
</tr>
<tr>
<td>Chinese</td>
<td>6</td>
<td>3%</td>
</tr>
<tr>
<td>Others</td>
<td>18</td>
<td>9%</td>
</tr>
<tr>
<td>Education (Grade)</td>
<td></td>
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<tr>
<td>&lt;10</td>
<td>47</td>
<td>23%</td>
</tr>
<tr>
<td>10 - 12</td>
<td>77</td>
<td>39%</td>
</tr>
<tr>
<td>&gt;12</td>
<td>73</td>
<td>37%</td>
</tr>
<tr>
<td>Current working status</td>
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</tr>
<tr>
<td>Working</td>
<td>44</td>
<td>22%</td>
</tr>
<tr>
<td>Not working</td>
<td>153</td>
<td>78%</td>
</tr>
<tr>
<td>Income (Canadian dollars)</td>
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<td></td>
</tr>
<tr>
<td>≤12,000</td>
<td>155</td>
<td>81%</td>
</tr>
<tr>
<td>&gt;12,000</td>
<td>36</td>
<td>19%</td>
</tr>
<tr>
<td>English fluency</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fluent</td>
<td>179</td>
<td>90%</td>
</tr>
<tr>
<td>Not fluent</td>
<td>19</td>
<td>10%</td>
</tr>
</tbody>
</table>

*a Missing values: Gender, Age, Ethnicity (N = 0); Education (N = 3); Current working status (N=3); Income (N=9); English fluency (N = 2).
Table 2 below summarizes the tobacco and alcohol consumption for the patients accepting screening. Participants were predominantly current smokers who started at a young age and who were long-term (≥ 20 years) and heavy (≥ 20 pack-years) users. These participants were also predominantly current alcohol consumers who started drinking at a young age and who were long-term (≥ 20 years) and heavy consumers. The majority of drinkers consumed a mixture of alcoholic beverages, including beer, wine and spirits/liquor.

In Table 2 below, a Missing data: Tobacco smoking status (N=0); Age at first regular smoking (N=27), Years of smoking (N=2); Pack-years (N=10); Alcohol consumption status (N=0), Age at first regular alcohol consumption (N=13), Alcohol score (N=48). b Type of alcohol: not mutually exclusive. c Number of years consuming alcohol x average alcohol consumption per week in units (unit equivalent = one bottle of beer = one glass of wine = 45 ml of spirit/liquor).
<table>
<thead>
<tr>
<th>Variable</th>
<th>N⁸</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Tobacco smoking status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Current</td>
<td>150</td>
<td>75%</td>
</tr>
<tr>
<td>Former</td>
<td>28</td>
<td>14%</td>
</tr>
<tr>
<td>Never</td>
<td>22</td>
<td>11%</td>
</tr>
<tr>
<td><strong>Age at first regular smoking (yr)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;14</td>
<td>73</td>
<td>42%</td>
</tr>
<tr>
<td>14-16</td>
<td>60</td>
<td>35%</td>
</tr>
<tr>
<td>&gt;16</td>
<td>40</td>
<td>23%</td>
</tr>
<tr>
<td><strong>Years of smoking</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>23</td>
<td>12%</td>
</tr>
<tr>
<td>&lt;20</td>
<td>65</td>
<td>33%</td>
</tr>
<tr>
<td>≥20</td>
<td>110</td>
<td>56%</td>
</tr>
<tr>
<td><strong>Pack-years</strong></td>
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<td></td>
</tr>
<tr>
<td>0</td>
<td>23</td>
<td>12%</td>
</tr>
<tr>
<td>&lt;20</td>
<td>76</td>
<td>40%</td>
</tr>
<tr>
<td>≥20</td>
<td>91</td>
<td>48%</td>
</tr>
<tr>
<td><strong>Alcohol consumption status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Current</td>
<td>121</td>
<td>61%</td>
</tr>
<tr>
<td>Former</td>
<td>55</td>
<td>28%</td>
</tr>
<tr>
<td>Never</td>
<td>24</td>
<td>11%</td>
</tr>
<tr>
<td><strong>Age at first regular alcohol consumption</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;14</td>
<td>60</td>
<td>32%</td>
</tr>
<tr>
<td>14-16</td>
<td>58</td>
<td>31%</td>
</tr>
<tr>
<td>&gt;16</td>
<td>69</td>
<td>37%</td>
</tr>
<tr>
<td><strong>Type of Alcohol (ever use)⁹</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Beer</td>
<td>160</td>
<td>91%</td>
</tr>
<tr>
<td>Wine</td>
<td>96</td>
<td>55%</td>
</tr>
<tr>
<td>Liquor</td>
<td>108</td>
<td>61%</td>
</tr>
<tr>
<td><strong>Years of alcohol consumption</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>24</td>
<td>12%</td>
</tr>
<tr>
<td>&lt;20</td>
<td>39</td>
<td>21%</td>
</tr>
<tr>
<td>≥20</td>
<td>124</td>
<td>67%</td>
</tr>
<tr>
<td><strong>Cumulative alcohol intake (units)⁰</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>22</td>
<td>14%</td>
</tr>
<tr>
<td>&lt;50</td>
<td>46</td>
<td>30%</td>
</tr>
<tr>
<td>50-199</td>
<td>32</td>
<td>21%</td>
</tr>
<tr>
<td>≥200</td>
<td>52</td>
<td>34%</td>
</tr>
</tbody>
</table>
The participants also displayed other high-risk behavior, as shown in Table 3. The majority reported use of recreational drugs, predominantly marijuana, crack/cocaine and heroin. There was also heavy use of prescription drugs associated with treatment for immunosuppression and mental health, most commonly antidepressants and pain medications. Twenty-one participants were using methadone. Over one-third (n = 76) of these patients also reported a history of HIV and/or Hepatitis C infection, and/or were Hepatitis B virus carriers.

Table 3. Recreational drug use, prescription drug use and infections compromising immune status (N =200)

<table>
<thead>
<tr>
<th>Variable</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Recreational drug use</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-user</td>
<td>63</td>
<td>32%</td>
</tr>
<tr>
<td>Ever use&lt;sup&gt;b&lt;/sup&gt;</td>
<td>137</td>
<td>69%</td>
</tr>
<tr>
<td>Marijuana</td>
<td>110</td>
<td>55%</td>
</tr>
<tr>
<td>Crack/Cocaine</td>
<td>82</td>
<td>41%</td>
</tr>
<tr>
<td>Heroin</td>
<td>56</td>
<td>28%</td>
</tr>
<tr>
<td>Crystal Meth</td>
<td>39</td>
<td>20%</td>
</tr>
<tr>
<td><strong>Prescription drug use</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-use</td>
<td>38</td>
<td>20%</td>
</tr>
<tr>
<td>Current regular use&lt;sup&gt;b&lt;/sup&gt;</td>
<td>150</td>
<td>80%</td>
</tr>
<tr>
<td>Anti-retroviral</td>
<td>12</td>
<td>6%</td>
</tr>
<tr>
<td>Antipsychotics</td>
<td>33</td>
<td>17%</td>
</tr>
<tr>
<td>Antidepressants</td>
<td>60</td>
<td>32%</td>
</tr>
<tr>
<td>Any pain medications</td>
<td>40</td>
<td>21%</td>
</tr>
<tr>
<td>Methadone</td>
<td>21</td>
<td>11%</td>
</tr>
<tr>
<td><strong>Infection compromising immune status&lt;sup&gt;b&lt;/sup&gt;</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HIV infection&lt;sup&gt;c&lt;/sup&gt;</td>
<td>22</td>
<td>11%</td>
</tr>
<tr>
<td>Hepatitis C virus infection</td>
<td>62</td>
<td>32%</td>
</tr>
<tr>
<td>Hepatitis B virus carrier</td>
<td>17</td>
<td>9%</td>
</tr>
</tbody>
</table>

<sup>a</sup> Missing data: Recreational drugs (N=0); Prescription drug use (N = 8); Infection which compromise immune status (N = 5).

<sup>b</sup> Not mutually exclusive.

<sup>c</sup> Human immunodeficiency virus.
Table 4 summarizes the screening results. One hundred and nineteen patients (61%) were found to have a significant clinical anomaly requiring further assessment. Of these, 31 (16%) of the patients had white patches in the oral cavity, called leukoplakia, that are clinical indicators of change in the oral cavity that requires biopsy to determine presence of cancer/precancer. Other common problems included the presence of traumatic lesions and infection (fungal or viral).

<table>
<thead>
<tr>
<th>Variable</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Conventional head and neck examination</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Normal</td>
<td>76</td>
<td>39%</td>
</tr>
<tr>
<td>Abnormal</td>
<td>119</td>
<td>61%</td>
</tr>
<tr>
<td>Clinical leukoplakia</td>
<td>31</td>
<td>16%</td>
</tr>
<tr>
<td>Traumatic ulcers</td>
<td>50</td>
<td>26%</td>
</tr>
<tr>
<td>Infection (candida)</td>
<td>22</td>
<td>11%</td>
</tr>
<tr>
<td>Othersa</td>
<td>16</td>
<td>8%</td>
</tr>
<tr>
<td><strong>Clinical Leukoplakia (N=31)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Site</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lateral /ventral tongue</td>
<td>14</td>
<td>45%</td>
</tr>
<tr>
<td>Floor of mouth</td>
<td>3</td>
<td>10%</td>
</tr>
<tr>
<td>Soft palate</td>
<td>8</td>
<td>26%</td>
</tr>
<tr>
<td>Buccal mucosa</td>
<td>2</td>
<td>6%</td>
</tr>
<tr>
<td>Gum</td>
<td>2</td>
<td>6%</td>
</tr>
<tr>
<td>Lower labial mucosa</td>
<td>2</td>
<td>6%</td>
</tr>
<tr>
<td><strong>Biopsy results (N=12)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Squamous cell carcinoma</td>
<td>2</td>
<td>17%</td>
</tr>
<tr>
<td>Mild/moderate dysplasia</td>
<td>8</td>
<td>67%</td>
</tr>
<tr>
<td>Hyperplastic candidiasis</td>
<td>2</td>
<td>17%</td>
</tr>
</tbody>
</table>

*Other anomalies included 2 cases each of lichen planus, trauma-induced fibrous epithelial hyperplasia, and angular cheilitis, and 10 cases of severe dry mouth.

bHistological grading for precancerous lesions
The majority (77%) of the 31 patients with clinical leukoplakia had lesions located at high-risk sites, including the tongue (n=14), floor of mouth (n=3) and soft palate (n=8). The clinical leukoplakia lesions for 12 of these 31 patients were biopsied, yielding 2 with histologically confirmed cancer, 8 with dysplasia (precancerous disease), and 2 with chronic hyperplastic candidiasis (chronic yeast infection) with basilar cellular atypical change requiring re-assessment after antifungal therapy to rule out possible precancerous disease.

IV.3. Discussion

Screening by periodic visual examination of the oral cavity is supported by a recent publication that reported a reduction in mortality from oral cancer in high-risk individuals (Sankaranarayanan et al, 2005). However, reaching marginalized individuals is a major challenge for screening programs. Although a growing literature has focused on barriers to screening, there are few outreaches to such communities. To our knowledge the oral cancer-screening clinic described in this study is the first in a high-risk community in Canada.

