**Western Sydney University**

# Exploring OrAL CAncer Risk BehaviouRs of Indian ImMigrants in Australia: A Mixed-Methods Study to Inform Preventative Strategies
## (The ALARRM Study)

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# Declaration

The work presented in this thesis is, to the best of my knowledge and belief, original, except as acknowledged in the text. I hereby declare that ethical clearance was obtained for this body of research, and I have not submitted any material contained herewith, either in full or in part, for a degree in this or any other institution.

**Signature:** 

**Date:** 18th September 2022

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# Anthology of Publications

## Quality Publications Statement

I confirm the following:

- All the publications are indexed on Web of Science/Scopus.
- I am the first author on the five publications in this thesis.
- All publications are published in Q1 & Q2 journals and no lower than Q3.
- The papers have been peer reviewed.

**Signature:**  **Date:** 18th September 2022

## Peer reviewed papers

1. **Saraswat, N.**, Pillay, R., Everett, B., George, A. (2020). Knowledge, attitudes, and practices of South Asian immigrants in developed countries regarding oral cancer: an integrative review. *BMC Cancer*, *20*(1), 1-16. doi: https://doi.org/10.1186/s12885-020-06944-9 (Impact Factor: 4.4; Quartile: Q2; Citations: 10)

2. **Saraswat, N.**, Everett, B., Pillay, R., Prabhu, N., George, A. (2020). Knowledge, attitudes, and practices of general medical practitioners in developed countries regarding oral cancer: an integrative review. *Family Practice*, *37*(5), 592-605. doi: https://doi.org/10.1093/fampra/cmaa026 (Impact Factor: 2.29; Quartile: Q1; Citations: 5)

3. **Saraswat, N.**, Prabhu, N., Pillay R., Everett, B., George, A. (2021). Oral cancer risk behaviours of Indian immigrants in Australia: A Qualitative Study. *Australian and*

*New Zealand Journal of Public Health*, *46*(1), 87-94. doi: https://doi.org/10.1111/1753-6405.13183 (Impact Factor: 3.7; Quartile: Q2; Citations: 2)

4. **Saraswat, N**., Pillay, R., Prabhu, N., Everett, B., George, A. (2021). Perceptions and Practices of General Practitioners towards Oral Cancer and Emerging Risk Factors among Indian Immigrants in Australia: A Qualitative Study. *International journal of environmental research and public health, 18*(21), 11111. doi: https://doi.org/10.3390/ijerph182111111 (Impact Factor: 3.39; Quartile: Q1; Citations: 2)

5. **Saraswat, N.**, Everett, B., Pillay, R., Prabhu, N., Villarosa, A., George, A. (2022). Knowledge, Attitudes and Practices of Indian Immigrants in Australia towards Oral Cancer and Their Perceived Role of General Practitioners: A Cross-Sectional Study. *International Journal of Environmental Research and Public Health*, *19*(14): p. 8596. doi: https://doi.org/10.3390/ijerph19148596 (Impact Factor: 3.39; Quartile: Q1)

## Author Contributions to Peer-Reviewed Manuscripts (Papers 1-5)

| Author | Concept & Design | Data Collection | Data Analysis | Interpretation & Discussion | Manuscript First Draft | Manuscript Revisions & Final Approval |
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| Bronwyn Everett | | | 3,4 | 1,2,3,4,5 | | 1,2,3,4,5 |
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| Neeta Prabhu | | | 3,4 | 2,3,4,5 | | 2,3,4,5 |
| Amy Villarosa | | | 5 | 5 | | 5 |
| Ajesh George | 1,2,3,4,5 | | 3,4 | 1,2,3,4,5 | 1,2,3,4,5 | 1,2,3,4,5 |

## Conferences

### *International*

1. **Saraswat, N**., Everett, B., Pillay, R., Prabhu, N., George, A. (2019, November 28-30). *General Medical Practitioners' views towards Oral Cancer: A Systematic Review*. International Association for Dental Research Asia-Pacific Region, Brisbane, Australia.

### *National*

1. **Saraswat, N**., Prabhu, N., Pillay, R., Everett, B., George, A. (2021, May 10-12). *Oral Cancer Risk Behaviours of Indian Migrants in Australia: A Qualitative Study.* Preventive Health Conference, Public Health Association, Virtual Edition.
2. **Saraswat, N**., Pillay, R., Prabhu, N., Everett, B., George, A. (2022, May 11-13). *General Medical Practitioners' perspective and practices regarding oral cancer in Australia*. Preventive Health Conference, Public Health Association, Virtual Edition.

### *Local*

1. **Saraswat, N.**, Everett, B., Pillay, R., George, A. (2019, June 5-6). *Oral cancer risk behaviours among South Asian immigrants- The current state in developed countries of the world*. Health Beyond Research & Innovation Showcase, The William Inglis Hotel, Warwick Farm, Australia.
2. **Saraswat, N.**, Everett, B., Pillay, R., George, A. (2019, June 28th). *Oral cancer risk knowledge, attitudes and practices of South Asian immigrants in developed countries.* Joanna Briggs Inaugural Symposium, St. George Hospital, Kogarah, Australia.

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## Other PhD-Related Outputs

### *Grants*

1. 2021-2022: Development of an educational resource for oral cancer causative factor betel nut NSW Ministry of Health, Investigators: George, A., Saraswat, N., Everett, B., Pillay, R., Prabhu, N. (Grant received- $2000)

### *Other publications*

2. 2020-2021: Development of a factsheet about Betel nut products and preparations for Health Professionals, NSW Ministry of Health, Investigators: Kuruppuarachchi, A., Masoe, A., George, A., Saraswat, N., Everett, B., Pillay, R., Prabhu, N.
   Link: https://www.health.nsw.gov.au/oralhealth/prevention/Pages/betel-nut-preparations-use.aspx

# Abbreviations

| Abbreviation | Terminology |
|---|---|
| **ABS** | Australian Bureau of Statistics |
| **ADA** | Australian Dental Association |
| **AIHW** | Australian Institute of Health and Welfare |
| **CALD** | Culturally and Linguistically Diverse |
| **CDBS** | Child Dental Benefit Scheme |
| **CIS** | Carcinoma In Situ |
| **CoC** | Confirmation of Candidature |
| **COHORT** | Centre for Oral Health Outcomes & Research Translation |
| **CPD** | Continuing Professional Development |
| **DNA** | Deoxyribonucleic Acid |
| **EBV** | Epstein Barr Virus |
| **FDA** | Food and Drug Administration |
| **FDI** | FDI (Federation Dentaire Internationale)/ World Dental Federation |
| **GLOBOCAN** | Global Cancer Database |
| **GPs** | General Practitioners/General Medical Practitioners |
| **HDI** | Human Development Index |
| **HBM** | Health Belief Model |
| **HHV** | Human Herpes Virus |
| **HIV** | Human Immunodeficiency Virus |
| **HPV** | Human Papilloma Virus |
| **HSV** | Herpes Simplex Virus |
| **ICD** | International Classification of Diseases |
| **IFIS** | Imported Food Inspection Scheme |
| **KAP** | Knowledge, Attitudes and Practices |
| **NCD** | Non-Communicable Diseases |
| **NCI** | National Cancer Institute |
| **NICE** | National Institute for Health and Care Excellence |
| **NSW** | New South Wales |
| **PhD** | Doctor of Philosophy |
| **PHN** | Primary Health Networks |
| **PRISMA** | Preferred Reporting Items for Systematic Reviews |
| **QCA** | Qualitative Content Analysis |
| **RACGP** | Royal Australian College of General Practitioners |
| **SPSS** | Statistical Product and Service Solutions |
| **TNF** | Tumour Necrosis Factor |
| **TSNs** | Tobacco Specific Nitrosamines |

| | |
|---|---|
| **UK** | United Kingdom |
| **USA** | United States of America |
| **VIC** | Victoria |
| **WHO** | World Health Organisation |
| **WSU** | Western Sydney University |

# Glossary of Terms

| Term | Definition of Terms |
|---|---|
| **Access** | Access refers to the use of health services and everything that facilitates or impedes their use. |
| **Attitudes** | This term depicts peoples' inclinations, perceptions, and beliefs regarding a particular situation/subject (oral cancer risk in this context). |
| **Behaviours** | The way in which a person conducts oneself and behaves in response to a particular situation (oral cancer risk in this context). It is the outcome of mutual interaction of knowledge, attitudes, and practices. |
| **Dental care professionals/oral health care professionals** | These include dentists, dental specialists, dental hygienists, dental therapists, oral health therapists. |
| **Dental care services/oral health services** | Dental care/ Oral health services offered to people including oral health assessment, management, treatment, and evaluation performed by dental health professionals. |
| **Developed and Developing countries** | There is no established convention for the designation of 'developed' and 'developing' countries or areas in the United Nations system. For this thesis, high income countries with developed economies (e.g., the United Kingdom, the United States of America, Canada, Australia, New Zealand) have been referred to as 'developed' countries and low-income or middle-income countries (e.g., India, Pakistan, Nepal) have been referred to as 'developing' countries. |
| **GLOBOCAN** | A comprehensive cancer surveillance database managed by the International Association of Cancer Registries (IARC). The aim of IARC is to calculate incidence and cancer mortality worldwide (184 countries) and the prevalence of various cancers. |
| **Knowledge** | Knowledge refers to a person's awareness, and level of information and understanding about a particular situation/subject (oral cancer risk in this context). |
| **Practices** | Practices refers to the actions relating to the initiation, continuation and quitting of particular habits (oral cancer risk in this context). |

| | |
|---|---|
| **Indian Immigrants** | Immigrants are the people who move into a country other than that of their nationality. Here, Indians who themselves or their parents were born in India, were considered as Indian immigrants. |
| **Oral cancer** | Oral cancer is the 'Cancer that forms in tissues of the oral cavity or in unspecified parts of the mouth.' |
| **Preventive oral cancer services** | Providing oral cancer education, screening, and referrals |
| **Risk products** | Term given to commonly used products (e.g., alcohol, tobacco, and areca nut preparations) which can cause oral cancer when consumed for a longer duration of time. |
| **Regular medical/dental visit** | Visiting a General Practitioner/Dental Practitioner at least once a year regularly |
| **Sociodemographic characteristics** | Involves a combination of social and demographic factors including age, education, income, region of living. |
| **Sociocultural characteristics** | Involves a combination of social and cultural factors including religion, ethnicity, and cultural traditions. |
| **Systemic diseases** | Diseases that affect the entire body, rather than a single organ or body part |

# Abstract

***Background***: Oral cancer is one of the most common cancers and has become a serious public health concern. It has been linked to numerous risk factors including tobacco consumption and cultural practices of using areca (betel) nut preparations, which are highly prevalent in South Asian countries, particularly India. Over recent decades, oral cancer has also been increasing in many developed countries including Australia. Every year in Australia, more than 4,000 new cases of head, neck and lip cancers are diagnosed and more than 600 of these cancers comprise oral cavity cancers. This is disturbing since the overall mortality rate has remained the same despite fluctuations in the number of oral cancer reports in the past few years. The upsurge in population due to migration, specifically from India, could be a contributing factor to the rise in oral cancer cases. Indians are one of the fastest-growing communities constituting over 2.6% of the total population in Australia. However, very little is known about the oral cancer risk among Indian immigrants in Australia. Furthermore, no research has been undertaken to understand the perceptions and practices of general practitioners in Australia towards oral cancer and emerging risk factors particularly relevant to Indian populations.

***Aim***: The broad aim of this mixed methods study was to explore oral cancer risk behaviours of Indian immigrants and identify preventative strategies to raise oral cancer awareness. The specific aims were to examine the self-reported oral cancer knowledge, attitudes, and practices of Indian immigrants in Australia and perceived barriers and facilitators in adopting preventative strategies. Similarly, the oral cancer-related knowledge, attitudes, and clinical practices of General Practitioners (GPs) were investigated along with their perceived barriers and facilitators in promoting preventative strategies in Australia.

***Methods***: This thesis is presented as a series of five published papers. Two publications are presented as the literature review and the remaining three papers are from the qualitative and quantitative results. The study adopted an integrated model (informed by the knowledge, attitude, and behaviour (K-A-B) model and Health Belief model (HBM)) and used a sequential exploratory mixed methods research design. Qualitative data were collected through concurrent semi-structured interviews with Indian immigrants (*n*=14) and GPs (*n*=14) from the suburbs of Sydney (New South Wales) and Melbourne (Victoria), Australia. Both cities are preferred destinations for Indian immigrants. Quantitative data were collected using a cross-sectional survey with 164 Indian immigrants residing in different parts of Australia. The cross-sectional survey questionnaire was developed based on a review of existing literature and results from the qualitative phase. Qualitative data were analysed using content analysis while descriptive and inferential statistics were used to analyse the quantitative data.

***Results***: Qualitative analysis revealed that all Indian immigrant participants admitted engaging in oral cancer risk practices and were knowledgeable about oral cancer risks associated with tobacco and alcohol; however, few were familiar with the harmful effects of areca nut use. Varied attitudes were evident with most participants acknowledging the importance of oral cancer check-ups, yet very few followed this practice. On the other hand, all GPs were found knowledgeable of major oral cancer causative factors, including tobacco and alcohol, with some having a limited understanding about the risks associated with areca nut consumption. Although GPs expressed positive attitudes regarding the importance of oral cancer risk assessment, inconsistent clinical practices relating to oral cancer screening were evident. Quantitative results showed respondents had varying levels of knowledge about oral cancer (mean total score 61%), particularly around oral cancer-related signs/symptoms.

Participants were also comparatively less knowledgeable about betel quid/nut and alcohol as risk factors for oral cancer compared to traditional factors like smoking or chewing tobacco. Almost half (45.8%, *n*=70) of the respondents thought people of Indian background were at higher risk of oral cancer and attributed this to addiction (83.0%, *n*=127), leisure/lifestyle (69.3%, *n*=106), and cultural practices (32.7%, *n*=50). Respondents were engaging in positive preventative oral health care, though few were currently (6.7%) or previously (14.7%) using tobacco and/or areca nut preparations. Most (87.7%, *n*=146) had not received any information about oral cancer in a health care setting but were receptive (71-90%) to general practitioners playing a more active role in this area.

***Conclusion***: The ALARRM study has provided valuable insight into the under-researched area of oral cancer risk in Australia. It has revealed varying levels of knowledge about oral cancer among the sample of Indian immigrants, particularly around risk factors like alcohol and areca nut use as well as oral cancer-related signs/symptoms. Positive attitudes about preventative oral health practices were evident, although some participants were involved in oral cancer risk practices. The findings have also highlighted the lack of adequate information regarding oral cancer being provided in primary health care settings and uncertainty around the scope of practice of GPs in this area. GPs play a vital role as primary health care providers and are a gateway to access specialist health services. However, a lack of relevant oral health training is making it difficult for GPs to actively promote oral cancer prevention.

The overall findings suggest the need for the formulation of community-centred oral cancer preventative and awareness strategies along with capacity building of primary health care professionals. Steps taken on a policy level could also help in reducing oral cancer incidence. Further research through larger studies and a more representative sample is warranted to

explore this area in Australia and confirm the study findings. Greater knowledge in this area will help inform the development of culturally sensitive and tailored strategies to raise awareness of oral cancer risk among the growing Indian immigrant population in Australia.

# Chapter 1: Introduction

## 1.1 Problem Statement and Overview

Cancer is a major cause of mortality in the world and is continually growing (Mukherjee, 2010). The World Health Organisation defines cancer as a "large group of diseases that are characterised by abnormal growth of cells beyond the limits of their usual boundaries, often accompanied by invasion into adjoining parts of the body and spreading to other organs" (World Health Organisation, 2018). A 2020 *Global Report* identified cancer as the first or second leading cause of premature death for persons aged 30 to 69 years in 134 of 183 countries (World Health Organisation, 2020). In 2020, there were an estimated 19.3 million new cases of cancer with almost 10 million related deaths (Sung et al., 2021). Oral cancer is one of the most common cancers and has become a serious public health concern both in developing and developed countries (Conway et al., 2018; Sarode et al., 2020). It has been linked to numerous risk factors including cultural practices of betel quid chewing and is highly prevalent in South Asia, particularly India (Sarode et al., 2020). In the last decade, oral cancer has also been increasing in many developed countries including the United Kingdom (UK) and United States of America (USA) and this has been partly attributed to changing migration trends from South Asian countries like India (Auluck et al., 2009; Curtis et al., 2020; Petti & Warnakulasuriya, 2018)

Similar migration patterns have been occurring in Australia and Indians are now the third most common immigrant group. However, very little is known about oral cancer risk behaviours among Indian immigrants in Australia. Furthermore, no research has been undertaken to understand the knowledge, attitudes, and practices of general practitioners in Australia towards oral cancer and emerging risk factors, particularly among Indian

communities. Gathering this information could greatly help in identifying culturally appropriate strategies that could be implemented at the community, primary health care and policy levels to potentially reduce the burden of oral cancer. This thesis will address these research gaps using a mixed methods approach and an integrated conceptual model to help identify suitable preventative strategies in this area.

This chapter will provide an overview of oral cancer including its characteristics, prevalence, and risk factors. This will be followed by a description of oral cancer in developed countries and the impact of migration, focusing particularly on the Australian context as well as preventative strategies including the role of general practitioners. The chapter will also describe dental health and oral cancer care services in Australia and conclude with the significance, aims and outline of this thesis.