We have positioned an oral cancer-screening clinic within a previously existing dental clinic serving a high-risk and hard-to-reach community and have demonstrated both the ability to recruit high-risk individuals for screening and the need for such a service. This screening activity identified a significant disease burden in this community. Among the 200 participants who were screened in the pilot study and who were from a population of 284 persons, we detected 2 patients with oral cancer and 8
with precancers. This is a very high incidence of disease given that the national average incidence for oral cancer is only 1 in 10,000 (NCIC, 2004). These data support our continuing development of a more effective strategy to reach this high-risk and underserved community.

We have also identified the following issues that need to be addressed.

1) Our sample was not representative of all DTES residents. Compared to DTES census data for 2001, our sample contained fewer females (sample vs. census: 23% vs. 38%), younger and senior ages (< 44 years of age, 38% vs. 49%; > 65 years of age, 4% vs. 22%), and Chinese (3% vs. 27%). The proportion of aboriginals in our sample was similar to census data. Our sample also contained fewer persons who were currently working (22% vs. 41%) and more with lower income. The screening program clearly was not reaching women or the Chinese community. Also, seniors (commonly edentulous) and those in the work force were not using the clinic.

2) Although the clinic was located in 1 of 6 Portland Hotels, only 15-screened patients resided in a Portland Hotel. Although this is a small neighborhood, residents are hesitant to move outside very small boundaries. The observed territorial trend for reduced mobility in the DTES may be attributed to a variety of reasons, including safety issues and the distribution of ethnic groups within the neighborhood.

3) Many residents had no fixed address, making follow-up for further investigation and treatment difficult. We were only able to evaluate a small portion of the
participants with abnormal screening results (12 of 31 patients with clinical leukoplakia were biopsied). This was largely due to the difficulty in getting patients to stay for biopsy by the specialist or return for a biopsy at a later date. Since many patients are homeless and have no fixed address, contacting patients for follow up was a challenge. Another factor was the shortage of clinic time and infrastructure for providing biopsy.
V. PHASE II

As part of phase I, we found that a further outreach to the community was required -- that restricting screening efforts solely to a drop-in clinic was not sufficient, as many residents in the community would not come voluntarily to this facility, even though the access to the clinic would appear easy to us given the seemingly close proximity of the neighborhood to it (i.e. the DTES covers only 40-50 blocks overall). The need for a mobile extension into the community was envisaged that would include screening activity at various sites in the community with referral of cases requiring follow-up to the dental clinic. Before launching this initiative a decision was made to consult among individuals chosen to represent different segments of the community to better design the outreach. This objective triggered the development of phase II, where focus groups were used as an approach to determining the barriers and facilitators to an oral cancer-screening program in this community to tailor a future screening outreach.

V.1. Methods

V.1.1. Participants and groups

The DTES Oral Cancer Screening Clinic (Phase I study, see section IV) is situated within one of 5 hotels of the Portland Hotel Society, which provides housing for approximately 400 residents. These residents represent a stable cross-section of DTES population including young (New Stanley Hotel), elderly (Portland Hotel), and
substance-dependent and HIV-infected patients (Washington, Sunrise and Regal Hotels).

Through the recruitment of our community liaison, Ms. Culbertson, a total of 38 individuals were invited to participate in 6 focus group discussions. All participants were residents of the hotels and/or users of the Life Skills Centre, facilities owned and operated by the Portland Hotel Society.

The following is a description of each focus group. General information on the participants at each locale was provided by the staff of the individual hotels or the Centre and included information on resident demographics, mental health status and drug use (summarized in Table 5). Staff at the hotels play an important role in the lives of the residents. Besides administrative duties at the hotel, staff administer medications to the residents, helping them to remain medication compliant, act as confidants and to co-ordinate medical appointments. Most residents look upon the staff as someone they can trust and depend upon.
Table 5. Summary of characteristics of Portland Hotels & Life Skills Centre

<table>
<thead>
<tr>
<th>Hotel</th>
<th>Address</th>
<th>Residents</th>
<th>Age (years)</th>
<th>Resident Profile</th>
</tr>
</thead>
</table>
| Portland Hotel            | 20 W. Hastings        | 87        | 25% >30
                               |           |            | 75% > 40            | Mental illness         |
| Sunrise Hotel             | 101 E. Hastings       | 50        | 16% > 30             | High Drug Use          |
                               |                      |           | 84% > 40            |                        |
| Washington Hotel          | 177 E. Hastings       | 87        | 25% > 30             | High Drug Use          |
                               |                      |           | 75% > 40            |                        |
| Regal Hotel               | 144 W. Hastings       | 40        | All > 45             | More stable
                               |                      |           |                     | Low drug use
                               |                      |           |                     | Mental illness         |
| Stanley New Fountain      | 36 Blood Alley        | 75        | 40% - 20 – 30        | High Drug Use          |
                               |                      |           | 30% - 30 – 40       | Mental illness         |
                               |                      |           | 30% - 40 – 50       |                        |
| Portland Life Skills Centre| 412 E. Cordova       | 160/day   | All ages             | Unstable, transient    |
                               |                      |           |                     | Ethnic minorities      |
                               |                      |           |                     | High drug use          |
The following is a brief summary of key characteristics of each focus group.

V.1.1.1. Focus Group I – The Portland Hotel

- Number of participants: 11
- Age range: 35-66 years
- Gender: 6 Males, 5 females
- Location: Portland Hotel Ballroom
- Time: February 8, 2006, 10:20 am – 11:30 am

The total number of residents in the Portland hotel is 87. It is a mature population with 75% of residents over the age of forty and 25% are between thirty and forty years. Few residents are under the age of thirty. Thirty-nine percent of the residents have a diagnosed mental illness with another 48% with some form of undiagnosed mental illness. All but a few residents are highly addicted to alcohol and/or drugs. The Portland Hotel provides housing to those who are considered difficult to house and at the same time enables their access to mental health support, home support, an in-house doctor and nursing team, nutritional support, assistance for remaining medication compliant, and a methadone program. Mental health support staff dispenses the medications.

This was a large group, with 11 participants for a focus group discussion. Ms. Coco Culbertson, the Director for the Life Skills Centre and recruiter for the focus groups, facilitated this first focus group discussion. It was a round table format; the facilitator’s rapport with the participants was beneficial and enabled a successful focus
group discussion although the large number of participants made it more difficult for everyone to have their say.

V.1.1.2. Focus Group II – The New Stanley Fountain Hotel

- Number of participants: 5
- Age range: 23-41 years
- Gender: 4 Males, 1 female
- Location: New Stanley Hotel Meeting Room
- Time: April 5, 2006, 10:00 am – 11:00 am

The New Stanley Hotel, housing 75 street involved residents, is unique due to the younger demographic profile of the residents, the type of substance abuse and their history of intake. The majority of residents (40%) are between the ages of twenty and thirty years. The remaining population is divided evenly with 30% between the ages of thirty and forty years of age and 30% between forty and fifty years of age. Only 10% are diagnosed with mental health issues and are in touch with mental health support. Half of the residents are in need of mental health assessment; however, they are very difficult to reach due to illicit drug addiction. The drug of choice for this population is primarily crystal methamphetamine. Ninety-five percent of residents self-report to being crystal methamphetamine users with 50% smoking and 50% injecting the drug. Most residents have difficulty maintaining housing; a significant number (40%) of the residents of this hotel are former Woodward’s squatters and were chronically under
housed or homeless subsequent to its closure and prior to coming to the New Stanley Fountain Hotel. Most residents have low or no access to health care.

Another unique feature of this hotel is that it has a Transitional Care Unit consisting of 10 beds. These beds are for people requiring long term intravenous (IV) antibiotics (e.g. for bacterial endocarditis patients and/or HIV) and that are not easily compliant in a hospital setting. This unit staffs one Registered Nurse to do the IVs.

In general, participants were interactive during the discussion; however, there were 3 participants who dominated the conversation. One participant in particular kept falling asleep and had to be prompted to participate and another participant was quiet - both had to be prompted to participate in the discussion. During the discussion, the participants freely helped themselves to the sandwiches and refreshments. Because they are mainly crystal methamphetamine users they were hyperactive and generally hungry.

V.1.1.3. Focus group III – Sunrise and Washington Hotels

- Number of participants: 5 (4 reside at Sunrise and 1 at Washington)
- Age range: 32-56 years
- Gender: 2 Males, 3 females
- Location: Interurban Art Gallery
- Time: May 10, 2006, 11:00 am – 12:00 pm

In general, the Sunrise and Washington Hotels house high-risk drug users and alcoholics who are healthy enough to live a more independent lifestyle. The Sunrise
Hotel has 50 residents with 84% over the age of forty years and the other 16% over age thirty. Again, drug use is prevalent, with the majority of residents using alcohol, crack cocaine and occasionally crystal methamphetamine when there is no cocaine available on the street. Heroin and opiate dependence is also high. Fifty percent are injection drug users and 50% smoke the drugs. Two residents report being solvent and alcohol dependant and 2 residents are diagnosed with mental illness and on antipsychotics.

The Washington Hotel has 87 residents, 75% over the age of forty and the other 25% over age thirty. The majority of residents are multi-addicted to a variety of drugs but use crack cocaine as the fall-back drug. Crystal methamphetamine (or crystal meth) use is minimal; however residents use this when there is no cocaine available on the street. Again, 50% are injection drug users and 50% smoke or snort. Several residents are on antiretroviral therapy for HIV, and one is on antipsychotic medication. Some residents receive support from staff to remain medication compliant. Most have low access to health care due to barriers.

This focus group was held outside the hotel setting at the Interurban Art Gallery, as there was not a suitable meeting room at either the Sunrise or the Washington Hotel. The Gallery is located one block away from the hotels (as is the case with the next group - Focus Group IV). The participants in this focus group were more marginalized than other groups and were all medically compromised HIV patients and were undergoing methadone therapy. Everyone participated actively in the discussion, although one participant was restless and left her seat a few times wandering to another part of the room. Females outnumbered males in this focus group discussion.
V.1.1.4. Focus Group IV – Regal Hotel

- Number of participants: 6
- Age range: 38 – 68 years
- Gender: 5 Males, 1 Females
- Location: Interurban Art Gallery
- Time: June 20, 2006, 11:00 am – 12:40 pm

The Regal Hotel is home to 40 to 50 residents who comprise a mature, stable population. All are over 45 years of age; many are palliative. While residents are not street-involved and drug use is low and mainly recreational, many have diagnosed mental health illness. There is access for residents to mental health support, home support, assistance with medication, and a methadone program. Mental health support staff dispenses the medications. Additionally, respite beds are offered at this hotel, which offers a quieter environment.

This was also a very interactive discussion group. Participants were interested and engaged in the discussion. This mostly male group had one transgender member who chose to present herself as a male at the focus group discussion but used her female name. The lone female participant was a “pot activist” and worked as a local political harm reduction activist as well. One very vocal male participant with HIV/AIDS dominated the discussion and tended to digress from the topic, much to the annoyance of the other participants. This focus group discussion lasted 1 hour and 40 minutes, the longest of all the discussion groups.
The Life Skills Centre located at 412 East Cordova supports a very diverse ethnic and transient population. Many users of the facilities are homeless, or under housed and have difficulty maintaining housing of any kind. Users of the Life Skills Centre are typically underemployed, survival sex trade workers, mental health consumers and have very low access to health care.

The Life Skills Centre offers clients basic life skills training, job training, employment in the facility, peer-based training, counselling and outreach. This centre provides links to health and community services such as addiction treatment, mental health services, health education and assistance with housing, transportation and legal issues. At least 80 free lunches and 160 cups of coffee are served here per day.

Additionally, the Life Skills Centre serves as a teaching centre for those who want to change their lives, including a lounge for women, a teaching kitchen to train people how to cook meals, showering and laundry facilities, a food store, two classrooms and a large meeting space for various seminars.

The participants in this all-women’s focus group are all users of the Life Skills Centre. They are not living in the Portland Hotels and most live in single room
occupancy rentals in the Downtown Eastside. All the women are current or former drug users and sex trade workers. The participants were very vocal and forthcoming with their opinions and experiences about oral health care and oral cancer.

V.1.1.6. Focus Group VI – Portland Life skills Centre (All-men’s group)

- Number of participants: 6
- Age range: 26 – 58 years
- Gender: 6 Males, 0 females
- Location: Portland Life Skills Centre
- Time: June 14, 2006, 11:20 am – 12:25 pm

This group of participants was an all-men’s Latino group. All were users of the Portland Life Skills Centre and lived in single room occupancy housing in the Downtown Eastside. Some are former or current substance users, mainly alcohol, tobacco, crystal meth and crack cocaine. Spanish was the first language for everyone, although all spoke English well with the exception of one participant who needed a translator to participate. One participant was an obvious peer leader and dominated the focus group discussion. He was very protective of fellow participants and strongly defended the culture of the Downtown Eastside. This was the most interactive discussion with many questions being raised about oral cancer causes, risks and treatment by the participants.
V.1.2. The Approach

The British Columbia Cancer Agency and the University of British Columbia Ethics Committee for Behavioural Research approved the conduct of this study. The steps involved in the conduct of these studies are given in Table 6 and are described in more detail below.

Table 6. Summary of the steps for focus group discussion.

<table>
<thead>
<tr>
<th>Recruitment of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Poster advertising</td>
</tr>
<tr>
<td>• Recruitment assistance from community liaison person prior to and day of focus group</td>
</tr>
</tbody>
</table>

Focus Group Sign in

| • Demographic survey |
| • Refreshments |

Focus Group discussion Session (60 – 90 minutes)

| • Facilitator led using guiding questions |

Oral Cancer Screening Demonstration

| • Volunteer from focus group |

Question Period

Addendum questionnaire

| • Preferences for time and location of screening program |

Sign Out

Stipend for participants
V.1.2.1. Recruitment

Working with the community liaison, Ms. Coco Culbertson, posters (see appendix A.3.) advertising the focus group discussions were posted in the hotels and Life Skills Centre one week prior to the focus group sessions. Due to the unstable nature of this high-risk population, Ms. Culbertson facilitated the recruitment for all 6 focus groups. She is well known and respected by most residents of the hotels and users of the facilities of the Life Skills Centre. Depending on availability, she identified and invited the most vocal subjects. Often, on the day of the focus group, participants had to be reminded and seconded from their hotel in order to have them attend the discussion.

For inclusion in the study, participants had to live in one of the designated Portland Hotels or be a user of the facilities of the Portland Life Skills Centre and be able to speak English and capable of presenting opinion in a group discussion setting.

V.1.2.2. Steps for focus group discussions

Focus groups had 5 –6 participants in each session with the exception of the first focus group, which had 11. Most individuals participating in the same focus group knew one another.

Participants were given an information sheet explaining the details of the study and were asked to sign a consent form if they agreed to participate (see appendix A. 2).

The participants were then asked to fill out a demographics survey (see appendix A.5). Each focus group session was 60 to 90 minutes long and was audio recorded. Random photographs during the focus group session were taken with signed permission of the participants. A facilitator using structured guiding questions (see
appendix A.4 and A.4.1.) and verbal prompts conducted the focus groups. The focus
group questions were designed to explore the subjective experiences and insight of the
participants with regard to their understanding of oral cancer and oral cancer screening,
their concern about developing oral cancer, their perceived barriers and facilitators to
screening. A co-facilitator and several volunteers took notes throughout the sessions
and recorded the mannerisms and mood of the participants. Everyone was encouraged
to share his or her opinions about all of these topics.

Participants were given a demonstration on the procedure in an oral cancer
screening during the discussion in order to address any questions or concerns they
might have about the screening process.

At the end of the discussion, participants filled out an addendum questionnaire
asking them about preferences regarding location and time for an oral cancer-screening
program in their community (see appendix A.6). All participants were offered
sandwiches and light refreshments before and/or after the discussion sessions.
Depending on the status of the drug use of a particular group, sandwiches were
sometimes not offered until after the focus group session. For instance, those
individuals who were on a methadone treatment regime would likely fall asleep once
they had eaten, therefore a refreshment only would be offered to those participants at
the end of the focus group discussion. At the meantime, any questions or concerns
about the content of the discussion were addressed. Once participants signed out, a
$10.00 stipend to acknowledge their time was given to each individual participant.
V.1.3. Transcription and data analysis

Immediately following the focus group sessions, one person, skilled in focus group transcription, transcribed the tape-recorded discussions verbatim. Data was analyzed, sorted and coded using a Microsoft Excel spreadsheet. This method was used as opposed to other methods of qualitative analysis as the structure of the Excel spreadsheet allowed for easy classification and more direct comparisons of individual responses. The transcripts were repeatedly read in order to become familiar with the data, and identify major recurrent themes. Once the major themes were identified and coded, this data was extracted and regrouped according to the appropriate thematic reference on a Microsoft Excel spreadsheet thus allowing comparisons between and within groups (see appendix A.7). In addition, the data was sorted in a systematic manner to allow comparisons and interpretations of key themes within the participant's original context. In order to assess the appropriateness of the identified themes and the coding of the responses, the transcripts were read independently by other members of the research team (CP, JB, GH, MR).

V.2. Results

A total of thirty-eight individuals participated in the study. The participants of each of the focus groups were similar in that they were all considered high-risk for developing oral cancer due to their lifestyle and excessive use of tobacco, alcohol and drugs. However, the demographic make-up of each focus group varied somewhat depending upon from which hotel (or Life Skills Center group) the participants were
recruited from. Each of the participant groups contributed a unique perspective to the focus group discussions. Almost all the participants were informative and actively participated in the discussion. The data collected from 6 focus group discussions conducted were enormous.

V.2.1. Demographic characteristics of the participants

The majority of participants were male (24, with 14 females) with a mean age of 43 years. While most were Caucasian (53%), there were 26% were First Nations, 13% Black and 6% others, with 84% reporting English as being their first language. Thirty-nine percent of participants reported completing Grade 12 while 8% indicated at least one year of post secondary education. Most (71%) participants lived alone while 81% indicated that they were single or not married. Ten percent of participants reported that they were currently employed while 55% reported an income of less than $12,000 (Table 7).
### Table 7. Demographic characteristics of the Participants (N=38)

<table>
<thead>
<tr>
<th>Variable</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>24</td>
<td>63</td>
</tr>
<tr>
<td>Female</td>
<td>14</td>
<td>37</td>
</tr>
<tr>
<td><strong>Age (yrs)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20 – 40</td>
<td>12</td>
<td>32</td>
</tr>
<tr>
<td>40 – 60</td>
<td>24</td>
<td>63</td>
</tr>
<tr>
<td>&gt; 60</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>20</td>
<td>53</td>
</tr>
<tr>
<td>Aboriginal</td>
<td>10</td>
<td>26</td>
</tr>
<tr>
<td>Chinese</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Others</td>
<td>8</td>
<td>21</td>
</tr>
<tr>
<td><strong>Education (Grade)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;10</td>
<td>6</td>
<td>16</td>
</tr>
<tr>
<td>10 - 12</td>
<td>29</td>
<td>76</td>
</tr>
<tr>
<td>&gt;12</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td><strong>First Language</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>English</td>
<td>32</td>
<td>84</td>
</tr>
<tr>
<td>Spanish</td>
<td>6</td>
<td>16</td>
</tr>
<tr>
<td><strong>Income (Canadian dollars)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤12,000</td>
<td>21</td>
<td>55</td>
</tr>
<tr>
<td>&gt;12,000</td>
<td>4</td>
<td>11</td>
</tr>
<tr>
<td>Decline to answer</td>
<td>6</td>
<td>16</td>
</tr>
<tr>
<td>Don’t know</td>
<td>7</td>
<td>18</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>7</td>
<td>19</td>
</tr>
<tr>
<td>Unmarried</td>
<td>31</td>
<td>81</td>
</tr>
</tbody>
</table>
V.2.2 Known risk factors – tobacco and alcohol use

A survey of known risk factors for participants in the focus group discussions indicated that 97% were smokers, having smoked 100 or more cigarettes in their life, while 68% reported use of alcohol more than twice a week. While the data for smoking was reported as having smoked 100 or more cigarettes in a lifetime, this was used as a benchmark for having ever or never smoked. However, risk status data from the 2 year pilot oral cancer-screening program in the DTES showed that of those surveyed (N=200), most were long-term heavy smokers (> 20 pack year) and users of alcohol, having started smoking or using alcohol at a young age (14 –16 years). All participants in the focus group discussions reported current drug use that included marijuana, crack cocaine, crystal meth and/or heroin. Only twenty-nine percent of participants reported that they had seen a dentist recently. One percent indicated that they had previously been informed about their risk for oral cancer while only 8% reported that they had ever been checked for oral cancer (or so they thought).

V.2.3 Focus group questions

A number of guiding questions (see Appendices A.4 and A.4.1) were asked of the participants in each of the focus group discussions. As the result of the analysis of the focus group discussions, 4 main themes were used to represent the views of participants:

1. Perceived understanding and concern of oral cancer.

2. Perceived barriers to screening.
3. Perceived facilitators to screening.


Results from the narrative data are summarized below. Quotations from the focus group discussions are used to highlight the responses from the participants and are quoted verbatim. Findings from the focus groups are discussed in the following sections.

V.2.3.1. Perceived knowledge, risk factors and concern of oral cancer

Knowledge of oral cancer: The overall knowledge level about oral cancer was low. Many individuals were not aware about oral cancer specifically prior to the focus group discussions; they tended to extrapolate their beliefs about causes of cancer in general to also include oral cancer. Representative comments included: "I have never heard of mouth cancer", "it has not been talked about" and "there are not too many people knowing much about it."

There were many varying perceptions about oral cancer. No one reported a first hand experience with oral cancer. Several participants thought that oral cancer was not contagious but that it was likely hereditary. Most did not know what oral cancer looked like in the mouth but perceived it to be painful, had the ability to spread to other parts of the body, and could be curable. One participant summed up his belief about oral cancer in this statement:

"I've a friend of mine that died of cancer, not mouth cancer, but cancer. It was really painful and he suffered a lot. I have heard that it's not transferable from
person to person, um, but if you get mouth cancer then it can spread to the
throat."

Another participant noted that she read in the newspaper that oral cancer was a
lot more serious than people think and that it had a survival rate of only 20%. One
individual felt that he could mentally control whether or not he developed cancer by
maintaining a positive outlook."