## 1.2 Background

### 1.2.1 Oral cancer

The term ‘oral cancer’ describes a range of malignancies emerging in distinct sites of the oral cavity (Speight & Farthing, 2018). Since more than 90% of cases for this cancer histologically originate in the squamous cells, it is also widely known as oral squamous cell carcinoma (OSCC) (Rivera, 2015). OSCC arise from the epithelial lining of the oral cavity and has well characterised histopathological features, often referred to as 'conventional' squamous cell carcinoma (Speight & Farthing, 2018). It is a highly morbid disease with sequelae of pain, loss of function, and diminished quality of life, often causing disfiguring impairment and death (Ahluwalia, 2005). Lip and oral cavity cancers (10.2 per 100,000) constitute 2% of all sites of cancers and are widely prevalent in terms of incidence and

mortality, especially in lower Human Development Index (HDI) countries (Sung et al., 2021). In 2020, the total number of estimated new cases of these types of cancers were 377,713, while death estimates were 177,757 (Sung et al., 2021).

Oral cancer develops in various precursor lesions and conditions which altogether are referred to as oral potentially malignant disorders (OPMDs) as recognized by the World Health Organization (WHO) (D. R. Nair et al., 2012). Some of these OPMDs are relatively common and affect at least 1-5% of the population (Mustafa et al., 2021). OPMDs pose a risk for malignancy with a wide range of transformation rates between 13 and 70% (Mustafa et al., 2021). The commonest types of OPMDs are white patches (leukoplakia), red patches (erythroplakia) and submucous fibrosis (Mustafa et al., 2021). Leukoplakia has an overall prevalence of 2.9% in the general population (Bánóczy et al., 2001) while submucous fibrosis has a prevalence of almost 11% in high-risk populations (Wollina et al., 2015). Most OPMDs are asymptomatic and clinically detectable in form of morphologically altered tissue during conventional oral examination (D. R. Nair et al., 2012). Management can be in three categories namely close observation, surgical excision/laser ablation and medical treatment (D. R. Nair et al., 2012). Early detection of OPMDs may help in preventing malignant transformation or down staging the disease (D. R. Nair et al., 2012). Therefore, knowledge of the patterns of presentation of OPMDs is important as the timely identification of these potentially malignant disorders offers a window for intervention before transformation into cancerous state (Mustafa et al., 2021). Further sections of this thesis provide details of oral cancer's definition, characteristics, geographic distribution and aetiology.

### *1.2.1.1 Definition of oral cancer*

There is a general lack of consensus in the literature on the terminologies used to define oral cancer (Tapia & Goldberg, 2011). Currently, there are two main schools of thought regarding the international classification of diseases (ICD). The first is based on an anatomical method of definition which considers the boundaries of the various subsites of cancer, while the second is an aetiological method of definition mainly focused on association with risk factors (D'Souza et al., 2007). There are also different views about whether the lip cancers should be considered as oral cancers or should be mentioned separately with oral cavity cancers (Miranda-Filho & Bray, 2020; Rivera, 2015; Weinberg & Estefan, 2002). However, cancer tumours rarely follow specific anatomical boundaries and the associated signs and symptoms affecting various subsites in the head and neck region overlap considerably. As a result, for this thesis a hybrid (anatomical and aetiological) method of defining oral cancer is used when describing the burden and trends. This generalised definition of oral cancer includes cancers at the base of the tongue (C01), inner lip (C00.3-C00.9), other parts of the tongue (C02), gum (C03), floor of the mouth (C04), palate (C05), and other unspecified parts of the mouth (C06). Despite the different opinions in past about inclusion of lip cancers in oral cancers (Brown & Langdon, 1995; Weinberg & Estefan, 2002), cancers of the lip are the most common malignancies affecting head and neck region and require distinct consideration as their aetiology differs from oral cavity cancers (Kerawala et al., 2016).

### *1.2.1.2 Characteristics and clinical features*

Oral cancer develops over many years and is a highly complex process (Tanaka & Ishigamori, 2011). Oral carcinogenesis occurs when epithelial cells are affected by various

genetic alterations (Curry et al., 2014; Fukuda et al., 2012). These modifications may be caused by random mutation, exposure to carcinogens or *error*s in the DNA repair processes, resulting in malignant neoplastic changes (Feller et al., 2013). Oral cancer originates from non-aberrant keratinocytes which are chronically exposed to a stimulus that breaks its homeostasis, followed by epithelial hyperplasia, dysplasia in different degrees, carcinoma in situ (CIS) and an invasive carcinoma leading to the generation of distant metastases (Rivera, 2015), with consequent clinical manifestations.

Clinically, patients may complain of discomfort and/or a sore inside the lip or other parts of the mouth. Most common clinical presentation for oral cancer is ulceration, especially with fissuring or raised exophytic margins or rolled edges with a granular floor which does not heal. In addition, white and red lesions (leukoplakia and erythroplakia) may be present, sometimes accompanied by lumps with or without pain, tooth mobility, difficulty with tongue movement, chewing and swallowing (*Figure 1.1*) (Bagan et al., 2010). A bleeding surface of the lesion is a diagnostic characteristic of malignancy and can be detected in an oral cavity examination (Scully & Felix, 2006)

***Figure 1.1*** *Clinical Presentation of Oral Cancer*

*Source:* Prof. Michael McCullough (clinical case)

Common sites for oral cancers are the posterior surface of the tongue and the inner side of the lower lip (Scully & Felix, 2006). Gender predilection can be observed in oral cancer trends, as it is more common in men than women (Neville & Day, 2002). The risk for oral cancer increases with age and most cases occur in people aged 50 years or over (Warnakulasuriya, 2010). However, many cases have been reported before the age of 40 years in high incidence countries (Warnakulasuriya, 2010). Oral cancer survival rates are among the lowest of major cancers and have not shown significant improvement over recent years (Villa et al., 2011). The majority of such cancer cases are initially asymptomatic and diagnosed at a late stage with the prognosis decreasing with an advanced stage of the disease (Kruger & Tennant, 2016). Other factors responsible for poor prognosis are low socio-economic status (SES), increased age and risky lifestyles (Kruger & Tennant, 2016).

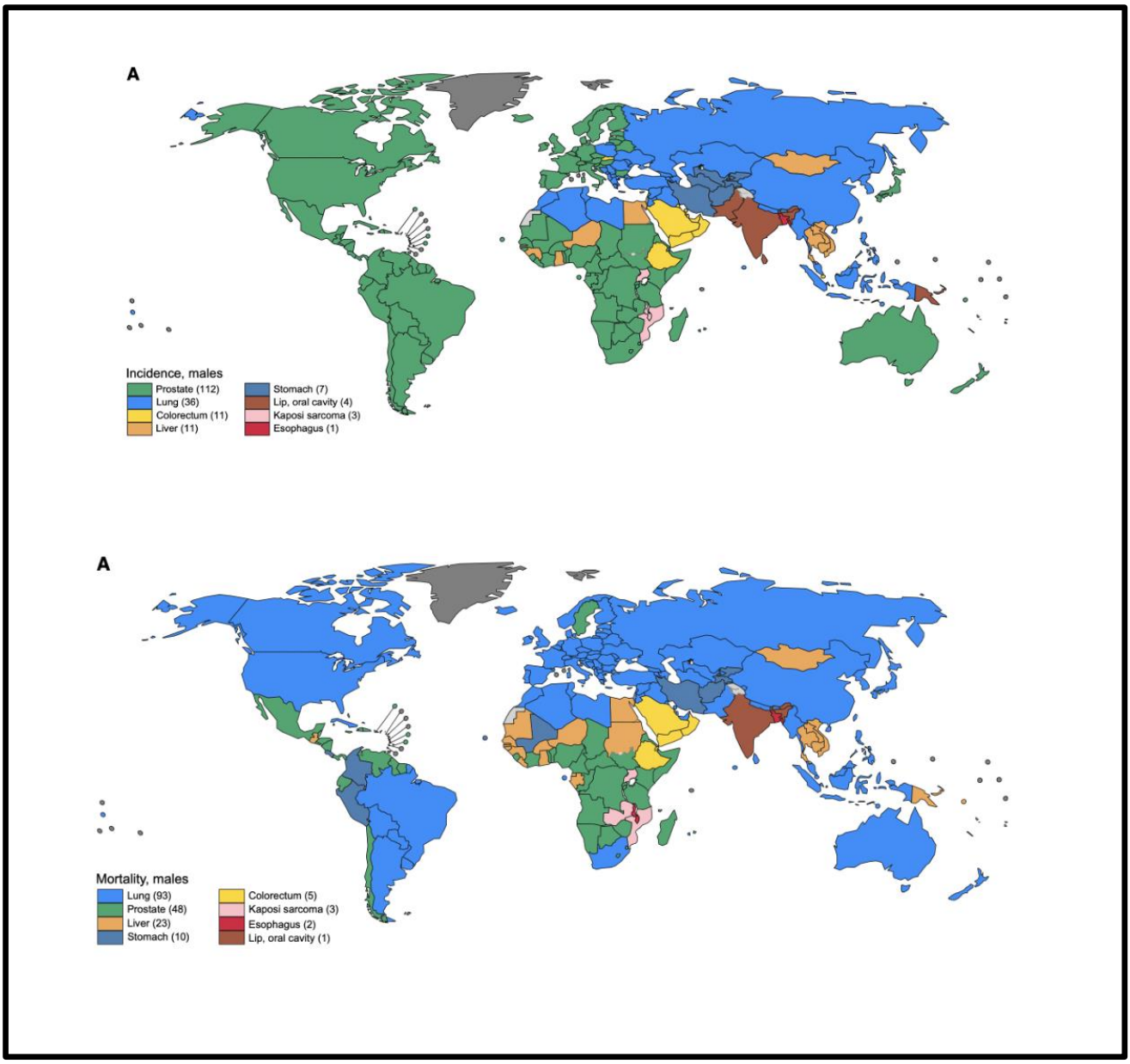
#### *1.2.1.3 Geographical distribution of oral cancer*

A vast geographical variation exists in the occurrence of oral cancer around the world (García-Martín et al., 2019). These deviations are as much as 20-fold among different

countries, age groups and ethnic groups (García-Martín et al., 2019). According to available global data, oral cancer is most commonly diagnosed in Asia (64.2%), followed by Europe (17.4%), North America (7.6%), Latin America and the Caribbean (5.6%), Africa (3.8%) and Oceania (1.3%) (Bray et al., 2018). A slightly different pattern of mortality is noted with the highest rates in Asia (73.3%) followed by Europe (13.6%), Africa (5.3%), Latin America and the Caribbean (4.4%), North America (2.9%) and Oceania (0.56%) (Bray et al., 2018).

Oral cancer is most prevalent in South Asian countries, which include Sri Lanka, Pakistan, and India and Bangladesh, contributing to approximately 25% of all newly-reported cases (Sarode et al., 2020). Oral cancer is widespread in these countries with prevalence nearly twice the global rate (Ahluwalia, 2005). It is the most common malignancy among males and second most common among both the sexes combined in the Indian and Sri Lankan population (Bray et al., 2018). It is also regarded as the second and fourth most common reason of cancer deaths in India and Sri Lanka, with age-standardized mortality rates of 5.6 and 3.8 per 100,000, respectively (Bray et al., 2018). The Indian subcontinent alone accounts for one-third of the total oral cancer burden in the world (García-Martín et al., 2019; Sung et al., 2021) (*Figure 1.2*).

***Figure 1.2*** *Global Incidence and Mortality of Lip and Oral Cavity Cancer*




Source: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries, 2020

## 1.2.2 Risk factors and practices

Oral cancer is a multifactorial disease associated with various risk factors and variable causative practices.

### *1.2.2.1 Risk factors*

The development of oral cancer has been linked to genetics as well as various environmental risk factors (Kumar et al., 2016; Ram et al., 2011). While lip cancers are largely related to ultraviolet radiation exposure (Rivera, 2015), oral cavity cancer is associated with numerous potential risk factors and causative agents, which have been classified as modifiable, non-modifiable and emerging risk factors (Warnakulasuriya, 2009).

*1.2.2.1.1 Modifiable factors*

- Tobacco consumption: The relationship between oral cancer and consumption of tobacco is well established (Kumar et al., 2016; Ram et al., 2011; Warnakulasuriya, 2009; Warnakulasuriya et al., 2005). Tobacco smoke from various products (e.g., bidi, cigarettes, hookah) contain carcinogens including the aromatic hydrocarbon benzopyrene and the Tobacco Specific Nitrosamines (TSNs) which cause deoxyribonucleic acid (DNA) mutations (Kumar et al., 2016). Smokeless tobacco in chewable forms has also become a concern in different parts of the world, as nicotine present in tobacco produces the same carcinogenic effect while in contact with oral mucosa and is also responsible for DNA damage (Kumar et al., 2016; Ram et al., 2011).
- Alcohol: Alcohol consumption raises the permeability of the oral mucosa (mucous membrane lining the inside of mouth) by assisting in dissolution of lipid components, followed by epithelial atrophy (a wasting or decrease in size of

epithelium) as well as interference in DNA synthesis and repair (Rivera, 2015). Along with genotoxic and mutagenic effects, alcohol also causes the impairment of immunity by hepatic damage leading to increased susceptibility to infections and malignancies (Rivera, 2015).

- Diet and nutrition: Lack of essential nutrition is generally common in people with low socio-economic status. Reduced intake of fruits and vegetables results in increased risk of cancer development due to a decrease in macronutrients and micronutrients (Kumar et al., 2016). Micronutrients act as antioxidants which are necessary to minimize free radical reactions and consequently inhibiting DNA mutations as well as peroxidation of cellular membranes (Kumar et al., 2016).
- Betel quid: Betel quid is chewed in the form of a preparation that usually consists of betel leaf, areca nut, slaked lime and tobacco along with other flavoring substances (Kumar et al., 2016). The incorporation of smokeless tobacco elevates the corresponding risk of oral cancer by almost 15 times (Warnakulasuriya et al., 2005). Ingredients of betel quid are genotoxic, cytotoxic, and the metabolic intermediates from betel quid chewing induce DNA damage (Kumar et al., 2016).

*1.2.2.1.2 Non-modifiable factors*

Oral cancer is commonly found to be prevalent in middle-aged or older adults and sometimes associated with intra-country ethnic differences (Scully & Bedi, 2000; Warnakulasuriya, 2009). In addition, genetic predisposition can also be responsible for this disease (Joseph, 2002).

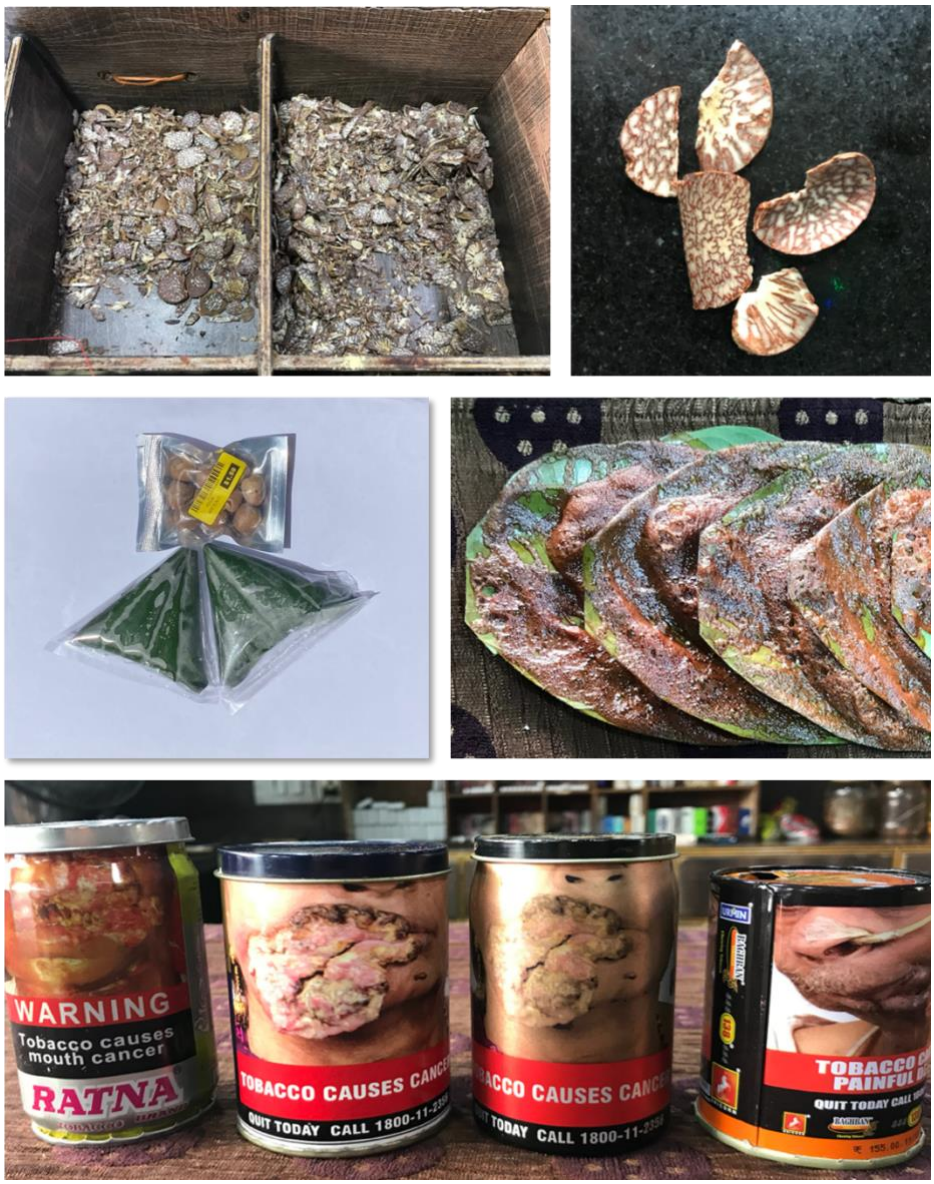
*1.2.2.1.3 Emerging risk factors*

Viral infections and immunosuppression: The role of Human Papilloma Virus (HPV) in oropharyngeal cancers has been described in various studies (Warnakulasuriya, 2009). Oncogenic viruses are capable of hijacking host cellular structures as well as modifying DNA and the chromosomal framework, leading to proliferative changes in cells (Ram et al., 2011). The Herpes simplex virus (HSV-1), which is commonly associated with oral sores has also been suggested to be a causative agent of oral cancer (Ram et al., 2011). Oral cancer has also been linked with other viruses such as Epstein Barr virus (EBV), Human herpes virus-8 (HHV-8), syphilis, cytomegalovirus and fungal infections like candida albicans (Al Moustafa et al., 2009; Kumar et al., 2016). Oral cancer risk is almost double among individuals with Human Immunodeficiency Virus (HIV) compared to healthy individuals (Ram et al., 2011).