Most individuals were not aware of early signs and symptoms of oral cancer. In
fact there were many varying ideas about the presentation of oral cancer. Some of the
more common comments that emerged from the focus group dialogue, were:

“How do I know when I have oral cancer, and what are the signs for it?”

“It could be an infection, mouth sores, canker sores, it looks disgusting.”

“It’s growing inside, it’s not contagious.”

Participants were curious to know about oral cancer: They wanted to know more
about the “damage” oral cancer could cause if the disease was not treated. Other
questions that arose in the focus group discussions were: “Can one still eat with oral
cancer?” “Is oral cancer on the rise?” ”Is there a medicine for oral cancer?” and “Is there
support once there is diagnosis of oral cancer?”

Perceived risk factors (causes) of oral cancer: Most participants were uninformed
about the causes and risk factors specifically for oral cancer. However, most were
aware about the connection between smoking cigarettes or chewing tobacco and other
cancers, mainly from warnings on cigarette packages, from commercials on television, and from knowing someone who had cancer that was attributed to smoking. Participants were not aware of the link between alcohol and oral cancer.

Participants knew that cigarette smoking was a risk to health in general due to chemicals such as "formaldehyde and other chemicals in cigarettes" but they were not aware of the specific link to oral cancer. Some thought that chewing tobacco would be a greater risk for oral cancer than smoking. As stated by one individual: "That's one of the ways that mouth cancer gets started, not so much smoking, it's the actual chewing tobacco that's the big major problem." Other beliefs included the thought that a chain smoker was more at risk for mouth cancer than one who smokes only three or four cigarettes per day.

There were unique beliefs about what might cause oral cancer. One female participant thought that females specifically might be at risk for oral cancer from the chemicals in the latex condoms that they come in contact with when performing certain sexual acts with their mouths. Another individual, a young girl, felt that poor oral hygiene might be a cause of oral cancer. Her boyfriend's mother had oral cancer, the whole family had poor teeth and, therefore, she felt there might be a connection.

Participants, in general, did not think street drug usage was a cause of oral cancer, however, there were a few that believed that crack, cocaine and crystal meth specifically might be a risk factor for oral cancer due to the chemical particles in these drugs. Other perceived causes of oral cancer were environmental, and related to this, "living near power poles" or second-hand smoke, while others suspected biological factors, and linked cancer to "genes" or "a compromised immune system". Again, most
participants seemed to extrapolate their thoughts about the causes/risk factors of other cancers and apply them.

**Knowledge of oral cancer screening:** Most participants did not know about oral cancer screening or what it involved. Several individuals speculated that screening might include x-rays, applying a dye, or looking for white spots in the mouth. One male participant said that he did not know and did not want to think about it.

During the course of the focus group discussion, participants were given a demonstration on oral cancer screening utilizing the conventional visual examination and an adjunctive tool for diagnosis. This served to answer deter fears about oral cancer screening being painful and time consuming, and as a result, most noted that they were impressed with the ease and quickness of the screening.

**Concern about developing oral cancer:** While participants had differing beliefs about oral cancer, the prevailing theme was that participants were generally not concerned about their susceptibility to developing oral cancer. Most residents in this high-risk community were severely immune compromised and dealing with already serious medical conditions such as HIV/AIDS, Hepatitis C, and mental illness. As one woman with AIDS said: *"We live in a different reality here. Keeping a roof over our heads is the priority."* Another participant echoed this thought by remarking,

*"I don't really worry about it (oral cancer), and there are more things to worry about."*
While there were some individuals who recognized that they might be at risk for oral cancer, because of their lifestyle choices, they did not seem concerned about developing oral cancer as a result.

"I have a friend who survives from AIDS for 20 years. Do you know why she can survive? She did not care if she will die or live. I know I am at risk."

"No worry. But I know I am at risk. If I got mouth cancer, I am just going to die. So I am not worried. This is not top priority."

Sadly, another participant, an elderly man, highlighted the reality of living with an already fatal disease by saying: "I've already got three things that are going to kill me what the hell do I care about mouth cancer?"

There was some hint of philosophizing their risk of developing oral cancer. One man stated, "The script has been written, you know, we'll die when we're supposed to, no sooner, no later." Another participant expressed similar sentiments when she stated:

"No I don't think that I'll ever get mouth cancer, I think I'm going to die of HIV."

In contrast, a male participant noted that he was more concerned about getting prostate cancer than oral cancer, a sentiment that was common amongst most of the males in the discussion group.

Other participants marginalized their risk for oral cancer: "No I don't think I am going to get cancer. I don't chew tobacco and I'm not a heavy smoker." This perception was further supported by the belief that family history makes a difference as to whether or not people will get cancer: "I'm not going to get cancer because nobody in my family
has cancer. Everybody that hasn't been shot, stabbed or run over by something is over a hundred years old."

Some participants felt protected due to genetics. One, a heavy smoker said: “I’ve heard about genetics, all my family, my father, my mother and grandmother all died in their nineties, and each one was a chain smoker all their life.” Another participant felt that he was more at risk for heart disease because of family history: “Now when they do die in my family history, it’s fast and quick, they all died from heart attacks.”

V.2.3.2. Perceived barriers to screening

Participants reported various barriers (Table 8) that would likely deter them from attending an oral cancer-screening program in their community. Among the responses, having to wait in line, cost, location/access, fear of diagnosis and being in an uncomfortable environment were the most common barriers that were cited.

While many of the residents in the DTES community do not have employment, because of an entrenchment in street life, time seems to be an important factor for them. Many participants expressed that they would not be willing (or have time) to wait in long lines to get an oral cancer screen. The reality for most of the individuals participating in the focus groups is that survival is their top priority on a day-to-day basis.

Cost is another barrier. Fifty-five percent reported an income of less than $12,000.00 per year, sixty-one percent of that income coming from welfare. This reality was reflected in the comments from most participants regarding whether they would be willing to pay for an oral cancer screening. The participants' response to the issue of
cost for screening was typical, “one thing that would stop me is if I had to pay for it.” Another woman said that they are short of money all of the time, therefore even ten dollars would be too much to pay. One woman admitted that if she were really concerned about her mouth she would pay for screening, but it would be an extreme situation.

Location of the screening was identified as another possible barrier to attending a screening program. Residents in the DTES tend to be very territorial, not ambulating off the block that they live on. Most do not drive or have bus passes; they may not be able to physically walk a few blocks for a screening. Therefore, the concept of a mobile screening was favoured. One young man put it this way:

_Just because it's got to be somewhere central where everybody can go to because a lot of people don't like to ride the bus, some of them can't walk very far, some of them will think, oh, I live seven blocks away and it's way down there like some of them get really freaked out of huge crowds._

Past experience with a different screening initiative in the DTES left some women who participated feeling that they might have no support when they received the diagnosis. As a result, the women said that they would not attend an oral cancer-screening program unless the appropriate pre- and post-counselling services were available to them. One woman was very clear when she stated: _“Once there was this exam for HIV in women. They gave 20 bucks for a vial of blood. After they found out that they had HIV, there was no support. This is very awful (looking very angry). It has to have resources and support.”_
Feelings of vulnerability, another potential barrier for women, were expressed through the issue of confidentiality. As one woman said,

*Confidentiality is important. For example, my family doctor lives close to my parents. I don't want them to know my condition. I don't want my results to be sent to my family doctor.*

While many residents in this community have multiple serious health issues to deal with, the fear about receiving a cancer diagnosis was evident for a few and would prevent them from attending an oral cancer screening program.

Another identified barrier was an association with a previous bad dental experience combined with a lack of understanding about oral cancer screening eliciting fear for some. One man expressed that he was afraid of needles and dentists and therefore would likely not attend an oral cancer screening.

The belief that oral cancer is not that common combined with not knowing anyone who has oral cancer was a barrier for one man:

*I believe that oral cancer is not that common, like I haven’t seen one (person) with oral cancer. I've seen other types of cancer, skin cancer or lung cancer but not oral cancer, so I think that if there is no concern, people will not be motivated to go (for screening).*

V.2.3.3. Perceived facilitators to screening

There were many varied responses to questions related to what would motivate residents of this community to participate in an oral cancer-screening program.
(Table 8). However, the most significant motivator for the participants for attending a community-screening program was perceived to be receiving an incentive. This is because this community is the focus of much research and residents have come to expect to be compensated through incentives and money for their time. Furthermore, hearty sandwiches and juice may be the only sustenance they have that day. As one young man so eloquently stated,

"No, you'll find that in all honesty for the most part nobody down here will do anything unless it gets them drugs, sex or money."

Another participant, a young woman agreed,

"If I had something really nasty like in my mouth, then yes, if not then once again I mean if I was being offered like twenty, thirty bucks I'd go."

"If you can provide incentives, like lunch etc like the Life Skills, Open Door with the sandwich line-up and Women's Centre. A big poster and small incentive will get you into this community."

Several women from the women's focus group indicated that it was very important for them to feel valued for their time.

A convenient location where people would feel comfortable was the next most common motivator that was expressed by the majority of the participants. Even if they really did not want to participate in a screening, if screening was in a convenient place where they felt comfortable, they might be motivated to participate.

Having a family history of cancer was a motivator for some participants. The female participants rather than the males thought they would be more inclined to participate if there was a family history of cancer.
There were many suggestions about the best approach for motivating people to go to screening. By increasing their awareness about oral cancer, one woman stated:

"More information about mouth cancer, because, before I came here I didn't know that alcohol causes oral cancer, so I guess that more information about what causes it and stuff like that."

Another woman felt that advertising was the best approach to gain information:

"Advertising and promotion is very important. I am 54 years old and this is the first time I've heard of mouth cancer. I have never heard of mouth cancer before I came here."

"It (information) has to be graphics. Not words. Visual."

"The information should include symptoms, risk factors, description and be visual."

Many women in the women's focus group thought that early diagnosis was a motivator for screening. One stated:

"You're better off to know than not know, right? It's better to know like if you find out early or whatever you can have something done about it, right, and you would be able to like, have it dealt with or whatever."

Several men shared the same sentiment. "I want to live longer" one man responded. For others, they just simply wanted to know if they had oral cancer or not. One woman felt that she would really just like to know, "like with breast cancer."

It was interesting to note that while most participants clearly had other pressing health concerns and were not overly concerned about their risk of getting oral cancer, a few did think that they would be motivated if they had symptoms or thought that there
was something wrong in their mouth. As one woman said, “If I’m getting sores in my mouth I would get it done.” Another felt that if she “was inclined to believe that I could get cancer in my mouth, yes, I would (go for screening).” As might be expected, for most, the decision to participate in oral cancer screening seemed to depend upon their feelings of vulnerability or susceptibility to disease.

Other motivators for screening that were mentioned included ensuring the procedure was quick, painless and non-invasive.

“A lot of people down here, a lot of them don’t have the patience to sit and wait for you to do a test, whereas this is something that can be done quickly, fast, and they’re in and out in a couple of minutes.”