#### *1.2.2.2 Causative practices*

The predominance of oral cancer in South Asia is attributed to the consumption of primordial tobacco products like bidis, tobacco chewing, and culturally embedded use of areca nut products, which are utilised in different preparations (Ahluwalia, 2005). A typical practice associated with oral cancer in South Asia is the use of smokeless tobacco, commonly in conjunction with betel/areca nut in various forms (Cheong et al., 2017). Smokeless tobacco is most popular when used as the principal ingredient in betel quid along with areca nut (one of the most consumed psychotropic substances in the world), slaked lime and other flavouring substances (Cheong et al., 2017; Sharan et al., 2012) (*Figure 1.3*). Betel quid chewing is practiced by more than 600 million people worldwide, primarily in South Asian countries including the Indo-Pakistan subcontinent and in migrant populations in Africa, Europe and North America (Chen et al., 2011).

***Figure 1.3*** *Different Preparations and Commercial Products of Areca (betel) Nut and Betel Quid*




*Source: PhD Candidate*

*1.2.2.2.1 Different smokeless tobacco preparations*

Other than betel quid, smokeless tobacco is also consumed in forms like powdered tobacco and alkali blends such as *nass/naswar* (used widely in Pakistan), *khaini* (mixture of tobacco with lime used in Bihar state of India and Nepal) and *zarda* (boiled/sweetened

smokeless tobacco used in Bangladesh) (Warnakulasuriya et al., 2005). Given the use of smokeless tobacco preparations in South Asian countries, a potential steep increase in oral cancer reports in the near future has been speculated (Warnakulasuriya, 2009; Warnakulasuriya et al., 2005).

## 1.2.3 Oral cancer in developed countries and the impact of migration trends

Oral cancer is a serious and growing problem worldwide. Although it contributes up to a quarter of all new cases of cancer in high-risk South Asian countries, it has also gradually risen in other parts of the world in the past few decades (Warnakulasuriya, 2010).

### *1.2.3.1 Scenario in developed countries*

Oral cancer is characterised by wide diversity in its distribution across developed regions of the world. Oral and pharyngeal cancers combined are the 11th leading cause of cancer-related mortality in Europe (Diz et al., 2017). Owing to increase in population and other risk factors, the total number of reported oral cancer cases has increased in Europe by nearly 30% since 1990 (Sarode et al., 2020) and estimated new cases of oral and pharyngeal cancer are close to 100,000 per year (Diz et al., 2017). The incidence of oral cancer is higher in Central and Eastern Europe when compared with Western, Northern or Southern Europe, reaching extremely elevated rates in Hungary and Slovakia (Garavello et al., 2010). In the UK alone, oral cancer accounts for more than 2% of all malignancies, with 6,317 people diagnosed in 2020 (GLOBOCAN, 2020; Oral Health Foundation, 2021). Within England, a 2.8% rise in oral cancer incidence per annum for males and 3.0% per annum for females has been observed (Louie et al., 2015).

In the USA, new cases of lip and oral cavity cancers constituted 1.1% of the total

number of malignancies reported and were estimated roughly at 24,470 with 4,285 deaths (GLOBOCAN, 2020). A study by Kingsley et al. concluded that despite a decline in the overall incidence and mortality for oral cancers in the USA over past decades, a reversal of this trend has emerged from the short-term analysis (Kingsley et al., 2008). This trend is still continuing with apparent increase in oral cavity and pharynx cancer incidence, perhaps attributable to rising prevalence of HPV infection (Bosetti et al., 2020). Recent reports for lip and oral cavity cancer in Canada estimate 2,993 new cases and 700 deaths while constituting more than 1% of total cancers (GLOBOCAN, 2020). Similar trends can be observed in Australia and New Zealand in terms of oral cancer incidence and mortality (GLOBOCAN, 2020). In 2016, the projected incidence for lip and oral cavity cancer in Australia was 2414 (Australian Institute of Health and Welfare, 2022) while in 2020, it was approximately 2788 with 376 deaths (GLOBOCAN, 2020). In New Zealand, 308 new cases and 93 deaths from lip and oral cavity cancers were estimated in 2020 (GLOBOCAN, 2020).

#### *1.2.3.2 Migration trends and oral cancer*

Migration plays a key role in the impacting global economy and social transformations. In 2020, about 272 million international migrants were reported worldwide, which is approximately 3.5 per cent of the total population (International Organization for Migration, 2020). A considerable number of these immigrants reside in high-income countries including the USA, UK, Australia, Canada and New Zealand (International Organization for Migration, 2020). More than 40% of all international immigrants come from Asia, primarily South Asian countries such as India, Pakistan, Nepal and Bangladesh (International Organization for Migration, 2020). South Asian immigrants comprise almost a quarter of the world's total population and are considered one of the

fastest growing ethnic communities in many developed countries including the USA (Asian American Federation and S.A.L.T, 2015), Canada (Statistics Canada, 2013), UK (Vargas-Silva & Rienzo, 2019) and Australia (Department of Immigration and Border Protection (AU), 2017). Furthermore, India is the country with the greatest proportion of its population living outside its borders and is regarded as the largest source of international immigrants, totaling 17.5 million in 2019 (International Organization for Migration, 2020).

As the overall global trend of migration has changed, so have the epidemiological trends of oral cancer. Immigrants are believed to bring their native cultural behaviours, practices and beliefs to their new settlements (Mukherjea et al., 2011), which can contribute to changes in patterns of diseases including oral cancer (Auluck et al., 2009). Historically, oral potentially malignant disorders (OPMDs) were limited to South Asia and some parts of China and Taiwan. However, there has been a gradual increase in cases of such precancerous lesions in high income countries and this finding overlaps with a rise in the number of South Asian immigrants (Auluck et al., 2009). South Asians are at higher risk of oral cancer compared to other population groups and the ethnic disparity in oral cancer rates in many parts of the world is largely attributable to their lifestyles (Warnakulasuriya, 2010). Oral cancer rates among South Asian immigrants are higher on account of chewing practices of areca nut and betel quid, with or without tobacco, which is based on several foundational concepts like social acceptability, religious beliefs and perceived benefits (Auluck et al., 2009). Since South Asian communities are not homogeneous, the risk behaviours among their religious and ethnic subgroups are varied (Ahluwalia, 2005; Gupta, 1991). The growing communities of South Asian immigrants with distinct lifestyle habits in developed countries, coupled with easy access to tobacco products and a lack of awareness,

can contribute to increased oral cancer rates (Ahluwalia, 2005).

Oral cancer ranks among the top three cancers in India, validating it as the highest incident country among South Asian realms (Varshitha, 2015). In addition, lack of compulsory cancer registration in India further aggravates the situation with the lack of reliable incidence data (Varshitha, 2015). Therefore, India being the biggest source country of migration, raises concerns related to oral cancer risk behaviours of Indians in new settlements, which may lead to an increase in oral cancer cases worldwide (Changrani et al., 2006). India is one of the top source countries of immigrants with 21,791 allocated places in Australian immigration in 2020-21 (Department of Home Affairs, 2021). This high influx of Indian immigrants into Australia could be concerning given the high prevalence of oral cancer in India.

### 1.2.4 Role of general practitioners (GPs) in oral cancer prevention

Management of oral diseases and lesions are generally limited to the scope of dental practice (Ramirez et al., 2010), causing the marginalisation of oral health from mainstream healthcare services (Peres et al., 2019). In addition, limited access to affordable oral health care in most regions of the world including developed countries and poor awareness of preventing oral diseases like oral cancer has aggravated the situation (Benzian et al., 2015). Dentists undeniably have a definitive role in oral cancer diagnosis (Applebaum et al., 2009) but expensive dental services makes it difficult for people to visit dentists on a regular basis (Barnett et al., 2016). Thus, to address oral cancer prevention and management, general medical practitioners (GPs) and other non-oral health professionals (e.g., physician assistants, nurses, nurse practitioners) can potentially play a crucial role (Benzian et al., 2015). Adding to this, GPs are often the first point of contact for people in medical need

(Applebaum et al., 2009; Carter & Ogden, 2007), as they are the primary health care providers to access secondary health care services when required (Nicotera et al., 2004).

Early detection of oral cancer is possible by visual and tactile examination (Crossman et al., 2016), as most oral cancers are preceded by clinically-evident oral lesions (Applebaum et al., 2009; Canto et al., 2002). Undertaking this role by GPs is important, as poor prognosis rates for oral cancer are primarily correlated to delayed diagnosis at the advanced stage of disease (Crossman et al., 2016). Routine oral cancer risk assessments, preventative counselling and oral cavity examination by GPs could considerably reduce the morbidity associated with oral cancer (Sarumathi et al., 2013).

Models incorporating GPs to actively engage in oral cancer screening and prevention have been advised. The National Institute for Health and Care Excellence (NICE) in the UK recommends GPs to refer suspected oral cancer patients to cancer specialists in case of a persistent mouth ulcer or lump for three weeks, yet there is a paucity of research evaluating this area (Grafton-Clarke et al., 2019). Prior to this, in 2007, the UK's National Health Service Cancer Reform Strategy (Department of Health, 2007) recommended the implementation of a population-wide screening programme for early diagnosis of oral cancer, which ultimately did not progress as it was not cost-effective (Speight et al., 2006). However, opportunistic screening by primary health care professionals has been encouraged in the UK, based on decision models and research (Wade et al., 2010). Furthermore, as per the Cochrane Collaboration and a European consortium, population-based annual or semi-annual screening for oral cancer is not cost-effective but rather targeting high-risk groups such as

tobacco/alcohol consumers over 40 years of age with opportunistic screening should be promoted in the primary care setting (Webster et al., 2019).

Unfortunately, very little is known regarding oral cancer-related roles, perspectives, and practices of GPs, as most literature has focussed on the awareness of dental professionals regarding oral cancer (Allen et al., 2015; Awan et al., 2014; Carter & Ogden, 2007; Hassona et al., 2015; Patton et al., 2006; Slade et al., 2004; Thacker et al., 2016).

## 1.2.5 Oral cancer in Australia

### *1.2.5.1 Current situation in Australia*

Every year in Australia, more than 4,000 new cases of head, neck and lip cancers are diagnosed and more than 600 of these cancers comprise oral cavity cancers (Australian Institute of Health and Welfare, 2017; Wong & Wiesenfeld, 2018). Lip cancers constitute a considerable share in oral cancers, which were estimated around 652 cases in the year 2017 while the oral cavity cancers were predicted approximately 1629 indicating a substantial increase in tongue cancers (Australian Institute of Health and Welfare, 2022). Oral cancer incidence in Australia has increased and in the year 2009, new cases of oral cavity cancer contributed to 52.3% of all new head and neck cancers diagnosed (Australian Institute of Health and Welfare, 2014). This trend of increase in oral cancer cases has been more visible in last few years (Australian Institute of Health and Welfare, 2022; GLOBOCAN, 2020). Furthermore, despite the fluctuations in the number of oral cancer reports, the overall mortality rate has remained the same in the past decade (Farah et al., 2014), which is more concerning. The rising number of oral cancer cases could be attributed to an upsurge in population due to migration (Australian Institute of Health and Welfare, 2014). Ageing of the general population in Australia could also be a contributing factor as it has been observed

that most of these cases occur among older people (DeAngelis et al., 2018; Murray Thomson, 2014).

### *1.2.5.2 Rising migration and potential effect on oral cancer patterns*

In the last decade, there has been a significant increase in immigrants arriving in Australia from South Asian nations, primarily India, Pakistan, Sri Lanka, and Nepal (Department of Home Affairs, 2019). Among these countries, Indian immigrants have had a marked increase (Department of Immigration and Citizenship, 2011). According to the 2018-19 migration report of Australia, India was the main source country of immigrants with a total of 33,611 people comprising 20.9% of the total intake (Department of Home Affairs, 2019). Indians are one of the fastest-growing communities constituting over 2.6% of the total population in Australia (Australian Bureau of Statistics, 2019). The 2021 census data showed that India was the third largest country of birth for Australian residents (ABC News Australia, 2022).

Since tobacco chewing/smoking along with deleterious consumption of alcohol are strongly responsible for causing oral cancers (Australian Institute of Health and Welfare, 2014), an increase of such cases could be related to increasing number of immigrants in Australia (Department of Home Affairs, 2016). Immigrants often continue to indulge in distinctive oral habits of chewing tobacco and areca (betel) nut use (Australian Dental Association, 2020; Faa, 2020) although no data is currently available to show this connection. Historically, oral cancer has not received much attention in Australia because of its relatively low prevalence. Nonetheless, an increase in new oral cancer cases over recent decades poses a serious health issue highlighting the need for accessible cancer and oral health care services (Australian Institute of Health and Welfare, 2014, 2017).

### *1.2.5.3 Healthcare and cancer services in Australia*

#### *1.2.5.3.1 The Australian Healthcare system*

The healthcare system in Australia is a hybrid model where citizens, permanent residents and refugees can buy private insurance on top of public insurance and gain access to private and/or public hospitals (Willis & Parry, 2012). In 1984, the Australian Government introduced 'Medicare', a mandatory public insurance scheme which provides universal health care coverage to the Australian population (Willis & Parry, 2012). This scheme is financed from tax dollars and has two components—payments to public hospitals through the states/territories, and direct payments to health professionals (Dixit & Sambasivan, 2018). Primary health care is the front line of Australia's health care and is often the first point of contact a person has with the health system (Australian Institute of Health and Welfare, 2020). Health professionals (including GPs, nurses, allied health professionals) deliver primary health care services in a range of settings including community health centres, general practices, and through communication technology (Australian Institute of Health and Welfare, 2020).

General Practitioners are the frontline provider for primary care services, with nearly 43,000 GPs providing services to more than 22 million Australians every year and serving as a gateway to secondary or specialist health services (Royal Australian College of General Practitioners, 2021). Most of the remuneration for GPs comes from fee-for-service, made up of Commonwealth rebates with patient co-payments (Swerissen et al., 2018). The Australian health care system has been reformed over time to address the need for better care, for instance, setting up of Primary Health Networks (PHNs) and implementation of the My Health Record system (Australian National Audit Office, 2019; Department of Health, 2021).

In Australia, PHNs are directed towards increasing the efficiency and effectiveness of primary care services largely provided by GPs, particularly for those at risk of poor health outcomes (Henderson et al., 2018).

*1.2.5.3.2 Oral health and cancer care services in Australia*

Oro-dental health care services in Australia can be accessed privately, or through public dental clinics based on eligibility (Australian Institute of Health and Welfare, 2021). However, dental care is mainly provided by the private sector in the absence of a universal oral health care system, with dental costs partly covered by the Commonwealth Government (Brennan et al., 2008). Australian holders of welfare cards such as a health care card or a member of the defence force are also eligible for government subsidised oral health care services (Brennan et al., 2008). In contrast, private health insurance can cover all or part of the cost of dental services received from private dental practices, depending on the type of policy purchased (Australian Institute of Health and Welfare, 2021). Eligibility criteria for public dental services differ among the Australian states and have several limitations (Australian Institute of Health and Welfare, 2015). These include issues of access to public dental services with the lack of affordability and long waiting times reported as significant barriers (Brennan et al., 2008). In general, Australians face financial barriers in accessing dental services and many individuals directly fund a significant proportion of total expenditure on dental services, estimated at 57% in 2017–18 (Australian Institute of Health and Welfare, 2021). Almost one-fifth of dentate adults aged 15 years and over avoided or delayed dental care owing to cost in 2019–20 (Australian Institute of Health and Welfare, 2021). In the context of waiting times, people can wait up to 12 months or more to receive public dental services (Lalloo & Kroon, 2017). Differences in individual state and territory

oral health care funding, service models and eligibility requirements generally result in varied patterns of dental visiting among Australian residents, leading to variability in observed oral health status (Australian Institute of Health and Welfare, 2021).

Cancer care services in Australia are usually secondary to initial referral undertaken by GPs (Cancer Council, 2021d). After a physical examination to check for any potential signs of cancer, patients are referred for more specific tests or imaging to confirm, then a specialist referral is made depending on the type of cancer (Cancer Council, 2021d). Medicare contributes a certain amount towards the expenses of the tests and treatments, but the difference is paid out of a patient's own pocket until a threshold is met (Cancer Council, 2021a). Likewise, for oral (mouth) cancer, a doctor or dentist is likely to examine the mouth and then patients can be referred to a specialist for additional tests (Cancer Council, 2021b). Unfortunately, there is currently no national screening program for mouth cancer available in Australia and in the case of any concerns about symptoms, one must consult the GP or a dentist (Cancer Council, 2021b). The limited capacity of public dental services to provide care to all eligible Australians and long wait times (Australian Institute of Health and Welfare, 2021) could act as a barrier to access timely dental/oral cavity examinations, which is an essential step in the early identification of oral cancer lesions. Thus, GPs can play a crucial and accessible role in timely diagnosis and referral of oral cancer cases.

The role of the GPs is particularly important given the increase in South Asian immigrants in Australia (Department of Home Affairs, 2019), many of whom do not fully comprehend the concept of screening an otherwise healthy individual for an asymptomatic disease (Auluck et al., 2009). In addition, those engaged in potentially harmful oral habits

are less likely to participate in oral cancer screening initiatives and special efforts may be required to reach immigrants in order to provide education about risk practices, and interventions to help modify such behaviours (Auluck et al., 2009). Unfortunately, there is little data available assessing professional or diagnostic delay and access to health practitioners for oral cancer in the Australian health system (Webster et al., 2019).

## 1.3 Significance and Aims of the Study

Considering the current oral cancer situation and immigration from India, it is important to explore Indian immigrants' oral cancer risk behaviours and related health care practices in Australia while investigating the perspectives of GPs in this area. To date, no such studies have been undertaken in the Australian context and thus gathering this information could provide valuable insights into this under-researched area and inform strategies that could potentially decrease the rates of oral cancer in Australia. The overall aim of this study was to explore oral cancer risk behaviours of Indian immigrants in Australia and identify preventative strategies to raise awareness around oral cancer. The specific objectives are detailed in chapter 4.

## 1.4 Structure of the Thesis

This thesis will follow a series of chapters that will incorporate the related five publications and is consistent with Western Sydney University (WSU) regulations for a Doctor of Philosophy (PhD) by publication. An overview of the thesis structure, the study

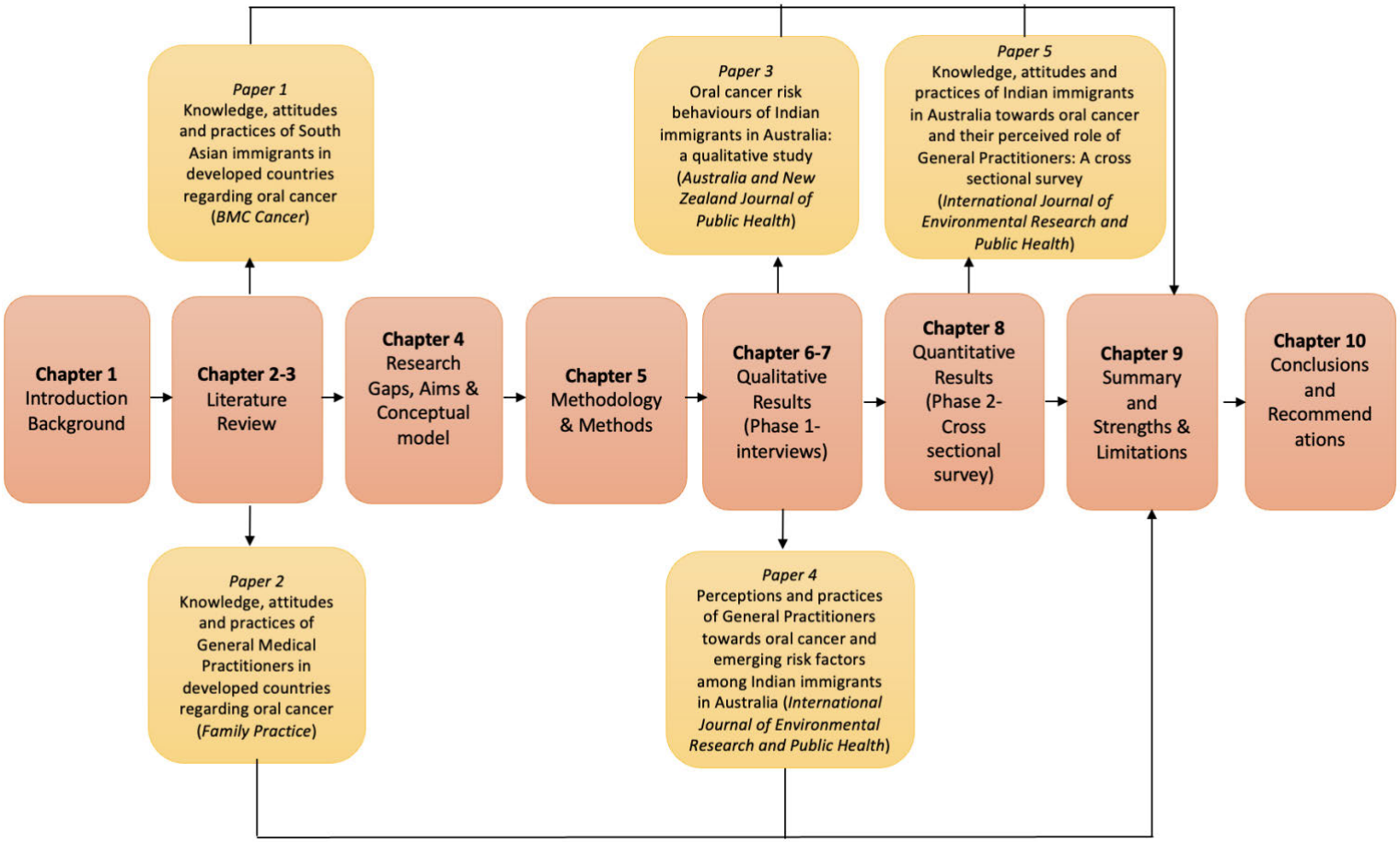
aims and research questions that align with the published results are presented in Figure 1.4.

- Chapter 1 has provided an introduction and overview of the thesis topic. It sets out the background and context underlying the research including the global burden of oral cancer, aetiology and the influence of migration in developed countries, focusing on the Australian setting, current services and preventative strategies.
- Chapters 2 and 3 present the literature reviews for this thesis, highlighting the research gaps and rationale for this study. Chapter 2 is the first part of the review and presents the results of the first publication (Thesis Paper 1) published in the journal BMC Cancer. This was an integrative review exploring global evidence on the oral cancer-related knowledge, attitudes, and practices of South Asian immigrants in developed countries. Chapter 3 comprises the second publication (Thesis Paper 2), published in the journal Family Practice. This integrative review synthesises the global evidence on oral cancer-related knowledge, attitudes, and practices of general practitioners (GPs) in developed countries.
- Chapter 4 provides an overview of the research gaps, study aims, questions and outline of the thesis. This chapter will also discuss the study's conceptual model informing the ALARRM study.
- Chapter 5 details the research methodology and the rationale behind the methods chosen for the research. It then outlines the different phases of the study methods, components of each phase, and information on how the methods were

adjusted to ensure cultural safety while following restrictions relating to the Coronavirus-2019 (COVID-19) pandemic.

- Chapters 6 and 7 present the qualitative findings from the thesis. In Chapter 6 the perspectives of Indian immigrants regarding oral cancer in Australia are presented. These findings are published in the journal Australian and New Zealand Journal of Public Health (Thesis Paper 3). Chapter 7 (Thesis Paper 4) reports the knowledge, attitudes and practices of general practitioners relating to oral cancer in Australia and is published in the International Journal of Environmental Research and Public Health.
- Chapter 8 presents the quantitative findings from the survey of Indian immigrants in Australia. These findings have been published in the International Journal of Environmental Research and Public Health (Thesis Paper 5) and present the self-reported oral cancer knowledge, attitudes, and practices of Indian immigrants in Australia and perceived barriers and facilitators in accessing preventative strategies.
- Chapter 9 integrates the study findings from Papers 1-5 and provides a comprehensive summary of the findings in light of the current evidence. This chapter also discusses the strengths and limitations of the study.
- Chapter 10 presents the conclusion and recommendations for practice, policy, and research to inform future preventative strategies to raise oral cancer awareness among Indian immigrants in Australia.

***Figure 1.4*** *Thesis Outline*



## 1.5 Conclusion

This chapter has provided the background to the study comprising the description of oral cancer disease, its geographical distribution, aetiology, and contributing factors including the potential impact of migration trends on prevalence rates, particularly in developed countries. The chapter also highlighted an overview of the current oral cancer situation in Australia and the challenges in accessing health and dental care services. In addition, the thesis structure, research aim, and objectives were provided.

The next two chapters (Chapters 2 and 3) are literature reviews which synthesise current global evidence on oral cancer-related knowledge, attitudes, and practices of Indian immigrants and GPs in developed countries.

# Chapter 2: Literature Review

## (Integrative review)

## 2.1 Overview: Thesis Paper 1

The previous chapter provided an overview of oral cancer, its distribution and the changing oral cancer patterns. This chapter includes the findings of an integrative review to synthesise the global evidence on oral cancer-related knowledge, attitudes, and practices of South Asian immigrants in developed countries. The results are published in the journal BMC Cancer:

Saraswat, N., Pillay, R., Everett, B., George, A. (2020). Knowledge, attitudes, and practices of South Asian immigrants in developed countries regarding oral cancer: an integrative review. *BMC Cancer*, *20*(1), 1-16. doi: https://doi.org/10.1186/s12885-020-06944-9

## 2.2 Aim: Thesis Paper 1

The aim of the paper was to review current evidence on the knowledge, attitudes, and practices of South Asian immigrants in developed countries regarding oral cancer.

## 2.3 Conclusion: Thesis Paper 1

This review confirmed that South Asians in developed countries lack sufficient knowledge about oral cancer, possess negative attitudes towards oral cancer risk and are strongly inclined towards engaging in oral cancer risk-enhancing practices. The review also suggests these immigrants are ill-informed about the health risk associated with tobacco and areca nut usage. Primary care providers can play a crucial role in promoting oral cancer awareness among migrant communities. The next chapter presents the results from a second integrative review focussing on the perceptions and practices of GPs in this area.

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BMC Cancer

RESEARCH ARTICLE Open Access

# Knowledge, attitudes and practices of South Asian immigrants in developed countries regarding oral cancer: an integrative review

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## Abstract

**Background:** Oral cancer is a growing problem worldwide, with high incidence rates in South Asian countries. With increasing numbers of South Asian immigrants in developed countries, a possible rise in oral cancer cases is expected given the high prevalence in their source countries and the continued oral cancer risk behaviours of immigrants. The aim of this review is to synthesise existing evidence regarding knowledge, attitudes and practices of South Asian immigrants in developed countries regarding oral cancer.

**Methods:** Five electronic databases were systematically searched to identify original, English language articles focussing on oral cancer risk knowledge, attitudes and practices of South Asian immigrants in developed countries. All studies that met the following inclusion criteria were included: conducted among South Asian immigrants in developed countries; explored at least one study outcome (knowledge or attitudes or practices); used either qualitative, quantitative or mixed methods. No restrictions were placed on the publication date, quality and setting of the study.

**Results:** A total of 16 studies involving 4772 participants were reviewed. These studies were mainly conducted in the USA, UK, Italy and New Zealand between 1994 and 2018. Findings were categorised into themes of oral cancer knowledge, attitudes and practices. General lack of oral cancer risk knowledge (43–76%) among participants was reported. More than 50% people were found engaging in one or more oral cancer risk practices like smoking, betel quid/pan/gutka chewing. Some of the participants perceived betel quid/pan/gutka chewing habit good for their health (12–43.6%).

**Conclusion:** This review has shown that oral cancer risk practices are prevalent among South Asian immigrants who possess limited knowledge and unfavourable attitude in this area. Culturally appropriate targeted interventions and strategies are needed to raise oral cancer awareness among South Asian communities in developed countries.

**Keywords:** Oral cancer, South Asians, Immigrants, Knowledge, Attitudes, Practices, Integrative review

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## Background

Oral cancer - a highly morbid disease which has become a serious public health concern [1]. It is defined as cancer that forms in the tissues of the oral cavity or the oropharynx [2] and often involves pain, impaired function, altered quality of life and death [3]. Oral cancer is one of the most common cancers globally [1, 4], and is estimated to have an annual incidence of approximately 300,000 cases worldwide [1, 5, 6]. In 2018, cancers of the lip and oral cavity were collectively estimated at 354,864 new cases with deaths reaching 177,384 worldwide [1].

There is a wide geographical variation in the incidence of oral cancer with the highest rates in South and South-East Asia [5, 6]. In particular, countries of South Asia such as India, Bangladesh, Pakistan, and Sri Lanka are considered high risk for oral cancer [6, 7]. According to the World Health Organisation (WHO), these countries have been estimated to contribute nearly 40% of newly diagnosed oral cancer cases worldwide [1, 8]. The oral cancer prevalence rates in these countries are almost twice global rates [5, 6].

Oral cancer is a multi-factorial disease linked with several risk factors and potential causative agents including consumption of tobacco and alcohol, betel quid chewing, human papilloma virus, syphilis, candidiasis, dietary deficiency, and dental trauma [4, 9, 10]. The predominance of oral cancer in South Asia is mainly attributed to the use of tobacco products like bidis, smokeless tobacco, and culturally embedded use of areca nut which is utilised in different commercial preparations [3, 9, 11]. The areca nut, is the dried seed of *Areca catechu*, often mistakenly referred to as the betel nut as it is commonly chewed along with the *Piper betel* leaf [12]. Chronic use of areca nut (with or without tobacco) in South Asian countries is based on several foundation concepts like social acceptability, religious beliefs and perceived advantages [3, 13]. However, areca nut is believed to be one of the most commonly consumed psychoactive substance [14] and has been shown to have carcinogenic potential which increases when mixed with tobacco [9]. Furthermore, the practice of areca nut chewing in any form often leads to addiction and may persist as a lifelong habit [13].

People from Afghanistan, Bangladesh, Bhutan, India, the Maldives, Nepal, Pakistan and Sri Lanka (collectively known as South Asians) comprise one quarter of the world's population and are one of the fastest growing ethnic groups in many developed countries including the United States of America [15] Canada [16], the United Kingdom [17] and Australia [18]. For several years India has been the largest source of international migrants among South Asian countries, with 17 million migrating in 2017 [19]. Bangladesh (7 million) and Pakistan (6 million) ranked 5th and 7th respectively in terms of largest country of origin of international migrants [19].

With increasing South Asian immigrants in developed countries, a possible rise in oral cancer cases could be expected given the high prevalence in their source countries [1]. As immigrants are believed to bring with them their native cultural behaviours, practices, and beliefs [3, 13], this can modify the patterns of oral diseases in destination countries too [13]. Previous literature [13, 20–22] has described typical lifestyles of immigrants in developed countries and its relevance to oral cancer incidence in their native nations. Although several studies have explored oral cancer risk behaviours of South Asian immigrants across various developed countries [20, 21, 23–28], a synthesis of these results has not yet been conducted. Gathering this information will help to inform health service planning and the need for educational and early oral cancer risk assessments in this population.

Aim- The aim of this integrative review is to synthesise all available evidence regarding the knowledge, attitudes and practices of South Asian immigrants in relation to oral cancer in developed countries.

## Methods

This study used the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) statement [29, 30] for reporting the findings from this integrative review. The protocol for this integrative review was registered with PROSPERO-International prospective register of systematic reviews (registration ID: CRD42019121410). The decision to do an integrative review [31, 32] was taken to have potential insights into qualitative, quantitative and mixed method studies.

### Inclusion and exclusion criteria

All studies included in this review met the following inclusion criteria: 1) Peer reviewed English language publications; 2) conducted on South Asian immigrant population in developed and High-income countries; and 3) explored at least one study outcome (knowledge, attitudes or practices associated with oral cancer risk). Since very little is known in this area; qualitative, quantitative and mixed method studies were eligible for inclusion in the review. Interventional studies with a pre-intervention survey component were also included. Further, no restrictions were placed on the year of publication, quality, and setting of the study.

### Data sources and search strategy

The first author worked closely with an experienced healthcare librarian to develop the search strategy which was undertaken using a combination of key words and search terms including: "oral cancer", "oropharyngeal cancer", "oropharyngeal neoplasm", "oropharyngeal tumour", "mouth neoplasms", "mouth cancer", "oral tumours", India*, Pakistan*, Nepal*, Sri Lanka*, Bangladesh*, "south

Asian", "Asian", immig*, and "immigrants" (see Additional file 1 for search terms/strategy for databases). Databases searched included Ovid-Medline, Embase, CINAHL, Scopus, and ProQuest Central. Individual search strategies were used considering the database specific indexing terms.

The search terms were used in combination using 'Boolean' operators (AND/OR) and MeSH (Medical Subject Heading) terms. The filter applied in the search included language (English). In addition, another experienced university librarian was consulted to ensure the appropriateness and relevance of the individual search strategies.

A final search was carried out in April 2020 to ensure inclusion of the most recent literature in this review. The reference lists of all relevant studies were also searched for additional studies.

### Article selection and screening

The search results were organised using the EndNote® bibliographic software. The title and abstract of the remaining studies were assessed by two experienced authors [NS and RP] for suitability using the inclusion and exclusion criteria. Full text articles were obtained in case of difficulty regarding decision making on the basis of title and abstract only. The full text articles were reviewed by two authors [NS and RP] independently, and then together if there was a doubt or discrepancy (see Additional file 2 for full text screening of articles). A third author [AG] was consulted to resolve any further discrepancies in judgement to assist with a final decision on inclusion or exclusion of the article. The search and selection process are illustrated in Fig. 1 (see Fig. 1 for study selection process).

### Quality assessment

The critical appraisal for selected articles was undertaken by two independent reviewers (RP and NS) to assess the methodological quality. For the quality assessment, two separate checklists were used- Critical Appraisal Skills Programme (CASP) checklist for Qualitative studies [33] and the Joanna Briggs Institute (JBI) checklist for Quantitative studies [34] (See Additional files 3 and 4). A third reviewer (AG) was consulted to reconcile any discrepancies in the quality assessments. The quality of these studies was calculated using a scoring criteria [35]. According to this criteria, score was given as a percentage (1 point for each applicable item) and the overall quality was rated as good (80–100%), fair (50–79%), and poor (< 50%) [35].