“If it wasn’t really painful or something or like harsh intrusive. Just as long as it’s not going to be like a lot of poking shit in my mouth.”
Table 8. Summary of barriers and facilitators for oral cancer screening

<table>
<thead>
<tr>
<th>Barriers</th>
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<tbody>
<tr>
<td>Waiting in a line-up</td>
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<td>Having to pay for screening</td>
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<tr>
<td>Confidentiality</td>
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<tr>
<td>Previous bad dental experience</td>
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<tr>
<td>Lack of knowledge about oral cancer</td>
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<tr>
<td>Inconvenient Location – difficult to access, uncomfortable environment</td>
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<tr>
<td>Fear of cancer diagnosis</td>
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<tr>
<td>Lack of support services upon diagnosis of disease</td>
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<tr>
<td>Lack of feeling of vulnerability for developing oral cancer – fatalism</td>
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<tr>
<td>attitude</td>
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<table>
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<tr>
<th>Facilitators</th>
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<tbody>
<tr>
<td>Receiving an incentive for participation</td>
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<tr>
<td>Free screening</td>
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<tr>
<td>Convenient location</td>
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<tr>
<td>More information about oral cancer, early signs of disease, risk factors</td>
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<tr>
<td>Early diagnosis</td>
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<tr>
<td>Feeling that there was something wrong in their mouth</td>
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<tr>
<td>Screening should be painless, quick, non-invasive</td>
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V.2.3.4. Suggested approaches

There were a wide variety of opinions on what would be the most appropriate approach for an oral cancer screening program in the DTES, however, the overall consensus was that mobile screenings in various locations would work best in order for everyone to have the opportunity to participate. There are a number of other healthcare initiatives, such as the “Papaloosa” (mobile pap smears for women), in place at various locations for residents in the DTES.

You can do it like the “Papaloosa”. It is a mobile set-up, not a clinic, with a street nurse that does pap smears.

The Portland Life Skills Centre, the Women’s Centre, The Downtown Community Clinic, the Carnegie Centre and the Health Contact Centre are all locations that the participants identified as being places where they feel comfortable going to and would therefore be more inclined to attend a screening program if available at those locations. Providing a comfortable, safe and familiar environment was identified as being important:

There’s places where people already have availed themselves of the services offered and they’re more likely to go there because they’re in the DTES and they’re in places that they’re aware of.

Another suggestion was to integrate oral cancer screening with other existing healthcare services:
It would be important in the DTES area for that to be integrated with street
nurses, doctors, dentists, anybody in health, because outside this area people
will not go because it's going outside their comfort zone.

Personal safety and respect are two issues that concerned women in the focus groups.
Therefore, the women felt that oral cancer screening should be held in places where
they feel safe such as the Women's Centre. They also did not want to be solicited for
screening using derogatory means. For example, one poster recruiting women for pap
smears was thought to be very insulting to the women as one participant recounted:

A poster targeting women for the Papaloosa was put up in the Welfare Office
saying “Come get your twat checked”. This is very disrespectful. It's like going
back to the 30s and 40s.

Some of the groups (women’s and men’s groups) also gave their opinions about
a “one-stop” approach for screening. With this concept, the oral cancer screen would be
done at the same location and the same time as other types of screening such as for
HIV, STDs, cervical and breast cancer etc. However, the majority of participants did not
think this was something they would support. One woman had this comment:

Nobody does this. (Shaking her head). I am saying no because not many people
are going for pap smears and breast exams. It is better to keep it dental. This is
not about convenience. It is not feasible. It is better to connect with the dentist,
should stick with dental. One male agreed that convenience screen tests would
not be a good idea although his reasons were different:
Yeah, I guess that the prostate cancer would, is uh, it's a very uncomfortable exam so that I wouldn't go for the prostate, however, for the cancer, mouth cancer I would go, but not for the prostate."

Other suggestions for approaches for oral cancer screening included having the screening as part of the yearly physical exam with the physician or as a standard part of the dental check-up. One participant believed that physicians should play a role by referring them for screening: I think it has to do with you get the clinics involved, and get the doctors and the clinics to maybe start pushing it (screening) and sending people to go and have a check up done, because if they don't hear it from a doctor, they are not going to do it on their own.

Most participants thought that there was a need to raise awareness about oral cancer in their community. Education through media such as television and posters were among the suggestions.

**Opinions most trusted:** Participants were asked their opinion on who they trusted the most to get their healthcare information and advice from. Many spoke of the close and trusting relationship that they have with their physician. Many were on methadone treatment for heroin addiction and were required to visit their family physician once per week. Because dentists are private and fee for service, it is not common for many participants to go to a dental office on a regular basis. Also, most thought that the physician would be the one to see for any health related matter, not a dentist.
A few however, did prefer to get health information from the dentist or street nurse. As is evident in the comment below from one participant, they believed that physicians are too busy and do not have enough time to spend with their patients.

*I was going to say the Downtown Clinic, now the reason I say not doctors and most dentists is because they are too busy doing everything else to add into mouth cancer. You are lucky if you see them for 5 minutes. The downtown clinic is more acceptable, you have more time, and they are friendly.*

Others indicated that they were comfortable with any healthcare worker. As one person remarked: "*Any medical person we can listen to. Then use gut instinct.*"
V.3. Discussion

V.3.1. The advantages in using focus group discussion

Focus group discussions reveal important information about oral cancer screening from the perspective of community members. This information can then be used to guide the development of strategies for a screening program that is appropriate for a particular community.

Phase II used focus group discussion as the methodology to explore and gain first person, rich, in-depth information on the community to begin an appropriate outreach tailored to the DTES. This approach focuses on the participants’ perceptions of how this initiative might work based on first-hand experience of the study group in their own voices. It is important to gain the perspective of people living the experience, thus avoiding the generalizations and stereotyping of a marginalized population by professionals who use their own language and filters. It allows participants to recommend strategies that will be most effective for them.

Due to the deep entrenchment of some of the participants in a lifestyle involving living on the streets and the use of illegal substances, many of the participants may not have felt comfortable sharing issues or stories of a personal nature to a “stranger” or outsider. In a group situation, however, they had the support of their peers.
V.3.2. Interpreting focus group data: use of public health models

The question content of the focus group discussions were based mainly upon the concepts of Health Belief Model (HBM) (Becker, 1974) and the Precede-Proceed framework (Green and Krueter 1991) and were designed to explore factors that would influence an oral cancer screening initiative in a high-risk underserved population.

The Health Belief Model is designed to provide information that will predict health behaviors that are explained by our health beliefs. In this model, there is the underlying belief that if a health threat is perceived to exist (vulnerability or susceptibility) a given course of action will affect that belief. Attitudes toward a behavior (such as oral cancer screening) are predisposing factors that are influenced by the beliefs regarding the outcomes it will bring about. For example, given a belief of vulnerability or perceived risk for developing a disease, screening behavior will be influenced by whether or not there is the inherent belief that early diagnosis will actually improve the chance to live longer and improve ones quality of life; this belief will then ultimately determine outcome.

The Precede-Proceed model provides a theoretical framework that will also guide in the planning of a health promotion program such as an oral cancer screening initiative. This model provides the means to facilitate and analyze such programs from the planning stages right through to implementation and impact. The “precede” part of the model relates to planning of the health promotion program while the “proceed” part relates to the implementation and the evaluation of that program. One important attribute of this model is that it facilitates the identification of causal pathways or an “epidemiological diagnosis” among areas that are the concern of health promotion such
as health patterns and the behavioral and environmental factors that affect quality of life and ultimately determine behavior and outcome.

It was important that data obtained through focus group discussion questions elicited information that identified the health behavior patterns and environmental factors affecting the study population. These factors would influence screening behavior or adherence to a screening program. It was important that the focus group questions provided insight into these factors so that ultimately a screening program could be designed to create optimal environments that would reinforce a positive screening behavior.

The implementation of an oral cancer-screening program would be designed to promote oral cancer screening behavior based on the belief that the health related quality of life is influenced or improved by early detection of premalignant lesions. It would therefore be important to identify factors in the study population that would predispose a person to ultimately seek screening and other factors that would reinforce it. Table 9 outlines examples of the predisposing, enabling, reinforcing factors in “Precede” model that would potentially influence screening behavior in this population. Beliefs about cancer (predisposing factors) and access barriers and facilitators (enabling factors such as cost, access, and incentives) were identified as important factors for this community.
Table 9. Conceptual framework of Precede – Proceed Model

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<thead>
<tr>
<th>Predisposing Factors to oral cancer screening</th>
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<tr>
<td><strong>KNOWLEDGE OF ORAL CANCER</strong></td>
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<td>- Perceived susceptibility</td>
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<td>- Seriousness of the disease</td>
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<tr>
<td>Beliefs about oral cancer screening</td>
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<tr>
<td>- Barriers</td>
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<td>- Facilitators</td>
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<td>Fears/Anxiety</td>
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<td><strong>Enabling Factors to oral cancer screening</strong></td>
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<tr>
<td>- Free screening</td>
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<td>- Easy access</td>
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<td>- Incentives</td>
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<tr>
<td><strong>Reinforcing Factors for oral cancer screening</strong></td>
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<tr>
<td>- Physician or street nurse referral</td>
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<td>- Friends/peers</td>
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<tr>
<td>- Previous experience with screening</td>
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<td>- Easy access to screening</td>
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V.3.3. Main themes from the focus group

The themes that emerged from the analysis of the focus group narratives were derived from questions asking the participants about their thoughts, experiences and perceived barriers and facilitators to an oral cancer screening initiative in their community. Each theme was described in detail using the participant's own words to provide experience support for interpretations. Additionally, where possible, the quotations from the participants in the focus group discussions carry contextual information about their circumstances.

The four main themes that emerged are discussed in the following sections.

V.3.3.1. Lack of knowledge of oral cancer and oral cancer screening and lack of vulnerability

The themes "a lack of knowledge and awareness about oral cancer" and "lack of perceived vulnerability to developing oral cancer" were derived from narrative responses to several questions/topics asked of the study participants. These topics were: (i) the perceived causes of oral cancer, (ii) beliefs about oral cancer, (iii) perceived knowledge of oral cancer screening, and, (iv) lay questions about oral cancer and oral cancer screening. Together, the responses to these topics yielded some interesting self-expression around perceptions of oral cancer. Clearly, most participants had heard about cancer in general and could relate anecdotal stories and experiences
about family members or friends who developed or even died from the disease, and additionally most had personal beliefs about what caused the cancer.

Oral cancer on the other hand, was not a disease that most had heard of before, or if they had heard of it previously, they had very minimal knowledge about it. Accordingly, they did not have knowledge about the early signs of the disease or a clear idea about risk factors. Most participants were aware about the connection between cancer in general and smoking cigarettes and chewing tobacco, mainly from warnings on cigarette packages, commercials, and personal experience where they had knowledge of someone dying from a cancer attributed to smoking, such as lung cancer. This is an indication that they, like others in the general population, can gain information through the power of advertising.

Interestingly, most individuals in the focus group discussions were not aware of the link between alcohol and oral cancer. A few participants indicated that drinking alcohol was not healthy and may be harmful to the liver or heart, but they did not relate it specifically to a risk for oral cancer. Due to this lack of knowledge about oral cancer, as the focus group discussions evolved participants tended to extrapolate their beliefs about cancer in general to also include oral cancer.