### Data extraction and synthesis

Since both the qualitative and quantitative studies were to be included in the review, the decision was made to do a narrative synthesis in line with the guidance provided by Popay et al. [36]. The aim of narrative synthesis is to "tell the story" from the findings from the included studies, whether they are qualitative, quantitative or mixed methods [36].

Subsequently, the data extraction tables were developed and piloted independently by two authors (NS and RP) and modified as required (Table 1 and Table 2). The information extracted in these tables included author, year of publication, country, study characteristics and key outcomes. Data were extracted by one author (NS) and checked by two authors (RP and AG) for accuracy. A systematic review and meta-analysis of quantitative studies was not feasible due to the heterogeneity of the studies in relation to their approaches to measuring and reporting the knowledge, attitudes, and practices of South Asian immigrants regarding oral cancer risk.

### Definition of terms

For the purpose of this review, high-income countries with developed economies such as the United States of America, the United Kingdom, Canada, Australia, New Zealand have been referred to as 'developed countries' [45]. The terms 'knowledge', 'attitudes' and 'practices' have been used widely in this paper. The 'Knowledge' is the capacity to acquire, retain and use information; a mixture of comprehension, experience, discernment, and skill [46]. The 'Attitudes' refer to inclinations to react in a certain way to certain situations; to see and interpret events according to certain situations; to see and interpret events according to certain predispositions, or to organize opinions into coherent and interrelated structures [46]. The 'Practices' is the application of rules and knowledge that leads to action [46]. For the purpose of this paper; the terms of knowledge, attitudes and practices have been refined in relation to oral cancer risk. The term 'knowledge' in this paper refers to one's awareness, level of information and understanding regarding the oral cancer risk. The term 'attitudes' has been used here to depict the inclinations, perceptions, and beliefs of the people associated with oral cancer risk. The term 'practices' here relates to a person's oral cancer risk related habits and the actions regarding initiation, continuation or quitting of these habits.

## Results

### Study selection summary

The search of databases identified 162 records; 41 were duplicates and subsequently removed. A further 7 articles were found through a manual search of reference lists of identified studies which resulted in a total of 128 articles. The process of initial screening based on title and abstract resulted in the exclusion of 94 articles, leaving 34 for full-text screening. After full-text review, a further 18 articles were excluded as they were literature reviews ($n = 5$) and a case report ($n = 1$), did

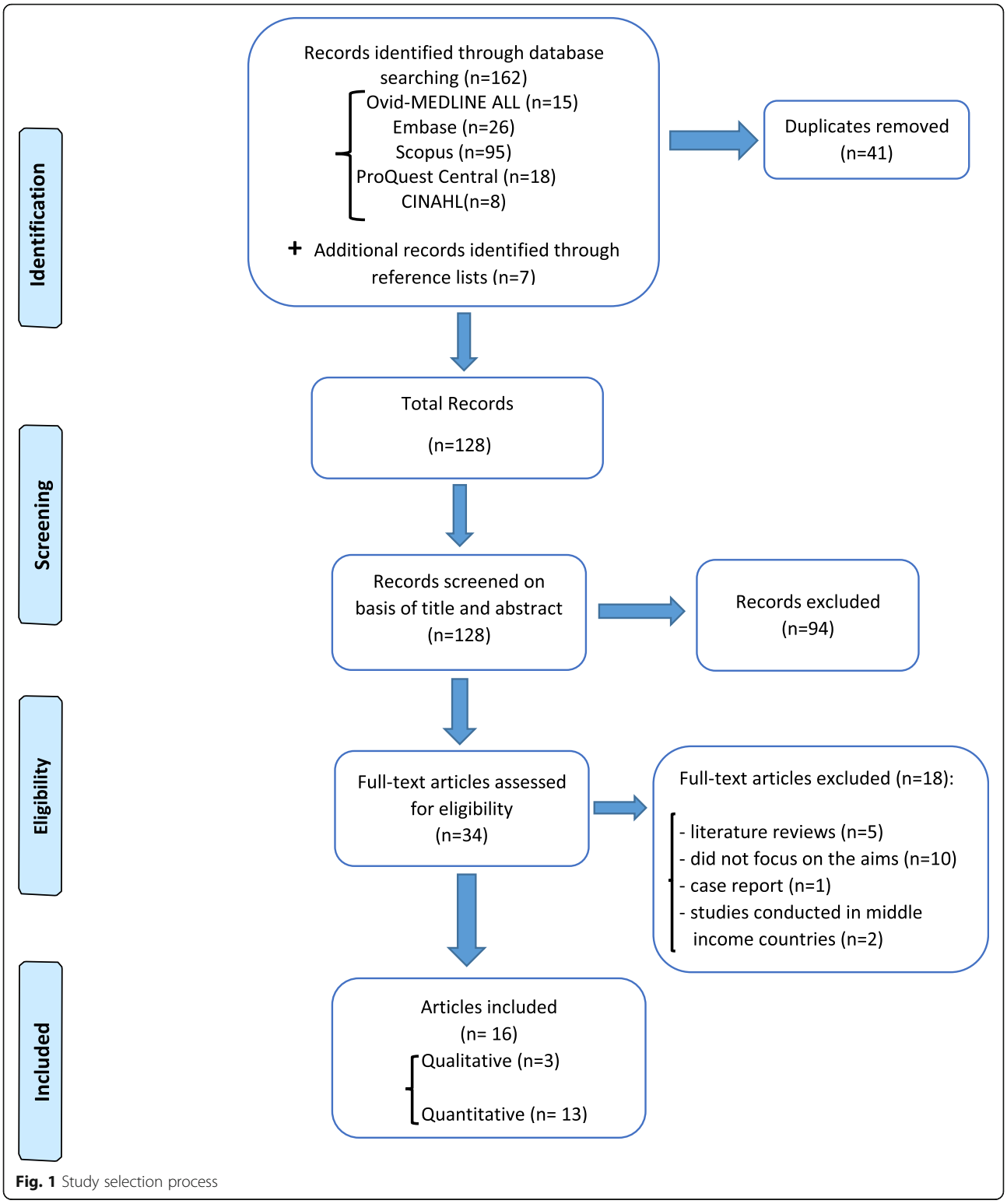


**Fig. 1** Study selection process

not focus specifically on oral cancer-related knowledge, attitudes and practices ($n = 10$), and were conducted in upper middle income countries ($n = 2$) (See Additional file 5 for Table of excluded studies). This resulted in 16 studies for inclusion in this review; three were qualitative [20, 22, 42] and 13 were quantitative [21, 24–28, 37–41, 43, 44]. (See Fig. 1 for the study selection process).

**Table 1** Study characteristics

| S.No. | Author Year of publication | Country | Methodology Data collection method | Sample characteristics | | | | | Response (rate %) |
|---|---|---|---|---|---|---|---|---|---|
| | | | | Sample size | Ethnic group | Gender (%) | Socio-economic status (as reported in study) | Age range (years) | |
| 1 | Summers et al. 1994 [37] | UK | Quantitative home-based structured interviews | 296 | Bangladeshi | F = 100 M = 0 | Low | 25–68 | 98.6 |
| 2 | Pearson et al. 1999 [38] | UK | Quantitative Questionnaire | 158 | Bangladeshi | F = 42 M = 58 | NR[a] | 40–83 | 85 |
| 3 | Shetty et al. 1999 [27] | UK | Quantitative Questionnaire | 367 | South Asians (Indian, Pakistani, Bangladeshi etc.)- percentage not reported clearly | M = 56.1 | Low-middle | 16–65 | NR |
| 4 | Khan et al. 2000 [39] | UK | Quantitative Questionnaire | 390 | Indian (21.5%), Pakistani (4.3%), Bangladeshi (9.2%) | F = 83.8 M = 16.2 | Low-middle | > 16 (Median age = 44) | NR |
| 5 | Vora et al. 2000 [28] | UK | Quantitative Questionnaire | 524 | South Asians (Indian, Pakistani, Bangladeshi, Sri Lankan)- percentage not reported | M = 100 F = 0 | Low | 16–87 | NR |
| 6 | Prabhu et al. 2001 [26] | UK | Quantitative Questionnaire | 204 | Bangladeshi | M = 51.5 | Low | 12–18 | 70.0 |
| 7 | Changrani et al. 2006 [21] | USA | Pilot study (quantitative) Questionnaire | 138 | Indian (30.4%) Bangladeshi (69.5%) | M = 55.79 | Low-middle | > 18 | 96 |
| 8 | Croucher et al.2011 [40] | UK | Quantitative Structured interviews | 369 | Bangladeshi | M = F | NR | > 30 | 77 |
| 9 | Siddique et al. 2013 [41] | UK | Quantitative Questionnaire | 96 | Indian-Gujarati | M = 53.1 | NR | 16–81 | 100 |
| 10 | Lokhande et al. 2013 [22] | New Zealand | Qualitative Semi-structured interview | 10 | South Asians (Indian = 90%, Pakistani = 10%) | M = 100 F = 0 | NR | 18–67 | NR |
| 11 | Banerjee et al. 2014 [23] | USA | Qualitative 6 Focus groups | 39 | Indian(38.5%), Pakistani(28.2%), Bangladeshi(33.3%) | M = 87.2 F = 12.8 | NR | 25–71 | NR |
| 12 | Hrywna et al. 2016 [42] | USA | Qualitative 8 Focus groups | 78 | South Asians (Indian = 83.3%), | M = 60.3 | NR | 18–67 | NR |
| 13 | Merchant et al. 2016 [24] | UK | Quantitative Questionnaire | 201 | South Asians (Indian = 77%, Pakistani = 16%, Bangladeshi, Sri Lankan, Malaysian-Indian) | M = 61 | NR | 18–44 | NR |
| 14 | Shi et al. 2017 [43] | USA | Quantitative Questionnaire | 73 | South Asian (12.3%) Rest (Other countries) | M = 50.7 F = 49.3 | NR | 37.67 | 54.8 |
| 15 | Mukherjea et al. 2018 [44] | USA | Quantitative (2004 CAITUS survey data) | 1618 | Asian Indians In California | NR | Middle | > 18 | NR |
| 16 | Petti et al. 2018 [25] | Italy | Quantitative Interviews using questionnaire | 211 | South Asians (Indian = 17.5%, Pakistani = 40.3%, Bangladeshi = 26.1%, Sri Lankan = 16.1%) | M = 100 F = 0 | NR | 18–73 | 72 |

[a]*NR* = Not Reported

**Table 2** Study findings and quality rating

| S.N. | Author<br>Year of Publication<br>Study design | Findings | | | Quality Rating (scores in %) |
|---|---|---|---|---|---|
| | | ***Knowledge*** | ***Attitudes*** | ***Practices*** | |
| 1 | Summers et al. 1994 [37]<br>Cross sectional study | • 62% perceived pan chewing practice as good, 20% as bad, 13% 'neither good nor bad' and 5% 'did not know"<br>• Participants frequently unaware of their oral condition as well as the harmful effects of Pan | • 4% stated that pan chewing was just a habit and 22% claimed that it was pleasant and refreshing.<br>• 12% claimed that it was good for teeth and gums. 11% thought it "aided digestion" and 6% considered that it relieved pain and had an anti-inflammatory effect.<br>• Believed that it made lips attractive (red)<br>• Pan used in Social gatherings, auspicious occasions and etiquette. | • > 16 quid daily use among heavy pan chewers<br>• Tobacco was employed in smoking, pan chewing and for oral hygiene purposes<br>• 59% women claimed that they spat pan out after finishing chewing pan, 24% swallowed it, 17% stored it in buccal sulcus and 3% were in habit of sleeping with quid in their mouth.<br>• The mean age of onset 17 years, but 51% were started at age of 10 years.<br>• 58% never had dental visits. | B (62.5) |
| 2 | Pearson et al. 1999 [38]<br>Cross sectional study | • 43% of participants did not know that pan chewing habit could be bad for health.<br>• More females (49%) than males (38%) were unaware of the harmful effects of pan chewing. | • 23% believed pan chewing habit was good for the health- relieves pain, aids in digestion, freshens mouth and keeps teeth strong.<br>• Females were less likely than males to feel that regular check-ups are important.<br>• Barriers to use of dental services included language, cost and fear (21%)<br>• 64% indicated preference for GP over dentist regarding check-up of mouth ulcer.<br>39% expressed the wish to learn more about oral healthcare. | • 78% reported habit of pan chewing and half of them developed it by the age of 17.<br>• 14% reported addiction to pan chewing habit.<br>• 33% were tobacco smokers and 64% of them started this habit before the age of 21.<br>• 71% of smokers also chewed pan.<br>• 25% never visited a dentist. | B (75) |
| 3 | Shetty et al. 1999 [27]<br>Cross sectional study | • 42% of respondents could not identify early sign of Oral Cancer.<br>• > 50% were not aware of sites of mouth prone for Oral Cancer.<br>• 80% indicated smoking as a possible risk factor for oral cancer.<br>• Misconceptions about the causes of oral cancer such as use of oral contraceptives, removal of teeth and eating sugary food. | | • Significant difference seen in Betel quid chewing habit among age groups (42.2% of adults in 50–80-year age group practicing this habit as compared to only 5.3%in 16–29-year age group.<br>• Traditional method of betel quid chewing is being replaced with readily processed areca nut and tobacco products. | B (62.5) |
| 4 | Khan et al. 2000 [39]<br>Cross sectional study | | | • Tobacco chewing habit was found common amongst Bangladeshis (approx. 50%), Indians (> 40%), and Pakistanis (> 20%).<br>• Only 3% of Bangladeshis and Pakistanis reported habit of drinking | B (50) |

**Table 2** Study findings and quality rating *(Continued)*

| S.N. | Author<br>Year of Publication<br>Study design | Findings | | | Quality Rating (scores in %) |
|---|---|---|---|---|---|
| | | ***Knowledge*** | ***Attitudes*** | ***Practices*** | |
| | | | | alcohol while > 20% of Indians were engaged in this habit.<br>• Indians educated beyond the age of 16 years were more likely to chew products containing tobacco.<br>• Less educated Bangladeshis were more engaged in practice of chewing tobacco.<br>• Smoking habits were found less common in Indians (< 10%) and Pakistanis (< 10%) as compared to Bangladeshis (approx.20%). | |
| 5 | Vora et al. 2000 [28]<br>Cross sectional study | • 78% of Sikh males did not know about oral cancer<br>• 10% recognized alcohol as a risk factor for oral cancer<br>• Major sources of knowledge included school/college education, the press and media, and health education leaflets | | • The chewing of pan is prevalent among 2nd generation Hindus, Muslims and Jains but low usage was observed among Sikhs.<br>• Sikh males tend to drink alcohol more, whereas Muslim males use tobacco and chew pan | B (62.5) |
| 6 | Prabhu et al. 2001 [26]<br>Cross sectional study | • Only few knew about association of pan chewing and oral cancer.<br>• Majority of teenagers have not identified with this cultural norm even if their parents were regular betel quid chewers. | • Many from lower socio-economic status and less inclined to think that it could cause cancer.<br>• More likely to agree that pan tasted good.<br>• Tended to think it made their teeth and gums stronger | • Median age of first chewing - 9 years<br>• Similar proportions of adolescent males and females chewed pan<br>• 28% chewed Pan & 51% of whom chewed on most days | B (62.5) |
| 7 | Changrani et al. 2006 [21]<br>Piot study | • Bangladeshis more likely to identify pan as a cause of oral cancer than Indians (66% vs 48%)<br>• Indians identified gutka as a cause of oral cancer more correctly than Bangladeshi (93% vs 60%) | • Health benefits of pan were cited as "relieves constipation," "improves stamina," "fights cold," relieving tension, and for mood improvement.<br>• Pan also believed to cause harms like cancer, dental problems, ulcers, addiction, and hypertension | • The communities migrated with pan and gutka use habits<br>• Pan was popular in Bangladeshis while gutkha use considerably limited. | B (50) |
| 8 | Croucher et al. 2011 [40]<br>Cross sectional study | • Superior oral cancer knowledge following campaign awareness.<br>• Younger male respondents with some completed education more likely to be aware of oral cancer | | • Limited dental attendance as compared to medical visits | B (75) |
| 9 | Siddique et al. 2013 [41]<br>Pre and Post intervention study | Gutka was the most correctly identified risk factor among first | | • First generation Gujarati Muslim males had the | B (62.5) |