Importantly, many participants had a sense of fatalism (having no control over the onset of illness) about cancer, feeling that it was a matter of chance, and that if it "is in your gene, there is nothing you can do about it". It is important to identify the attitude of fatalism as it may in fact be a barrier and play a role in whether or not individuals will ultimately accept advice pertaining to preventive measures such as oral cancer screening. Fatalistic beliefs about cancer in other populations are not unheard of and
have been identified through other focus group studies reported in the literature. Fatalistic views have been associated with non-attendance to free breast cancer screening programs in Chinese populations (Straughan & Seow 2000), to Pap test in Cambodia and Latin Americans (Chavez et al 1997; Taylor et al 1999) and to fecal occult blood testing in African-Americans (Powe, 1995).

Responses from the focus group discussions indicated that as in the general population, there is much misinformation and lack of knowledge about oral cancer. Studies in the literature show that overall the U.S adult public is not well-informed about the early signs of oral cancer or the risk factors such as alcohol use. In a 1990 Health Promotion and Disease Prevention Supplement of the National Health Interview Survey, the use of tobacco was the only risk factor correctly identified by most adults as being a cause of oral cancer (Horowitz, 1995). A general lack of public awareness towards oral cancer in Great Britain was also reported in a study by Warnakulasuriya (1999). The results of the study highlighted the need to inform and educate the public in matters pertaining to the causation and known risk factors associated with oral cancer, specifically the excess risk associated with alcohol. These results are significant because in addition to supporting the clear need for public education about oral cancer, a comprehensive harm reduction health promotion strategy to reduce smoking and excess alcohol consumption, particularly in high-risk populations, is essential to halt increases in oral cancer incidence. These results can also be used as a framework on which to develop, implement and monitor a comprehensive oral cancer education and promotion program. Additionally, education on the need for and providing oral cancer screenings, especially amongst high-risk groups is paramount.
In addition, most of the participants in this study had complicated medical histories, many with HIV/AIDS, Hepatitis C, and/or mental illness. Survival issues such as shelter, food and security are daily realities for most. As a result, a common sentiment heard amongst the participants in the focus group discussions was that they don't worry about (cancer/oral cancer) as there are many more pressing issues to deal with. Even though there were some individuals who acknowledged that due to lifestyle choices they might be at an increased risk for developing oral cancer, they did not articulate concern about developing oral cancer. This is another important attitude to acknowledge when planning for preventative health promotion strategies. Based on the predicative ability of the Health Belief Model for behavioral change, health seeking behavioral attitudes and changes will not be affected unless there is a perceived underlying vulnerability to a threat (such as developing oral cancer). Additionally, people's beliefs and health-seeking behaviors are predicted to change if they perceive that there is an attainable effective course of action as remedy to that threat (i.e. an oral cancer screening program).

The perception of vulnerability will not be attained until there is a greater general awareness about oral cancer, the early signs of disease and its risk factors. Furthermore, once there is that level of knowledge, high-risk individuals in particular need to be educated about their personal risks related to tobacco and alcohol and about effective courses of action to reduce their risks. Many participants had a fatalistic attitude toward developing cancer. Such attitudes contribute to marginalizing risk related to the use of tobacco and alcohol.
V.3.3.2. Perceived barriers to screening

Participants were very clear about the barriers that would impede them from attending an oral cancer-screening initiative in their neighborhood. Having to wait in a line-up, having to pay, an inconvenient and/or uncomfortable location and fear of diagnosis were the most commonly expressed barriers to attending a screening for oral cancer. Deep entrenchment in street activities such as prostitution, procurement of drugs for the next fix, looking for something to eat and a place to sleep took precedence over screening for most of the participants.

Cost, of course, was an issue. Living in a neighborhood known as the “poorest postal code in Canada” with most individuals unemployed or reporting an income of less than $12,000.00 per year, most expressed that they would not go to a screening if they had to pay for it. Interestingly, a few women said that if they felt that they were at risk, if they could not eat due to dysfunction or pain, they would find a way to go and get screened.

Location was another important factor. Most individuals living in the DTES do not drive or have bus passes; therefore, in order for a screening program to be accessible to everyone, it would have to be convenient for them to access and go to where the people are gathering, such as in the hotels, Life Skills Center, the Carnegie or even the park. Importantly, many participants in the study were not able to or felt comfortable to ambulate far from the hotel or single room occupancy rentals where they live.
Providing oral cancer screening in a mobile service may be successful. Many health initiatives available to the residents in the DTES are mobile and have been received positively by community members. Street nurses see clients on foot going to massage parlors, jails, or driving in a van along the strolls that the sex trade workers frequent. Street nurses also do their sexually transmitted disease (STD) testing at various locations such as the hotels, WISH, the Women’s Center, the Detox centers or the churches. Suggestions from street nurses for successful integration of a new health initiative such as an oral cancer screening program, into the DTES are that such a program be similar in approach to other existing health initiatives and offer a mobile service. Recognizing that while such an initiative may not be appropriate for all sub-populations in the DTES, depending on the level of entrenchment into drug activity and street life, offering a mobile service will minimize barriers and access issues for most.

Other identified barriers to screening included fear of finding out about a cancer diagnosis and an association of screening with previous bad dental experiences. Also, one participant felt that because he did not know of anyone with oral cancer and had not heard of it before, he felt that it was not a common cancer, such as lung or skin cancer and therefore not a concern. He said “if there is no concern, people will not be motivated to go (for screening)”. This attitude is supported by the concept of the Health Belief Model, which predicts that without feelings of vulnerability, there will not be the motivation to change existing behaviors.

Life in the DTES is not conducive to engaging in preventive health care because of competing priorities and health concerns. Accordingly, Self-care involving regular
preventative services such as breast mammography, cervical cancer screening (Pap Test) or prostate examinations received little attention from community members. For example, most women do not regularly schedule these services with their family physicians. It is only when the street nurses set up a mobile testing location known as the “Papaloosa” for example, that women receive a Pap test. Women and men tend to avoid visiting doctors or going to hospitals unless they needed to get a methadone prescription filled or they are taken to the hospital because they are sick. Clearly, education about oral cancer in high-risk populations and the general population is an important factor in the ultimate success of such an initiative.

V.3.3.3. Perceived facilitators to screen

Although attending preventative services were not a routine part of self-care for the population in this study, most participants indicated that they would be interested in attending an oral cancer screening if it was free, was conveniently located and they received an incentive to participate. Incentives were a big issue for most of the study participants. The DTES is a very well researched population. To quote one male participant, “No, you will find that in all honesty for the most part nobody down here will do anything unless it gets them drugs, sex or money”. Because they are used to participating in health related programs as part of research and not part of regular self-care, there is the expectation that they will be compensated for their time.

Participants also expressed the need and desire for more information about oral cancer, early signs of the disease, risk factors and treatment. Participants in the Latin
American men's focus group indicated that they would like to have a presentation about oral cancer at the Life Skills Center; they regularly receive information about other health issues in this format. Of course, simply having more information about oral cancer does not automatically translate into a change in health-seeking behavior, but certainly, having the correct and current knowledge or information about oral cancer is necessary for individuals to make intelligent and informed decisions about their self-care.

For many women and a few men in the focus groups, early diagnosis and treatment of oral cancer was a potential motivator for screening. This is an important message to include with information on oral cancer screening.

The participants for the all women's group also indicated the importance of emotional support once there is a diagnosis of disease. Anecdotal past experiences whereby they gave blood for HIV testing and then were not given any pre- or post-counseling or support has them left them feeling very vulnerable. This suggests that screening programs need to offer the appropriate pre and post counseling services that support a potentially life altering diagnosis.

V.3.3.4. Suggested approaches to screening

Due to nature of the residents, a mobile screening with no fixed address and time was the preferred approach suggested by participants. In keeping with the same approach as other health initiatives, such as the Papaloosa (Pap test) and the STD testing, participants indicated a variety of locations where they would feel comfortable
going to for an oral cancer screening. Also noted was the suggestion to integrate the oral cancer screening with other existing healthcare services in the DTES.

Some of the locations suggested were the Life Skills Center, the Women’s Center, the Downtown Community Clinic and the Carnegie Health Contract Center. These places were chosen because they were familiar, comfortable and safe places to go. Especially for female residents, safety was a main concern. Repeatedly emphasized was the need to provide the screening at places that are within their comfort zone.

Although the participants did not support the idea of integrating oral cancer screening with other types of screening, physician visits provide potentially important context for oral cancer screening. Although most participants did not see their physicians regularly for prevention services, they do see their physicians regularly, many as often as once per week, for methadone, used to manage their heroin addiction. Most felt comfortable seeing their physicians and felt that they could trust the information they received from them. Many individuals felt that it would help if physicians played a role in referring them for oral cancer screening; this would be reinforcement for them to go and get screened: “If my doctor told me I should go (for an oral cancer screening), I would go.”

Some suggested that having an oral cancer screening, as part of an annual physical examination by a physician would be acceptable.

The street nurse was also someone that participants identified as being trustworthy. These findings are important that both physicians and street nurses would play crucial role in the referral pathway for utilization of an oral cancer screening program. Clearly, educating the community about the importance of seeing a physician
for regular preventative self-care services would be an important factor in increasing attendance for regular screening.

V.3.4. Study Limitations

The results and observations from this exploratory qualitative study are related to the personal views and perceptions of the 38 participants who volunteered for the study. They may not be generalizable to all subgroups of the DTES population. Individuals who lived in other hotels or single occupancy rooms, seniors, those with language barriers, mental illness or those deeply entrenched in drug or street activities may have other opinions and screening barriers or facilitators not represented in the findings from this study. For instance, the sampling method for this study did not seek individuals that lived in hotels other than the Portland Hotels. Although, it should be noted that very few of those attending the Portland Clinic, resided in the Portland Hotels. Furthermore, the use of an individual familiar, and trustworthy to many living in the Portland Hotels, for the convenience selection of study participants, may have biased results and excluded information from many individuals who may have had a better knowledge base about oral cancer and different opinions on barriers and facilitators to oral cancer screening.

To gain a deeper understanding and validate results from this study, it would be useful to hear from other subgroups in this high-risk population by expanding the sampling base. This is particularly important given that the purpose of this research was to gain information that would enable an oral cancer-screening program to be widely available and accessible to all. Therefore, future qualitative and quantitative research is needed to evaluate the generalizability of the findings from this study.
The results of this study do not establish a causal relationship between the lack of knowledge about oral cancer for instance, and the participant's future oral cancer-screening behaviors. Despite this limitation, based on the concepts of the Health Belief Model and the Precede–Proceed Model, this study provides valuable information for future research, educational interventions and planning strategies related to a high-risk community-based oral cancer-screening initiative.

Results highlighted the need for improving the oral health of this high-risk population by enabling fair access for all to an oral cancer-screening program and the importance of focusing on educating high-risk communities about oral cancer. To maximize results and positive health behavior change, the promotion of tobacco and alcohol cessation should be encouraged. Results from this study will provide the basis for planning strategies and approaches for the development of an effective, sustainable community oral cancer-screening program in this high-risk population.
VI. THESIS CONCLUSION

The research described in this thesis represents the first efforts to develop a community screening outreach for the BC Oral Cancer Prevention Program that will specifically target hard-to-reach and high-risk communities. As demonstrated in Phase I, the DTES is one such community.

In Phase 1 of this research the first oral cancer-screening clinic in a high-risk community in Canada was established. The data from Phase I clearly demonstrates the need for this clinic. It also shows the complexity of issues that characterize this study population, including the heavy usage of tobacco and alcohol (known risk factors for oral cancer) but also immunocompromised health status, drug usage, and the plethora of conditions that characterize poverty.

Phase I identified a need for developing an outreach strategy tailored to the DTES. Key to this strategy was an active consultation with representative members of the community, to acquire first-hand information about the barriers and facilitators to an oral cancer-screening program as they perceived them. Through a series of focus group discussions with residents of the Portland Hotels (a cross-section of the stable population in DTES) and users of the Life Skills Center (a main gathering venue serving ethnic minorities), we found (1) a general lack of awareness about oral cancer, (2) a lack of feelings of vulnerability for developing oral cancer, (3) the desire and need for more education about oral cancer in the community, and (4) the perceived barriers and facilitators to an oral cancer screening program.
The results from this study highlight the need to focus on education to raise awareness about oral cancer, the early signs of this disease and risk factors associated with its development, concurrently promoting lifestyle changes such as smoking and alcohol cessation programs. This could increase the perceived sense of vulnerability for developing oral cancer in high-risk groups and thus could promote positive health behavior change based on current knowledge, which is necessary to enable informed self-care decisions.

Due to the complexity of this community, no one approach for screening will reach all residents, so a variety of approaches will be needed. These could include a mobile clinic setting with flexible locations and times of operation at strategic gathering sites (Life Skills Centre, Carnegie Health Contact Centre and Women's Centre) and community medical clinics (Downtown Community Clinic etc.) Participating in community health fairs is another approach. Networking with other health professionals in the community, especially with the physicians and street nurses who are most trusted, will not only promote the oral cancer screening initiative in DTES but also facilitate the referral pathway, especially for those with significant disease that needs to be triaged for treatment or be monitored over time.

There is a demonstrated need for continuation of this community screening initiative in Vancouver's DTES. Ongoing work in this community is necessary to establish a flexible infrastructure that will allow new technology and recourses to be readily transferred from research to the community. Such resources should be on the "battle front" of confronting this disease but need to be validated in such settings. The planned infrastructure will allow this validation.
In summary, the work described in this thesis is a first, critical step towards creation of an effective, sustainable community oral cancer-screening program to serve the DTES. The initiative (and others that will use it as a template) is critical to the overriding aim of the BC Oral Cancer Prevention Program: to reduce mortality due to oral cancer in British Columbia.
VII. EPILOGUE- MEETING WITH THE STREET NURSES

A meeting was held with two DTES street nurses after focus group discussions were completed. This meeting was not part of the planned work for this thesis, but rather represent an attempt to validate the findings of the focus group discussions in an independent setting. An additional objective was to identify strategies that have and have not worked for other outreach healthcare initiatives in the DTES by developing a network with other community health care providers.

The mandate of the street nurses is to provide harm reduction, STD testing and follow-up. Testing is done in mobile format where testing sites are set up at various locations and times. They do not work out of clinics but rather go to where people “hang out” and set up in available rooms in hotels, the Life Skills Center, Carnegie Center, the Women’s Centre, etc. They also go to jails, massage parlors, the reservations, Oppenheimer Park, the churches, and walk the stroll frequented by sex trade workers.

There was valuable information collected in the meeting with the street nurses. The discussion and observation from the street nurses is summarized as follows:

The DTES population is comprised of many subgroups:

- Diverse ethnic backgrounds, mental illness, seniors and retired residents, working people with minimal wages, drug users and sex trade workers, all requiring different approaches for access and screening. Some subgroups such as the deeply entrenched drug users or sex trade workers may not be appropriate or interested in an oral cancer-screening program.

The quality of life is decreasing in the DTES:
• This is evident by the increasing line-ups for food and shelters. There is also a major problem with poor oral health and dental problems that need to be addressed along with an oral cancer screening initiative. The high decay rate is largely due to poor nutrition and the high carbohydrate intake, poor oral hygiene and the use of street drugs such as crystal meth.

There is a general feeling of hopelessness by residents in the DTES:

• "That something can easily be done to help them", “it is their perception that there barriers such as cost of treatment, particularly related to dental treatment”, and the process involved in obtaining funds to defer those costs, i.e. having to go to the Welfare office and ask for money each time treatment is necessary. Other barriers that may prevent individuals in the DTES from accessing a screening program or other health initiatives include cultural and language barriers and the level of entrenchment in street life.

Suggested approaches by the street nurses for the successful integration of an oral cancer screening program in the DTES:

• Involves increasing the awareness of oral cancer both amongst residents in the community and amongst other outreach health care initiatives and health workers. They suggested participation in such events as the Brown Bag Lunch, a monthly meeting on Welfare Wednesday to network with other outreach healthcare workers, offer in-service education sessions and establish the presence of the oral cancer screening team by doing "walk along" with the street nurses to get known, establish trust and build
relationships. Also, offering incentives that will help improve oral health, such as a toothbrush, Oral Balance Gel for mouth dryness, and Sensodyne toothpaste for tooth sensitivity would go a long way in helping to establish interest in a screening program.

Approach confirmed by the street nurses:

- Setting up a mobile screening program with no fixed time and place will create access and minimize barriers. The locations for screening include in the lobbies of hotels, shelters, places where people go to eat and hang out and other familiar, comfortable main gathering places such as the Life Skills Centre, the Carnegie Health Contact Center and the Women's Centre. The street nurses can help pass out pamphlets about oral cancer and oral cancer screening to raise the awareness and to track clients who require follow up by networking with other outreach workers.

As an action plan for increasing awareness about oral cancer and a screening program:

- The street nurses suggested a poster and brochure campaign that focuses on a positive, simple and friendly message stressing "wellness, prevention and fair access to everyone". The slogans should emphasize that, "oral cancer can happen to anyone at any age", "the oral cancer screening program is helping your community to improve oral health and the prevention of oral cancer", their hope with prevention and early detection, and "the screening will come to you". The street nurses suggested avoiding fear tactics and the labeling of the DTES population.
as high-risk, but rather focusing on wellness and optimism. Additionally, in developing strategies, one must be sensitive to emotional support issues by following protocols for pre and post counseling when testing for life threatening disease.

The bottom line message from the street nurses:

- In order to have a successful oral cancer screening program, there are strong needs for increasing awareness in the community about the disease and the value of a screening program. As well, it is important to build relationships of trust with residents in the DTES, and network with other outreach health care workers.

Overall, the street nurses confirmed findings from the focus groups discussions. They were also able to provide valuable suggestions for planning strategies with regard to establishing a network in this high-risk community that will facilitate development of a successful oral cancer-screening program. To enhance the effectiveness of oral cancer screening programs and improve patient oral health awareness, behavioral risk factors would need to be reduced through education and by encouraging tobacco and alcohol cessation. Additionally, the intervention and appropriate treatment of identified pre-malignant disease is necessary in order to halt malignant transformation and reverse malignant progression (Patton, 2003).
VIII. BIBLIOGRAPHY


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Appendix A.1. Focus Group Opening Script

SCRIPT: 3 minutes
Thank you everyone for attending this discussion. We appreciate your time and your opinions.

We are interested in learning about what is important for the members in your community to participate in a program to check regularly for cancer inside the mouth. We would like to hear about your opinions and observations so that such a program would work well for you in your neighborhood.

Additionally, your opinions are important to us so that we can help to increase your access to regular mouth care by making policy makers in the government aware of your needs. We would like to see an increase in the amount of health dollars that are spent for oral health in order that you can have better care available to you and your community.

Mouth cancer is found more often among those who smoke or chew tobacco, and use alcohol. Regularly checking for mouth cancer is important because if this cancer is found early, it is very easily treated. Also, early recognition of mouth cancer is very important in order to have the best chance for survival and an improved quality of life. Checking for cancer inside the mouth is painless and only takes a few minutes.

Today, I am going to ask you a few questions so that we can understand how people will respond to a program to check for mouth cancer for your neighborhood. There are no right or wrong answers so please feel free to say what you think. If there is
something that you do not wish to share, that is fine, you do not have to talk about it. It is important that you feel comfortable and are absolutely honest about your opinions. When I write about this discussion, your ideas will be put together with everyone else’s so that you do not need to worry that anyone can identify you by what you are saying.

It is important for us to gather as much information as possible. All of the information that you share with us will only be used for research purposes and available to the research group only. We will audiotape the discussion so that we can accurately record your comments.

Once we have completed the focus group discussions, I will check back with you to see if I have understood everything that you told me correctly, or if there is anything that you forgot to tell me and would like to add.

I would encourage everyone to stay focused on our topic during the discussion. Please be courteous to one another when someone is speaking. Everyone’s opinion is important to us.

Are there any questions? Do you have any concerns? I am happy to answer them now or at any time during our discussion.
1. Background:

You are being invited to take part in this research study because you may be an individual who may or may not be considered high-risk for developing oral cancer (also known as mouth cancer) due to the use of tobacco and alcohol.

This research is funded by a grant from the National Institute of Dental and Craniofacial Research in the United States and the CIHR Development Grant Fund from the University of British Columbia. This consent form will tell you about the study, why the research is being done, how the study will be done and what your role will be if you choose to participate. Your participation is voluntary and you may decide not to participate or to withdraw at any time.

2. Purpose:

Oral (mouth) cancer is often found among those who chew or smoke tobacco and use alcohol. When mouth cancer is discovered early, the treatment is simple. Also, early recognition of mouth cancer is important in order to increase survival and improve the quality of life.

Our long-term goal is to set up a program in your community that checks for mouth cancer on a regular basis. The purpose of this study is to determine what factors are important in order for individuals in your community to participate in a program to check for cancer inside of the mouth.

3. Who can participate in the study?

You may participate in this study, if you live in the Downtown Eastside of Vancouver and reside in one of the hotels managed by the Portland Hotel Society (The Portland, the Sunrise, the New Stanley Fountain, the Washington and the Regal) or are a user of the facilities at the Portland Life Skills Center. You should be able to speak English and capable of presenting your opinion. You can give your informed consent to participate as demonstrated by signing this consent form.

4. Study Procedures:

If you decide to join this study, you will be asked to participate in a discussion group with 8 to 10 other individuals for approximately 1 to 2 hours to discuss your views on things that are important and should be considered for an oral (mouth) cancer screening (checking) program in your neighborhood.

A trained person(s) (facilitator) from our research group will lead the group discussion. You will be asked to complete a short questionnaire before the discussion group session. After the group discussion, you may be invited to participate in an individual interview in order to clarify information that was obtained in the group discussion.
If as a result of the focus group discussion you have concerns about your potential risk for mouth cancer, you will be invited to go to the Portland Community Dental Clinic for a check-up of your mouth. The discussion session will be audio taped so that we can review it and accurately record the information that we obtain from the discussion sessions.

5. Confidentiality:

Your confidentiality will be respected. No information that discloses your identity will be released or published without your specific consent. Your identity will not be used in any reports about the study. In records that leave this discussion session you will be identified by a study code only. The information that you give us will be put together with information from other men and women from the group discussions, therefore nobody will be able to identify you by what you have said. All information associated with this study will be kept behind locked doors or in secure computer files.

We encourage all participants to refrain from disclosing the contents of the discussion outside of the focus group; however, we cannot control what other participants do with the information discussed.