**Table 2** Study findings and quality rating *(Continued)*

| S.N. | Author<br>Year of Publication<br>Study design | Findings | | | Quality Rating (scores in %) |
|---|---|---|---|---|---|
| | | ***Knowledge*** | ***Attitudes*** | ***Practices*** | |
| | | generation females (50%) and second-generation males and females (63 and 69% respectively). | | highest proportion of regular supari users (33%), greater than their female counterparts (12%)<br>• Complete absence of regular gutka use in Gujarati Muslims except among first generation males (42%) | |
| 10 | Lokhande et al. 2013 [22]<br>Grounded theory case study | • Mixed understanding about harmful effects of chewing tobacco.<br>• More knowledge about ill effects of smoking. | • Flavoured gutka for "fresh breath"<br>• Find chewing mentally stimulating, gives pleasure, improved their mood and helped them relax<br>• Get the supply from friends of India or Fiji due to ban in New Zealand<br>• Cultural norms as barrier to cease tobacco chewing | • Gutka was preferred choice for chewing tobacco.<br>• Use ranged from twice a day to 12 times a day<br>• Daily use ranged from twice a day to 12 times a day | A (88.8) |
| 11 | Banerjee et al. 2014 [23]<br>Focus group study | • Acknowledgment of a ddiction<br>• Scepticism about the pan-cancer link | • Compensatory beliefs<br>• SATP believed to relieve boredom, aid in digestion after meals, reduce stress, and to increase alertness<br>• Encouraged by pleasant sensations of smell, taste and cosmetic benefits | • Early age initiation<br>• Easy availability<br>• Habit inherited from generations<br>• Changed patterns of gutka/ tambaku pan use behaviour after immigration | A (88.8) |
| 12 | Merchant et al. 2016 [24]<br>Cross sectional study | • Pakistani and Bangladeshi more likely to have low knowledge as compared to Indians.<br>• Followers of Islam were found low knowledge than Hindus.<br>• Males, and the better educated, more likely to report risk factors for oral cancer | | • 42% of total subjects used tobacco, Gutka or Pan in combination with alcohol; while 41% people stated habit of Smoking and 5% reported tobacco chewing habit.<br>• Participants of Indian or Sri Lankan ethnic origin were more likely to consume alcohol than those of Pakistani, Bangladeshi or Malaysian-Indian origin.<br>• Rare dental visits reported | B (50) |
| 13 | Hrywna et al. 2016 [42]<br>Focus group study | • Variety of opinions about the classification of SATP<br>• Awareness about health risks regarding use of tobacco products | • Use of SATP common at social gatherings or after meals.<br>• Perceived benefits with use of SATP like stress relief, relaxation, relieving boredom, mouth cleanse and as an aid for digestion. | • > 70% reported having tried at least one SATP and more than half (51.5%) currently use a SATP.<br>• Native born older males described gutkha as the most common SATP while native born older females described pan/pan masala as the most popular products | B (77.7) |
| 14 | Shi et al. 2017 [43]<br>Pre and Post intervention study | • 52.3% believed AN alone could cause cancer<br>• Overall low understanding of AN's carcinogenic | • Perceived harms like addiction, kidney stones and thinning of blood | • 64.6% used AN<br>• 8.2% reported social use<br>• 28.6% reported usage during celebrations only, and 28.6% | C (37.5) |

**Table 2** Study findings and quality rating *(Continued)*

| S.N. | Author<br>Year of Publication<br>Study design | Findings | | | Quality Rating (scores in %) |
|---|---|---|---|---|---|
| | | ***Knowledge*** | ***Attitudes*** | ***Practices*** | |
| | | properties | | reported daily use. | |
| 15 | Mukherjea et al. 2018 [44]<br>Based on old CAITUS cross sectional study | | | • Integral religious practices with CST use<br>• The prevalence of current CST use was 13.0% (14.0% for men and 11.8% for women).<br>• More CST use was reported by AIs who had a college degree or higher level of education, were born in India, and were practicing Hinduism. | C (37.5) |
| 16 | Petti et al. 2018 [25]<br>Cross sectional study | • knowledge about oral carcinogenicity of BQ was lower among chewers (41.2% vs 46.6%).<br>• Lack of awareness toward oral cancer and other BQ chewing-related diseases. | • Significantly associated attitudes were being a routine smoker, being born to parents who were also chewers, the perception that chewing is good for health (43.6%) and that it helps to relieve stress.<br>• two- thirds believed that pan chewing helps to relieve stress, while 17% stated that it led to stress relief | • The high BQ chewing prevalence rate (40%) in immigrants from the Asia / Indian subcontinent reported<br>• BQ usage, along with smoking and tobacco chewing, as an integral part of the lifestyle of these people before and after migration | B (75) |

*SATP* South Asian Tobacco products, *AN* Areca Nut, *BQ* Betel Quid, *AI* Asian Indians, *CST* Cultural Smokeless Tobacco
A = all or most of the criteria have been fulfilled (a score of 80–100%); B = some of the criteria have been fulfilled (50–79%); and C = few or none of the criteria have been fulfilled (< 50%)

### Study characteristics

The 16 studies included in this review were published between 1994 and 2018 and were conducted across four countries namely, United Kingdom (UK; $n = 9$), United States of America (USA; $n = 5$), Italy ($n = 1$), New Zealand (NZ; $n = 1$). Table 1 shows the salient features of the studies included in this review. The sample size (see Table 1 for study characteristics) of the studies ranged from 10 to 1618 participants with a total of 4772 in number. Participants were immigrants mainly from India, Pakistan and Bangladesh and consisted of first to third generations. The age of the participants ranged from 12 to 87 years and consisted of mostly males [20–22, 24–28, 38, 43]. Nine of the studies addressed all the themes of the oral cancer risk-related knowledge, attitudes and practices among South Asians in developed countries [21, 24–28, 37, 38, 43]. One quantitative study [25] mentioned use of validated questionnaire while five other quantitative studies [26, 27, 37–39] reported use of previously pilot-tested survey.

### Quality of the included studies

The quality of the studies was rated as good ($n = 2$) (score ≥ 80), fair ($n = 12$) (score 50–79%) and poor ($n = 2$) (score < 50%) (see Table 2 for study findings and quality rating). Due to limited available literature in this area, all the studies were included in this review irrespective of their quality, to allow the reader to make their own judgement.

(see Additional file 6 for critical appraisal of articles)

### Study findings

The findings of this review were categorised under themes of Oral cancer knowledge, Oral cancer attitudes and Oral cancer practices which are explained below:

### Theme 1: Oral cancer knowledge

Fourteen studies [20–22, 24–28, 37, 38, 40–43] explored the knowledge of South Asian immigrants regarding the oral cancer risk. These studies assessed the level of information as well as awareness of the participants in relation to the risk of oral cancer associated with the consumption of alcohol, tobacco and areca nut preparations. Most of the studies reported a general lack of knowledge (43–76%) regarding oral cancer risk across respondents from South Asian subgroups irrespective of the native country, age, gender and social class [21, 25–28, 37, 38, 40]. Few studies though did find an association between knowledge levels and religion/ethnicity. Pakistanis (69%) and Bangladeshis (85%) were reported having 'low knowledge' of oral cancer risk when compared to those of Indian (47%) ethnicity [24]. However, Bangladeshi immigrants (66%) were found more likely to identify 'pan' as a possible cause of oral cancer than Indian-Gujarati (48%) immigrants in the USA [21]. The adequate knowledge regarding oral cancer risk was also associated with religion, as Sikh participants were found less aware of oral cancer risk factors when compared to Muslim and Hindu participants [24, 28].

According to Shetty et al. there were many misconceptions among participants regarding possible causes of oral cancer including the use of oral contraceptives, removal of teeth and eating sugary food [27]. In contrast, a few studies did show that participants had knowledge (58–69%) about one or more risk factors responsible for causing oral cancer like smoking, alcohol use and gutka chewing [24, 41, 43]. This information was more common among more educated and second-generation individuals especially males [24, 38, 41, 43]. Sources of knowledge among participants included school/college education, press or media, relatives (27–43%), health education leaflets/awareness campaigns (24–57%), dentists (16–33%) [28, 40, 41].

Four studies also showed that even if respondents were aware of the harmful effects of chewing tobacco and alcohol use, there was scepticism regarding the association of pan/gutka with oral cancer [20, 22, 25, 42]. Similar qualitative findings were reported by Lokhande et al. [22], Hrywna et al. [42] and Banerjee et al. [20] as they found mixed understandings prevalent among participants regarding oral cancer risk:

> "*There is a mixture of happiness and sadness, but I sometimes feel sad and very low.. . I think there is "100% health risk" to chew tobacco which can cause mouth disease.*"(page 48) [22].

> *"I think supari is the most popular, that's not on the [survey] …. When I was younger I never even knew it was tobacco … I might have even put one in my mouth because I didn't know. It didn't even taste that bad from my memory. I would say supari and gutkha."* (page 5) [42].

### Theme 2: Oral cancer attitudes

The attitudes of South Asian immigrants towards oral cancer risk were reported in nine studies [20–22, 24–28, 37, 38, 40–44]. The relevant attitude items mainly were related to beliefs regarding the association of risk products with oral cancer, perceived benefits as well as harms of oral cancer risk practices and the context of the use of these risk substances. Some of the studies highlighted that the overall attitude of participants towards oral cancer risk was negative and unfavourable [25, 26, 37]. Poor beliefs were reported among participants (17–41%) regarding preventive health behaviours and modification of risk practices [24, 26, 27, 37, 38]. One study in UK involving Bangladeshi migrants found females were less

likely than males to regard regular dental check-ups as important for a healthy mouth [38].

Four studies [25, 26, 37, 38] found that people perceived betel quid/pan/gutka chewing habit good for their health (12–43.6%) which makes 'teeth and gum stronger' and believed that it helps them to reduce stress (11.6–51%), relieve boredom with refreshing feeling (22–44%). These findings were reiterated by participants in the qualitative studies by Hrywna et al. [42] and Banerjee et al. [20]:

> *"It has benefit; it can be therapeutic too sometimes,"* (page 7) [42].

> *"And there are people who feel good; they think it releases tension/worries. So sometimes I think that having a little can cool your mood if you are feeling angry or annoyed."* (page 535) [20].

Other specific health benefits of betel quid/pan/gutka perceived by participants included aiding in digestion (11–33.6%) and pain relief (6–34.1%) [21, 25, 26, 37, 38]. Furthermore, some studies found that use of pan/gutka was also encouraged among South Asians due to its fragrant smell (12.6%) [26], pleasant taste (35–37.4%) [25, 26, 37, 43] and cosmetically appealing red staining on lips [26, 37]. Some people were found consuming areca nut preparations just out of habit and for refreshment (3.3 to 42.7%) [25, 26, 37, 43]. Furthermore, such risk habits were found more popular among people from lower socio-economic status, who were less inclined to think about oral cancer risk associated with these products [21, 25, 26, 37].

Similar views were highlighted in the qualitative studies [20, 42]:

> *"I find the smell of it very pleasant when I chew it. When someone else eats, I am attracted to the smell. That's why I eat it."* (page 535) [20].

> *"To feel good or get a buzz. I'm sure that's why people use it."* (page 7) [42].

Respondents perceived few harms associated with areca nut products like dental problems, chest pain, hypertension and kidney stones [27, 43].

Some studies revealed wide cultural acceptability of areca nut products during festivals celebrations and special occasions (7.1–18.2%) [24, 25, 43]. The use of tobacco-related products such as hookah, pan, and supari were found common at social gatherings or after meals [42, 43]. Moreover, people believed that society played an important role in influencing their habits [20, 22, 42] and it was hard to refuse offers of these products [22]:

> *"My friends chew it and I cannot say no to them when they offer – it is rude to say no in our culture.. . Every third person in Pakistan chews tobacco."* (page 48) [22].

> *"I think paan is always a tradition at parties and weddings. A lot of these chewing things like supari and gutkha, I've seen when I was in India … the older men, after they eat their food or if they're going on a walk they just pack a lip …."* (page 6) [42].

One study in the USA found the use of tobacco and areca nut preparations among older South Asians helped them connect to their homeland [42].

> *"...If you go to Jersey City or Iselin [cities in New Jersey with large South Asian populations], you'll see it's something that's so deeply rooted in their culture that it's ok for us to do it. It justifies everything"*. (page 7) [42].

### Theme 3: Oral cancer practices

All studies [20–22, 24–28, 37–43, 47] explored the aspects of oral cancer risk related practices and reasons behind the initiation of these habits among South Asian immigrants. Up to 50% of participants were found engaged in one or more negative oral cancer risk related practices like smoking, alcohol drinking, chewing of betel quid and tobacco [20, 22, 24–28, 37–39, 44]. Pan/Betel quid chewing was revealed as the most popular practice (40–97%) followed by smoking and gutka chewing [25, 26, 37, 38]. Followers of Islam (8–23%) were found less likely to consume alcohol when compared to Sikh (43–100%) and Hindu communities (27.6–64%) [24, 28], Whereas, areca nut and pan use were found more common among Muslim participants (24–69%) along with Hindu (32–71%) and Sikh participants (0–95%) [24, 28, 41]. A study in UK involving a number of ethnic groups found that Indians educated beyond the age of 16 years were more likely to chew tobacco products while in the Bangladeshi population the contrary was true [39].

There were also notable age variations when the risk habits were initiated in their home countries ranging from 3 to 18 years [20, 21, 26, 37, 38]. Various reasons were cited behind the initiation of these practices such as social networks made up of South Asian friends or co-workers (45–48.2%), passing of habit from one generation to the next (3.3–81%), observation and encouragement within family members (27.5–81%) [21, 25, 26, 43, 44]. These findings were also reflected in the qualitative studies [20, 22, 42] as indicated in the quote below:

"*From observing. Mother would have it. Grandmother would have it. Aunts use it. When everyone would have it, I would have it too. To see what it's like.*" (page 535) [20].

*"I must have influenced my son to get addicted to chew tobacco."* (page 48) [22].

Despite legal restrictions in developed countries, the easy availability of gutka/customisable pan in Asian grocery stores, restaurants, specialised pan stalls, and supermarkets was highlighted as a factor responsible for the continuation of risk practices among respondents [20, 22, 43]. Similar views were raised in focus groups by Banerjee et al. [20]:

"*One of my brothers here said that it can be found in Pakistani...I mean Indian and Bangladeshi stores. Other stores don't sell it, it's true. Meaning...it is used by Bangladeshi and Indians as well...If someone says it is restricted, I won't agree. Not so much.*" (page 534) [20].

A pilot study [21] in the USA revealed that immigration can also influence the patterns of risk practices with participants switching habits from pan chewing to gutka use (nearly 54%) due to the social unacceptability of the former and ease of procurement /storage of the latter. Supporting this notion is a study in the USA that found that people preferred smoking and sometimes swallowing the tobacco/pan instead of spitting it out because of society finding this inappropriate [20]. However, some studies found that betel quid usage along with tobacco chewing/smoking was an integral part of lifestyles, deeply rooted in the culture of south Asians and that these practices simply continued in new settlements as a habit or addiction [25, 26, 42–44].

Studies also explored different actions and perspectives of South Asian immigrants on quitting oral cancer risk-related practices and found a general interest among respondents (30–80%) in quitting their risk practices [25, 26, 28, 37, 43]. However, quitting these practices was acknowledged to be difficult among users (18.2–38%) [25, 26, 28, 43] who attempted to quit. Participants highlighted the role of self-motivation [20, 22], doctor/dentist [20, 24, 27, 37, 41, 43] as well as government checks [20, 22] in curtailing their use of tobacco/pan products. However, participants did not regularly see a dentist (4–58%) but gave priority to visit general medical practitioners (39–91.3%) especially in case of medical need [24, 27, 37, 38]. Furthermore, general practitioners were found to usually lack knowledge about gutkha/pan use among South Asians [20, 43] and hence rarely discussed the ill-effects of these products during the consultation [20, 27, 37, 43]. Similar findings were reported by Banerjee et al. [20] in their qualitative study:

*"Now that we go to the doctor, doctor asks do you smoke, do you drink. That's all, not more than that. But they don't say that you should not touch this at all. They don't say that."* (page 537) [20].

## Discussion

This is the first integrative review to assess current evidence regarding the knowledge, attitudes, and practices of South Asian immigrants in relation to oral cancer risk in developed countries. The majority of studies were conducted in the USA [20, 21, 42–44] and UK [24, 26–28, 37–41], and more recently in Italy [14] reflecting the changing migratory patterns of South Asians. It is also evident from the diversity of populations studied that irrespective of native countries, the oral cancer risk behaviours are widespread across a broader age range, gender, generations, and social class.

Overall, this review shows a general lack of oral cancer risk-related knowledge among South Asian immigrants in developed countries with persistent low levels of information [21, 25–28, 37, 38, 40]. The scepticism and confusion regarding the link of areca nut/betel quid with oral cancer existed even among the well- informed South Asians [20, 22, 25, 42]. This finding echoes the observation from a study conducted in a developing country (South Africa), where more than half of the South Asians were unaware of health risks associated with the areca nut chewing [48]. It is also consistent with a systematic review exploring the social context of smokeless tobacco use in the South Asian population which found low levels of knowledge in this population regarding harmful health effects associated with the use of smokeless tobacco [49]. These similarities in findings suggest that South Asian immigrants have limited knowledge about oral cancer risk products regardless of their country of settlement. Similar to a recent research around areca nut chewing in Sri Lankan adolescents [50], the study findings showed that more educated migrants, particularly second-generation males were more likely to present better knowledge and level of awareness around risk products linked to oral cancer [24, 41, 43]. Surprisingly, school and university education were identified by participants as the primary source of knowledge in this area rather than awareness campaigns and advice received from health professionals including dentists [28, 40, 41]. These results reiterate Mukherjea et al.'s [51] call for a universally standard and consistent classification of smokeless carcinogenic products as tobacco products among clinicians, researchers, and policymakers to improve knowledge and awareness among South Asian people. This also supports the suggestion

by Awan et al. for employment of well-structured programmes for South Asians in terms of educating them about the health hazards of smokeless tobacco [52].

The level of knowledge around oral cancer risk factors among South Asians seems to be influenced by ethnicity and religion to some extent. The findings suggest that the South Asian community should not be classified as a homogenous group when formulating preventative strategies, because as also noted by Williams et al. [53, 54], South Asian population subgroups from different ethnic origins and varied religions present differences in risk factors, level of knowledge as well as health-related behaviours. This review indicates that a clear understanding and better assessment of the concepts regarding religion and ethnicity will help improve specific oral cancer risk awareness strategies among South Asian subgroups. Interestingly though none of the studies explored the impact of socioeconomic status on oral cancer related knowledge and awareness. This is an area that should be explored further in future studies particularly as this connection has been well documented in other areas [55–57].

The rigid beliefs of South Asian immigrants regarding the use of tobacco and areca nut products may be contributing to their negative attitudes towards oral cancer risks. This review revealed the poor beliefs and ignorant perspective of South Asians towards preventive health behaviours and modification of risk practices [24, 26, 27, 37, 38, 42]. Despite associated oral cancer risks, the perceived benefits of these products influenced many South Asians particularly those from lower socio-economic status [21, 25, 26, 37], to continue using risk products like betel nut/quid, gutka even after immigration. These results are further validated by another systematic review conducted around the use of smokeless tobacco in South Asians, which found respondents had more perceived health benefits than ill effects from using these risk product [49]. These findings strongly highlight an un-informed viewpoint of South Asian immigrants towards oral cancer risk which needs to be further explored, to deliver a more targeted and specific educational approach. Prabhu et al. [26] advocate the need for a Common Risk/Health Factor Approach (CRHFA) to improve awareness regarding particular ill effects related to any risk product rather than orienting it to oral cancer alone.

This review also explored the cultural perspective behind the use of oral cancer risk products among South Asians. The use of tobacco and areca nut preparations was found to be widely acceptable as cultural tradition during special occasions/festivals [24, 25, 43] which is further influenced by socialisation [20, 22, 42] and connection to their homeland [42]. These findings are consistent with a review by Mukherjea at al [47], which highlighted culturally-specific use of tobacco products among South Asian immigrants and suggested the need for a more detailed assessment on the use of such products. Since educational interventions and awareness campaigns in relation to oral cancer [40, 41] have proven effective in the past to improve the level of information among south Asian immigrants, community-based and culturally-tailored efforts are needed to change the social norms associated with the use of such risk products.

Lastly, a notable finding was that up to half of the respondents engaged in the risk practices such as smoking and chewing tobacco, areca nut products [20, 22, 24–28, 37–39, 44]. These practices were popular across almost all age groups and generations [20, 21, 26, 37] with various patterns of practices in different religions [24, 28, 41]. Of concern was the supportive role of family and friends in the initiation of this kind of practices [21, 25, 26, 43, 44]. These findings complement the recent WHO report [58] regarding trends of tobacco product use in the South-East Asia region. This review also echoes the higher frequency of these risk practices among South Asian immigrants in developed nations as reported by Health Survey of England 2004 [59] and CAITUS (California Asian Indian tobacco use survey) of California 2004 [60]. Easy availability of tobacco and areca nut product despite legal restrictions [20, 22, 43] was explored as an important factor in the continuation of risk practices among South Asians after immigration as well. This is in line with Awan et al. who observed higher consumption rates of such risk products due to cheap prices, easy accessibility and heavy marketing [61] in the native countries of South Asians. This review suggests the need for strengthening of government efforts and legislation around sale as well as health warning requirements specifically for smokeless tobacco products in developed countries.

Migration also had an effect on the usage of risk products [20, 21] among South Asians sometimes leading to people switching from one habit to another due to social unacceptance. Unfortunately, the success rates for quitting these practices were disappointingly low among the South Asian population despite some understanding of health risks associated with risk habits [25, 26, 28, 37, 43]. This reiterates the findings from study conducted in Malaysia, where majority of Indian immigrants perceived the habit of smoking and alcohol consumption difficult to give up [62]. Since quitting of these risk habits was difficult for participants, the need for the government and health care providers to play a more active role in this area was advocated in a number of studies [20, 27, 37, 43]. These findings highlight the need for more effective intervention strategies to address the oral cancer risk-related practices among South Asian immigrants. These findings also support the recommendations by Mukherjea et al. [47] for different approaches at the individual, community, organizational and policy levels to

curtail the use of tobacco products. The role of media [47] to change socio-cultural norms among South Asians and appropriate counselling at medical/dental centres to support quitting these practices should also be advocated.

### Implications of the findings

The study findings have significant implications for the development and implementation of preventative interventions to address oral cancer risk practices among South Asian immigrants. Considering the high prevalence of oral cancer in South Asian countries, the development of effective culturally sensitive programs is necessary to increase awareness among at-risk populations in developed countries. Appropriate screening and counselling regarding use of risk products should be provided through general practices as well as dentists. Community organisations should be involved in promoting the cessation of tobacco areca nut preparations at cultural events and festivals. The role of media/social media advertising and more targeted educational campaigns should also be explored to raise understanding among people about good oral health behaviours while minimising oral health risk habits. In addition, policy makers need to strengthen existing legislation regarding the sale of tobacco, areca nut products and the development of accessible oral cancer awareness resources. These findings also have implications for future research particularly in countries that currently have an active migration program and are attracting South Asian immigrants like Canada and Australia. It is important that further research is undertaken in these countries to confirm whether the review findings are relevant and inform preventative strategies in this area.

### Limitations

The studies included in this review varied in methodology as well as quality and hence, the reliability of these studies may be compromised. There is also a lack of information regarding the validated questionnaires and confounding factors in most of the studies which may have affected the results. The South Asian population is broad and findings from some studies may not be generalisable to all South Asians. This review has not included articles that were unpublished or published in other languages and therefore, all studies in this area may have not been retrieved. Moreover, comparisons between studies were too difficult given different methods employed and thus, this review has placed little focus on such comparisons considering these variations, but rather has tried to illustrate an overall picture. All these limitations should be taken into account for designing future studies to ensure reproducible and generalisable evidence.

## Conclusion

This integrative review confirms that South Asian immigrants in developed countries have inadequate oral cancer risk-related knowledge, poor attitudes towards oral cancer risk and a strong inclination towards negative oral cancer risk practices. From this review, it appears that they are ill-informed regarding health risks associated with the use of risk products especially tobacco, areca nut products and are also not receiving appropriate information in this area. The unpredictable and constantly changing migration pattern of South Asians are also concerning in the current scenario. In light of these facts, a multidisciplinary approach involving health professionals, community organisations and policymakers is required to promote oral cancer awareness among this population. Further, designing culturally relevant preventative strategies and educational programs is needed to encourage cessation of risk habits among South Asians.

## Supplementary information

**Supplementary information** accompanies this paper at https://doi.org/10.1186/s12885-020-06944-9.

**Additional file 1.** Search strategy/terms.
**Additional file 2.** Full text screening of articles.
**Additional file 3.** CASP checklist.
**Additional file 4.** JBI checklist.
**Additional file 5.** Table of excluded studies.
**Additional file 6.** Critical appraisal of articles.

#### Abbreviations

SATP: South Asian Tobacco products; AN: Areca Nut; BQ: Betel Quid; AI: Asian Indians; CST: Cultural Smokeless Tobacco

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#### Authors' contributions

NS and RP developed the search strategy and performed the literature search. NS did data synthesis and interpretations. NS and AG conceived and designed the study. NS and AG prepared the first draft of the manuscript. NS, RP, BE and AG provided input into versions of the manuscript and read and approved the final manuscript.

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No conflicting relationship exists for any author.

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# Chapter 3: Literature Review

## (Integrative review)

## 3.1 Overview: Thesis Paper 2

The previous chapter – **Thesis Paper 1** presented the results of an integrative review which concluded that South Asian immigrants have inadequate knowledge and negative attitudes regarding oral cancer risk and engage in risk-enhancing practices. This chapter reports the findings (**Thesis Paper 2**) from another review which synthesised evidence on oral cancer-related knowledge, attitudes, and practices of GPs.

The paper was published in BMC Family Practice:

Saraswat, N., Everett, B., Pillay, R., Prabhu, N., George, A. (2020). Knowledge, attitudes, and practices of general medical practitioners in developed countries regarding oral cancer: an integrative review. Family Practice, *37*(5), 592-605.

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## 3.2 Aim: Thesis Paper 2

The aim of the paper was to review current evidence on the knowledge, attitudes, and practices of general medical practitioners in developed countries regarding oral cancer.

## 3.3 Conclusion: Thesis Paper 2

This integrative review identified limited knowledge of GPs for oral cancer screening and emerging oral cancer risk products like areca (betel) nut. Mixed attitudes of GPs and inconsistent clinical practices relating to routine oral cancer screening and preventive counselling were identified. The next chapter highlights the research gaps, aim and

objectives of this research along with the conceptual model that informed this study.

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OXFORD

Systematic Review

# Knowledge, attitudes and practices of general medical practitioners in developed countries regarding oral cancer: an integrative review

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## Abstract

**Background:** Oral cancer is a public health concern and is widespread in developing countries, particularly in South Asia. However, oral cancer cases are also rising in developed nations due to various factors, including smoking, viruses and increased migration from South Asia. In this context, the role of general medical practitioners (GPs) in identifying oral cancer is becoming increasingly important and, while some studies have explored their perspective about oral cancer, a synthesis of these results has not been undertaken.
**Objective:** The objective of this integrative review is to synthesize existing evidence regarding oral cancer-related knowledge, attitudes and practices of GPs in developed countries.
**Methods:** Four electronic databases were searched to identify studies focussing on the objective of this review. The inclusion criteria were: peer-reviewed English language publications; studies conducted in developed countries involving GPs; explored at least one study outcome (knowledge/attitudes/practices). No restrictions were placed on the publication date.
**Results:** A total of 21 studies involving 3409 GPs were reviewed. Most studies revealed limited knowledge of GPs about emerging risk factors, such as betel nut chewing (0.8–50%). Significant variation (7–70%) was evident in routine oral examination practices of GPs. Most GPs felt unsure about diagnosing oral cancer and many (38–94%) raised the need for further education. No study explored the specific relevance of GPs' practices concerning South Asian immigrants.
**Conclusion:** This review suggests the need for educational programs to enhance GPs' knowledge regarding oral cancer. Further research exploring oral cancer-related practices of GPs caring for South Asian immigrants is warranted.

**Key words:** Attitudes, general practitioners, knowledge, oral cancer, physicians, practices.

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**Key Messages**

- Poor knowledge of emerging oral cancer risk factors among general medical practitioners (GPs).
- Lack of confidence and limited oral cancer screening practices among GPs.
- Need for oral cancer-related education and training for GPs.
- Further research required in other developed countries due to migration patterns.

## Background

Oral cancer is a growing public health problem worldwide. This non-communicable disease is one of the leading causes of death in some Asia-Pacific countries (1,2) and is among the top 15 most common cancers in the world (3,4). A total of 354 864 lip and oral cavity cancer cases were estimated worldwide in 2018 constituting 2% of all new cancer cases (3). Oral cancer contributes 1.9% to world cancer mortality rates despite the wide variation in its incidence across the globe (1,5). While this type of malignancy is more widespread in South Asia (3), it has also become a matter of concern in developed nations as well (6,7). Over the past decade, there has been an increase in oral cancer rates of developed countries, such as the USA (8), Australia (9), UK (10,11) and some other parts of Europe (12), adding to the economic burden in terms of health expenditure in these countries (13–18).

A myriad of factors is responsible for the aggressive nature of oral cancer worldwide. These include chronic smoking, frequent use of smokeless tobacco/areca nut/betel quid, alcohol consumption, radiation, viruses, poor oral hygiene and genetic factors (1,19). Further, oral cancer is more prevalent in men and older-aged people and frequently common among lower socio-economic groups (1, 20). Oral cancer incidence related to human papilloma virus (HPV) infections has also increased in some developed countries (21). The contribution of these risk factors to the oral cancer burden varies globally; for instance, smoking is responsible for approximately 71% of the deaths from oral cancer in high-income countries, while 37% in low-income and middle-income countries (21). There have also been reports suggesting increased migration as a contributing factor (22,23) to the rise of oral cancer in developed countries with studies exploring the potential association of risk practices of South Asian immigrants and oral cancer rates in countries like the USA (24–28), UK (29–32) and European countries (33).

In contrast to other malignancies, oral cancer is considered to be a more serious health issue due to its low 5-year survival rate, largely attributable to delayed diagnosis due to the asymptomatic nature of the condition in the early stages (34,35). Another contributing reason behind late identification of oral cancer is lack of accessible and affordable dental referral pathways in many countries (36), which often results in complex, invasive and expensive therapeutics (35,37). Thus, early identification and prompt referrals can potentially improve outcomes and prognosis, leading to higher survival rates (36).

Early diagnosis is crucial for reducing overall oral cancer morbidity. Although dentists have a definitive role in diagnosing oral cancer (38), the critical role of general medical practitioners (GPs) in early identification of such neoplasms cannot be underestimated (39). GPs are the most commonly sought primary health care provider and patients are more likely to visit GPs compared to dentists (40,41). This is particularly relevant in developed countries, which generally have well-structured, accessible and affordable health care systems (42,43). Further, the high cost of dental treatment also deters patients from visiting dentists regularly (44). Hence, it becomes even more pivotal to ensure that GPs have adequate knowledge and awareness of oral cancers.

In light of the growing emphasis on the role of GPs in early identification of oral cancer, some studies have been undertaken to assess their perspective and practices concerning oral cancer risk (35,40,41,45–51). However, a synthesis of these results has not yet been undertaken. This integrative review aims to synthesize all available evidence regarding the knowledge, attitudes and practices of GPs regarding oral cancer in developed countries.

## Methods

This integrative review used the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement (52) to report the findings. The protocol for this review was submitted to PROSPERO—International Prospective Register of Systematic Reviews (CRD42019146969). The integrative review approach allows the combination of diverse methodologies, including qualitative, quantitative and mixed-method studies, to gain better insights into the research area.

### Eligibility criteria

Studies were included provided they met the following criteria: (i) peer-reviewed publications in the English language; (ii) conducted with GPs in developed and high-income countries and (iii) explored at least one study outcome (knowledge, attitudes or practices associated with oral cancer risk). All qualitative, quantitative, and mixed-method designs were eligible. No restrictions were placed on the year of publication.

### Data sources and search strategy

A search of the four electronic databases Ovid-Medline All, CINAHL, Scopus and ProQuest Central was undertaken using Medical Subject Headings (MeSH) terms and synonyms including oral cancer, mouth neoplasms, general practitioners, primary health care providers, physicians, doctors, health professionals, developed countries, knowledge, perception and awareness. These terms were used in combination using 'Boolean' operators (AND/OR). The filter applied in the search included language (English). A university librarian experienced in undertaking literature reviews was also consulted to ensure the relevance of individual search strategies. The reference lists of selected articles chosen to be included in the review were explored to ensure that relevant studies were not missed. A detailed search strategy is included in Supplementary file 1 indicating the keywords used for the literature search.

### Study selection

The search results were organized using EndNote bibliographic software and duplicates were removed. Two experienced authors (NS and RP) independently assessed the suitability of extracted studies by screening title and abstract as per the inclusion criteria. Thereafter, the full text of selected articles was reviewed by two authors (NS

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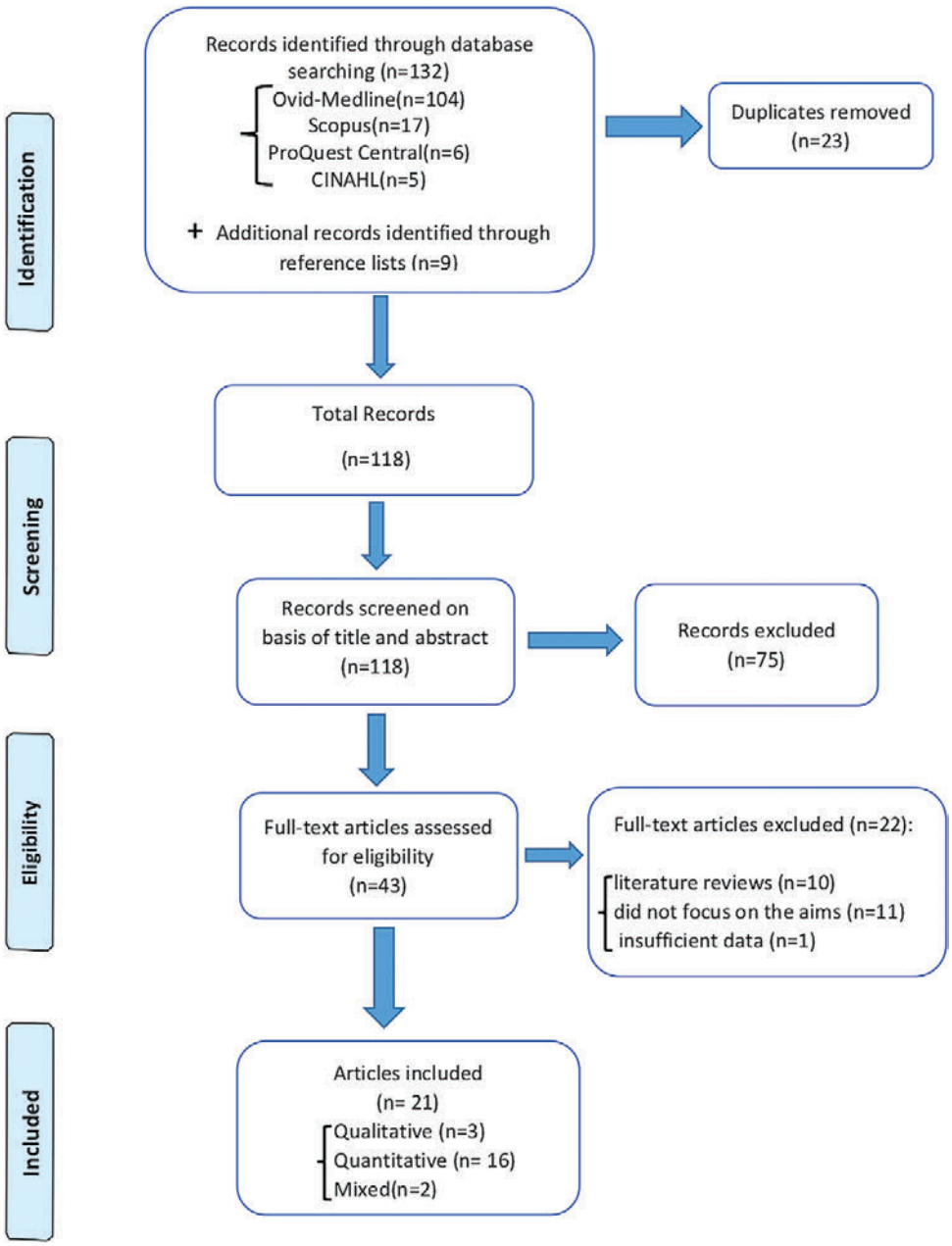


**Figure 1.** Study selection process.

and RP) independently and, then, together in case of doubt or discrepancy. This process of full-text screening has been explained in Supplementary file 2. A third author (AG) was consulted to resolve any discrepancies in judgement regarding the inclusion of articles. The screening and selection process has been illustrated in Figure 1 (study selection process).