The information gathered from this study, with information identifying you removed, will provide information for set-up a program in your community that checks for mouth cancer on a regular basis. This information will be a part of Master's thesis and will be shared with the investigators who have conducted his study and other researchers throughout the world through publication of the results of this study.

Your rights to privacy are legally protected and guaranteed by federal and provincial laws that require safeguards to insure that your privacy is respected and also give you the right of access to the information about you that has been provided to the sponsor and, if need be, an opportunity to correct any errors in this information. Further details about these laws are available on request to your study doctor or the UBC BCCA Research Ethics Board.

6. Benefits and Risks:

There are no direct benefits from participating in this study. However, we hope that the information learned from you may improve the health care provided to your community in the future. You will not incur any personal expenses as a result of your participation in this study.
Subject Consent

I understand that participation in this study is entirely voluntary. I may choose not to participate or I may withdraw from the study at any time and I will continue to be offered the best available medical care. I understand that I may ask questions about this study in the future.

I will receive a signed copy of this consent form including all attachments, for my own records.

I consent to participate in this study.

Subject’s Signature  Printed name  Date

Witness’ Signature  Printed name  Date

Signature of  Printed name  Study Role  Date
Person Obtaining Consent

* If you are nervous about signing a form, or if you are not able to read or write, someone from the research team (facilitator) will read the form to you and obtain your verbal consent. The facilitator will then sign both forms to witness your verbal consent, and make note that you are unable to read and write or that you are uneasy about signing a form.

Signature of  Printed name  Date
Person Obtaining Verbal Consent
Appendix A.4. Focus group discussion questions

1. Based on your own experience, and what you have heard about or read, what can you tell me about your understanding of cancer of the mouth? Causes? Risks?

2. Based on your knowledge of mouth cancer, what is your opinion on how people might get cancer of the mouth?

3. Based on your opinion, do you feel that mouth cancer is a concern for you, your family members or your friends or your community?

4. If available in your community, would you be interested in attending a program that could check for mouth cancer? Why?

5. If available in your community, why would you want to come and be checked for mouth cancer? It is important (or not); I was recommended to go for screening;

6. If available in your community, why would you NOT want to come to be checked? Fear of cancer? Fear of treatment? Cost? Transportation?

7. Whose opinions do you feel that you trust and value the most when it comes to you making your health related decisions? Physician, dentist, friend, family member, street nurse or other HCW?

8. In your opinion, where would the best place be for you to come and get checked for mouth cancer? Medical/dental clinic, community center, health unit, park, hotels, library, mobile clinic

9. In your opinion, what is the best way for you to receive information about attending a program to check for mouth cancer? Brochures, posters, street nurse, doctor or dentist or other HCW, social worker

10. Are there any other comments or observations?

Focus group discussion questions Rev. 20051123
Appendix A.4.1. Focus group questions for women’s group

1. In general what is your understanding of mouth cancer?
   What have you heard/read about mouth cancer (Myths)
   What causes mouth cancer? (Myths)
   What are the risks? Kissing, smoking, alcohol, drugs?

2. Are you concerned about getting mouth cancer? Why?
   Are you worried about friends, family members getting mouth cancer? Why?
   Do you know anyone with mouth cancer?

3. We are setting up a province wide mouth-screening program, what do you think a mouth cancer screening involves?
   DEMO: I would like to demonstrate to you what is involved in a mouth screening to help you decide if it is something you might be interested in. (Discuss pain, time involved etc).

   After seeing what is involved in a mouth screening, I would like to get some of your ideas about your possible interest in a program to check for mouth cancer.

4. What would motivate you to attend?
   • Do you think that screening may prevent mouth cancer

5. What would deter/stop you from attending?
   • Dental neglect, embarrassed about condition of mouth
   • Fear
   • Transportation, location

6. How do you/other women in this community feel about getting regular pap smears and breast exams?
   • Is it worthwhile? Why/why not?
   • Would/do you personally attend?
   • Would you be interested in having a screening for mouth cancer at the same time as you get a pap test, mammography or breast exam, prostate etc all in the same place?
     Why or why not?

8. What is the best way to raise the awareness about mouth cancer in this community?
   • By showing posters of what it looks like?
   • Symptoms?
   • Who gets it?
   • How it’s treated?
   • How it’s prevented
9. What is the best way to contact you to let you know about a mouth-screening program? Why? Physician, street nurse, dentist, hotel staff, friends, other?
Appendix A.5. Focus group questionnaire

NAME: ___________________________ ID#: ___________________________
Date of Birth: ___________________________ (YYYY/MM/DD) Date: ___________________________ (YYYY/MM/DD)
Age: ______ Sex: ______
If First Nations Status: specify.

1. Have you recently visited a dentist?
   □ Yes. If yes, when? ___________________________
   □ No

2. Has anyone told you that you are at risk for mouth cancer?
   □ Yes
   □ No

3. Has a family member or friend had mouth cancer?
   □ Yes
   □ No

4. Have you ever been checked for mouth cancer?
   □ Yes
   □ No

5. Have you ever been told that you have mouth cancer?
   □ Yes
   □ No

6. What is your ethnic or cultural heritage? Check one box only:
   □ White or Caucasian
   □ First Nations STATUS: Yes □; No □
   □ East or South-east Asian (eg. China, Japan, Indonesia, Philippines, Vietnam)
   □ South Asian (eg. India, Pakistan, Sri Lanka)
   □ Black or African-North American
   □ Other (Please Specify) ___________________________

7. What is the language that you are most fluent in? Check one box only:
   □ English
8. a) What is the highest grade (or year) of high school or elementary school that you have completed?
   Grade ____  Never attended school ____

   b) How many years of post-secondary school have you completed (college, university)?
      Years ____  None ____

9. What is your current marital status? Check one box only:
   □ Married or Living Common Law
   □ Divorced
   □ Separated
   □ Widowed
   □ Never married

10. Are you currently living at one of the following hotels? Check one box only:
    □ The Portland Hotel
    □ The Sunrise
    □ The Washington
    □ The Regal
    □ The New Stanley Fountain
    □ The Marpole
    □ None of the above

11. Who do you live with? Check one box only:
    □ Alone
    □ With family
    □ With others

12. Are you currently working?
    □ Yes
    □ No

13. What is your annual family income before taxes. (Family is a group of individuals related by blood, marriage including common-law, or adoption, who currently share a common dwelling unit). Check one box only:
    □ less than 12,000
    □ 12,001 – 15,000
    □ 15,001 – 20,000
    □ 20,001 – 25,000
    □ 25,001 – 30,000
    □ 30,001 – 35,000
    □ >55,000
    □ Don't know
    □ Decline to answer
14. In the past 12 months, did you (or your family) receive income from any of the following assistance programs:
   □ Child Tax Benefit
   □ Guaranteed Income Supplement or Spouse's Allowance
   □ Income Assistance or Welfare
   □ Disability Insurance
   □ Employment Insurance
   □ None of the Above

15. Have you smoked 100 or more cigarettes in your life?
   □ Yes
   □ No

16. Have you ever used the following: (Please check all that apply)
   □ Betel nut
   □ Chewing Tobacco
   □ Marijuana;
   □ Crack/Cocaine; if yes, □ smoke, □ sniff, □ injection
   □ Crystal Meth; if yes, □ smoke, □ sniff, □ injection
   □ Heroin; if yes, □ smoke, □ sniff, □ injection
   □ None of the Above

17. Do you now drink or have you ever consumed alcoholic beverages more than once or twice a week?
   □ Yes; if yes, □ beer, □ wine, □ liquor
   □ No

Please specify who completed questionnaire:
   Self ☐; Family Member ☐; Other ☐ Please specify ___________________
   OHN Staff ☐ (Name) ___________________
Appendix A.6. Focus group addendum questionnaire

1. If there is a community program to examine your mouth regularly for mouth cancer, where is the best place for you to go?
   - Medical Clinic
   - Health Unit
   - Life Skills Center
   - Mobile Unit
   - Dental Clinic
   - Your Hotel residence
   - Library
   - Park
   - Other

2. What time/days would work best for you and/or your family/friends to come?
   - Same day for 1 week
   - Vary the days
   - Morning
   - Afternoon

3. What is the best way for you to receive information about such a program?
   - Brochure
   - Posters
   - Through your doctor
   - Through your street nurse
   - Through your dentist
   - Through your social worker
   - Other health care worker
   - Public Health
Appendix A.7. Example of Microsoft Excel sheet for data analysis

<table>
<thead>
<tr>
<th></th>
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<tbody>
<tr>
<td>1</td>
<td>I've heard, I peruse the notes and especially the notes that people who consume alcohol smoke tobacco are</td>
<td>5</td>
<td>Lay understanding of what causes oral cancer</td>
<td>Jor</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>more prone to have oral cancer.</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>1</td>
<td>Okay, you heard about that before today?</td>
<td>5</td>
<td>Lay understanding of what causes oral cancer</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Jor: I heard that smoking causes oral cancer but not alcohol.</td>
<td></td>
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<tr>
<td></td>
<td>This is the first time.</td>
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<tr>
<td></td>
<td>BC: It's the first time, okay; you've heard about other types of cancer, did you hear anything about smoking and cancer?</td>
<td>5</td>
<td>Lay understanding of what causes oral cancer</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>C: Yeah.</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>BC: But nothing related to mouth cancer in particular?</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>C: No.</td>
<td></td>
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</tr>
<tr>
<td>1</td>
<td>O: [translating] He only knows that his knowledge is about that you can get oral cancer if you're a heavy smoker or chewing tobacco.</td>
<td>5</td>
<td>Lay understanding of what causes oral cancer</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>cement finishing and I've heard that is pretty toxic, not just for the lungs, right, but there's a lot of, a lot of that thing, I don't know what the name is, you hold in your throat, and they know now through the years you can have oral cancer?You know what I'm talking about cement finishing?BC: I'm sorry, I'm not sure; I'm not a hundred percent certain about that because I don't know what the toxic chemical is O: Chemical component right. BC: Chemical component? O: I guess so, yeah.</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>
Certificate of Expedited Approval: Annual Renewal

<table>
<thead>
<tr>
<th>PRINCIPAL INVESTIGATOR:</th>
<th>Catherine F. Poh</th>
</tr>
</thead>
<tbody>
<tr>
<td>INSTITUTION / DEPARTMENT:</td>
<td>BCCA/Systemic Therapy - VA (BCCA)</td>
</tr>
<tr>
<td>NUMBER:</td>
<td>H05-60175</td>
</tr>
</tbody>
</table>

| INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT: | N/A Other locations where the research will be conducted: N/A |

| PRINCIPAL INVESTIGATOR FOR EACH ADDITIONAL PARTICIPATING BCCA CENTRE: | N/A |

| SPONSORING AGENCIES AND COORDINATING GROUPS: | Canadian Institutes of Health Research |
| PROJECT TITLE: | Optical Techniques And Oral Precancer Management - A Community Study Component |

EXPIRY DATE OF THIS APPROVAL: January 8, 2008

AMENDMENT(S) APPROVED WITH THIS RENEWAL: N/A

CERTIFICATION:
1. The membership of the UBC BCCA REB complies with the membership requirements for research ethics boards defined in Division 5 of the Food and Drug Regulations of Canada.
2. The UBC BCCA REB carries out its functions in a manner fully consistent with Good Clinical Practices.