## Quality assessment

The critical appraisal for all the selected articles was undertaken independently by two reviewers (NS and RP) to assess the methodological quality. Two separate quality checklists tools were used—Critical Appraisal Skills Programme (CASP) checklist for qualitative studies (53) and the Joanna Briggs Institute (JBI) checklist for analytical cross-sectional studies (54). Both of these tools have been commonly used for assessing qualitative and cross-sectional studies (55). A third reviewer (AG) was referred for the final decision in case of differences in quality assessments. The quality of these studies was calculated using scoring criteria (56). The score was given as a percentage (1 point for each applicable item) and the overall quality was rated as good (80–100%), fair (50–79%) and poor (<50%) (56). The critical appraisal of the studies is provided in Supplementary file 3.

## Data extraction

The data extraction form (see Supplementary file 4) was developed independently by two authors (NS and RP) and modified as required. The data extraction tables (see Tables 1 and 2) comprised information regarding author, year of publication, country, study characteristics and key outcomes. These tables were further checked by two other authors (RP and AG) for accuracy.

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**Table 1.** Characteristics of included studies (dated 1995–2018)

| S.N. | Author and year of publication | Country | Methodology; data collection method | Sample size (GPs) | Sample characteristics | Response rate (%) | | |
|---|---|---|---|---|---|---|---|---|
| | | | | | Age (in years) | Gender (%) | Years of experience (range) | |
| 1 | Yellowitz *et al.* 1995 (45) | USA | Quantitative survey (questionnaire) | 93 | 20–79 | M = 88; F = 12 | NR | 78.8 |
| 2 | McCunniff 2000 (49) | USA | Quantitative survey (questionnaire) | 110 | NR | M | NR | NR |
| 3 | Greenwood and Lowry 2001 (61) | UK | Quantitative survey (questionnaire) | 151 | NR | NR | 8–31 | 71.9 |
| 4 | Canto *et al.* 2002 (46) | USA | Quantitative survey (questionnaire) | 240 | NR | M = 58; F = 42 | 4–32 | 35.4 |
| 5 | Canto *et al.* 2002 (47) | USA | Qualitative one focus group with 10 GPs + face-to-face interviews with 9 GPs | 19 | NR | NR | NR | NR |
| 6 | Macpherson *et al.* 2003 (68) | Scotland (UK) | Mixed-method interviews + questionnaire (face-to-face, semi-structured interviews of 11 GPs + survey of 198 GPs) | 209 | NR | M = 56; F = 44 | NR | 57 |
| 7 | Nicotera *et al.* 2003 (41) | Italy (Europe) | Quantitative survey (questionnaire) | 189 | Mean age = 51 | M = 64.4; F = 35.6 | NR | 38.8 |
| 8 | Sohn *et al.* 2005 (50) | USA | Quantitative survey (questionnaire) | 79 | 29–60 | M = 39.5; F = 60.5 | NR | 56.4 |
| 9 | Patton *et al.* 2006 (35) | USA | Quantitative survey (questionnaire) | 273 | Mean age > 40 | M = 67.9; F = 32.1 | NR | 25.8 |
| 10 | Cruz *et al.* 2007 (51) | USA | Qualitative interviews (face-to-face, structured interviews) | 4 | NR | NR | NR | 70[a] |
| 11 | Carter and Ogden 2007 (40) | UK | Quantitative survey (questionnaire) | 238 | NR | NR | NR | 71.26 |
| 12 | NiRiordain and McCreary 2009 (64) | Ireland (Europe) | Quantitative survey (questionnaire) | 236 | NR | M = 61.9; F = 38.1 | 4–57 | 52.2 |
| 13 | Applebaum *et al.* 2009 (38) | USA | Quantitative survey (questionnaire) | 118 | NR | M = 53; F = 47 | 7–65 | 25.8 |
| 14 | Reed *et al.* 2010 (65) | USA | Quantitative survey (questionnaire) | 165 | 40–59 | M = 100 | 23 (average) | 43 |
| 15 | Morse *et al.* 2011 (60) | Puerto Rico[b] | Qualitative interviews (face-to-face, key-informant interviews) | 2 | NR | NR | NR | 90.9[a] |
| 16 | Ismail *et al.* 2012 (67) | USA | Mixed-method survey (pre-questionnaire) | 274 | 30–69 | M = 64.6; F = 35.1 | NR | 16.7 |
| 17 | Hertrampf *et al.* 2014 (62) | Germany (Europe) | Quantitative survey (questionnaire) | 327 | 30–69 | M = 50; F = 47 | NR | 13[a] |
| 18 | Shanahan *et al.* 2018 (48) | Ireland (Europe) | Quantitative survey (questionnaire) | 221 | 19–29 | M = 34.8; F = 64.2 | 3–6[c] | 5.2 |
| 19 | Shimpi *et al.* 2018 (66) | USA | Quantitative survey (questionnaire) | 43 | 25–70 | M = 45.9[a]; F = 54.1[a] | NR | 20[a] |
| 20 | Gelažius *et al.* 2018 (19) | Lithuania (Europe) | Quantitative survey (questionnaire) | 42 | Mean age = 52 | M = 35.7; F = 64.3 | NR | NR |
| 21 | Lechner *et al.* 2018 (63) | UK | Quantitative survey (questionnaire) | 376 | NR | M = 40.9; F = 59.1 | NR | 72.9 |

[a]Data reported for all the participants (multiple health professionals involved).
[b]Puerto Rico is unincorporated territory of the USA.
[c]Data reported for 77% of the participants.

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**Table 2.** Findings and quality rating of the studies (dated 1995–2018)

| S.N. | Author, year of publication and country | Method and sample size | Findings | | | Quality scores and quality rating[a] |
|---|---|---|---|---|---|---|
| | | | Knowledge | Attitudes | Practices | |
| 1 | Yellowitz *et al.* 1995 (45); USA | Questionnaire; *n* = 93 | • 63.3% Responded that early detection of oral cancer lesions improves survival rates.<br>• 92.6% considered patients (>45 years) at higher risk for oral cancer.<br>• 55.8% could distinguish oral cancer lesions if any lesion was bigger than 3 mm size. | • 32.6% believed their knowledge to be current.<br>• 20.9% strongly felt their knowledge not being up to date.<br>• 84.1% strongly agreed about the importance of examining elderly patients for oral cancer.<br>• 45% felt inadequately trained for oral cancer. | • 18% provided routine oral examination of 50% of their patients.<br>• 7% indicated conducting complete examination of patients for oral cancer. | 75%; B |
| 2 | McCunniff 2000 (49); USA | Questionnaire; *n* = 110 | • Identified major risk factors as alcohol use (68%) and tobacco consumption (97%).<br>• 77% mentioned floor of the mouth as a common site for oral cancer. | | • 7% routinely examined oral cavity for oral cancer lesions. | 50%; B |
| 3 | Greenwood and Lowry 2001 (61); UK | Questionnaire; *n* = 151 | • Habits (e.g. Betel quid chewing) predisposing to oral cancer identified 50.3%.<br>• 90.7% identified smoking as a risk factor and alcohol was identified as a cause by 45.7%.<br>• 47.3% had knowledge of premalignant lesions.<br>• All GPs mentioned more than one treatment modality. | | • 68.2% were likely to examine all sites of mouth in relation to oral cancer.<br>• 74.2% gave preference to OMFS for referrals, while ENT was a second priority for 24% in terms of referrals. | 50%; B |
| 4 | Canto *et al.* 2002 (46); USA | Questionnaire; *n* = 240 | • 83% knew oral cancer increases with age.<br>• 89% identified alcohol as a risk factor.<br>• More than 80% specified SCC as the commonest type of oral cancer.<br>• 60% knew that oral cancer lesions are diagnosed at the advanced stages.<br>• GPs who graduated before 1970 presented better knowledge scores. | • More recently graduated were less likely to agree that their oral cancer knowledge was current.<br>• 12% rated oral cancer training as very good during medical school education.<br>• 62% strongly agreed they were adequately trained to examine patients for oral cancer. | • More than 80% knew how to examine patients for oral cancer.<br>• 77% used to ask about risk factors for oral cancer while taking medical history.<br>• 15% said they provided an oral cancer examination of patients aged >40 years.<br>• 32% never provided oral cancer examination to patients of age group 18–39 years. | 37.5%; C |
| 5 | Canto *et al.* 2002 (47); USA | Focus groups and interviews; *n* = 19 | • All unaware and surprised by high oral cancer mortality rates<br>• Highly aware of major risk factors like tobacco and alcohol use | • Did not accept and trust the validity of the statistics<br>• Believed that patients are more likely to see them more than dentists due to cost factor<br>• Prioritized their role as gatekeeper in managed care during referrals<br>• Agreed about raising oral cancer awareness among public and health professionals<br>• Interested in receiving oral cancer education as part of CME | • Seen very few cases of oral cancer in their practices<br>• Used standard practice to assess patients' risk behaviours, such as tobacco and alcohol use<br>• Generally, do not talk about risks of oral cancer<br>• Often conduct risk assessment themselves rather than asking a nurse to do it<br>• No one reported conducting routinely a comprehensive oral cancer examination<br>• More likely to refer cases of suspicious lesions to ENT specialists | 80%; A |





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**Table 2. Continued**

| S.N. | Author, year of publication and country | Method and sample size | Findings | | | Quality scores and quality rating[a] |
|---|---|---|---|---|---|---|
| | | | Knowledge | Attitudes | Practices | |
| 6 | Macpherson *et al.* 2003 (68); Scotland (UK) | Mixed method; *n* = 209 | • High awareness about smoking (97%) as a risk factor for oral cancer but less for alcohol (79%) and age (76%)<br>• 72% GP considered leukoplakia as a potentially malignant lesion.<br>• 43% considered trauma as an important causative factor.<br>• 20% mentioned fungal infections responsible for oral cancer.<br>• 23% considered viruses as a relevant risk factor.<br>• 26% underwent formal training for counselling regarding smoking.<br>• 37% never received any organized tuition on oral cancer. | • 15% felt confident detecting of detecting malignant oral lesions.<br>• 23% expressed confidence in their ability to assess urgent referrals of oral lesions.<br>• All felt dentist as mouth specialist.<br>• 66% felt that their role to be major in oral cancer detection.<br>• 70% expressed confidence in giving advice to patients regarding oral cancer.<br>• Wished for more training in oral cancer detection (91%) and prevention (79%)<br>• Preferences for the format of training were not profession specific. | • Lack of training (70%) and lack of time (47%) were perceived as barriers to undertake oral cancer examination.<br>• 94% indicated they examined patients' mouth usually in response to complaint of soreness.<br>• 81% conducted oral cavity examination as a result of knowledge of a pre-existing oral condition.<br>• 57% stated to consider urgent referral in case of persistence of oral lesion more than 4–5 weeks.<br>• 87% routinely made enquiries to patients in relation to smoking habits.<br>• 67% wanted additional advice on referral pathways | 37.5%; C |
| 7 | Nicotera *et al.* 2003 (41); Italy (Europe) | Questionnaire; *n* = 189 | • 87.6% correctly indicated tobacco usage and 64% identified alcohol consumption as risk factor for oral cancer.<br>• Some mentioned prior oral lesion (31.5%) and older age (2.8%) as risk factor.<br>• 60.9% knew SCC as the most common form of oral cancer.<br>• 25.8% mention both common sites (tongue and floor of mouth) for oral cancer.<br>• Scientific journals (85.1%), continuing education courses (52.1%) and colleagues (16.5%) were reported as sources of information. | • 84.9% felt the need for additional information. | • 26.8% knew how to examine the tongue.<br>• 63.8% routinely examined the oral cavity of patients.<br>• 37.1% responded that they provided oral examination to patients older than 40 years.<br>• Reported asking about tobacco use (85.1%) and alcohol consumption (82.5%). | 50%; B |
| 8 | Sohn *et al.* 2005 (50); USA | Questionnaire; *n* = 79 | • 44% were labelled as high knowledge score and 56% with low knowledge regarding oral cancer.<br>• 45% were not aware of areas of the tongue more likely to develop oral cancer.<br>• 50% mentioned the relevance of size of swelling to determine the staging of oral cancer.<br>• 60% prioritized the role of bleeding in determining the diagnosis.<br>• 85% learnt from mailings sent from professional medical organizations.<br>• Preferred sources of information were CME, professional meetings, journal articles and educational mailings. | • 92% agreed that annual oral cancer examinations should be performed for adults aged ≥40 years.<br>• 96% strongly agreed for an annual examination of tobacco users.<br>• 48% agreed that oral cancer exams should be separate reimbursable procedures.<br>• 76% felt the need for more oral cancer education through CME.<br>• 51% felt the need for a referral system to increase oral cancer screening.<br>• 45% were willing to participate in a network to promote early screening for oral cancer. | • 70% reported screening patients for oral cancer during routine examination.<br>• More likely to be male physicians who regularly performed oral cancer screening.<br>• 89% could correctly examine the tongue for oral cancer screening.<br>• More than 50% considered the age of patients while screening patients for oral cancer.<br>• Lack of adequate training (64%), shortage of specialists for referrals (48%) and lack of time (15%) were perceived as possible barriers for oral cancer examinations. | 50%; B |



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**Table 2. Continued**

| S.N. | Author, year of publication and country | Method and sample size | Findings | | | Quality scores and quality rating[a] |
|---|---|---|---|---|---|---|
| | | | Knowledge | Attitudes | Practices | |
| 9 | Patton *et al.* 2006 (35); USA | Questionnaire; *n* = 273 | • 92% stated that early detection of oral cancer improves 5-year survival rates.<br>• 31% considered their oral cancer knowledge to be current. | • 61.2 felt confident and adequately trained to examine patients of oral cancer.<br>• More confident (81%) in their training for tobacco cessation than alcohol cessation | • More than 90% usually asked patients about cancer history and the use of tobacco and alcohol. | 62.5%; B |
| 10 | Cruz *et al.* 2007 (51); USA | Interviews; *n* = 4 | • Described little understanding of oral cancer<br>• Low awareness and less knowledge of signs, symptoms and risk factors<br>• Received very little training on oral cancer in medical school | • Agreed on lack of appropriate access to health care in communities where they practice<br>• All cited a lack of compliance by their patients.<br>• Half agreed that oral cancer examination should be a shared responsibility. | • Mentioned communication difficulties as barriers for preventive regimens.<br>• Half of the participants reported routinely checking for signs of oral cancer as general medical workup.<br>• All routinely counsel their patients about smoking cessation.<br>• All preferred dentists for referrals of oral lesions | 80%; A |
| 11 | Carter and Ogden 2007 (40); UK | Questionnaire; *n* = 238 | • 43.28% identified alcohol as a risk factor for oral cancer.<br>• More than 90% knew about smoking as a cause of oral cancer.<br>• Less than 10% knew about the association of betel nut with oral cancer.<br>• Approx. 72% named ulceration as a major oral change associated with oral cancer.<br>• No one mentioned erythroplakia linked with oral cancer. | • 25.2% felt that they had sufficient knowledge regarding the prevention and detection of oral cancer.<br>• 71.4% requested further information/training on oral cancer as a preferred format compared to meetings/seminars. | • 20.17% routinely examined patients' oral mucosa.<br>• 65.1% did not examine the oral mucosa of high-risk patients.<br>• More than one-third reported regularly advising their patients on risk factors for oral cancer.<br>• Preferred oral medicine and OMFS as their preferred points of referral. | 25%; C |
| 12 | NiRiordain and McCreary 2009 (64); Ireland (Europe) | Questionnaire; *n* = 236 | • Identified risk factors (mean number of factors = 1.9) for oral cancer.<br>• Smoking (98.7%), alcohol (50.8%) and poor oral hygiene (20.7%) were identified as major risk factors.<br>• 0.8% identified betel nut chewing as a causative factor.<br>• Ulceration (67.4%) was identified as a major oral change associated with oral cancer.<br>• 0.4% identified erythroplakia associated to be associated with oral cancer.<br>• 89.4% denied the availability of any CME course in their region.<br>• 21.6% received formal teaching on oral cavity examination during under graduation. | • 34.3% felt confident in their ability to detect oral malignancies.<br>• Two-thirds were unsure about their ability to detect oral cancer.<br>• 94% declared interest in further information or training on oral cancer. | • 65.3% reported regularly examining oral mucosa of the patients.<br>• Preferred referrals to ENT (37.7%) and dentist (9.3%) | 37.5%; C |





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**Table 2. Continued**

| S.N. | Author, year of publication and country | Method and sample size | Findings | | | Quality scores and quality rating[a] |
|---|---|---|---|---|---|---|
| | | | Knowledge | Attitudes | Practices | |
| 13 | Applebaum *et al.* 2009; USA (38) | Questionnaire; *n* = 118 | • 96% mentioned eight risk factors for oral cancer correctly.<br>• 99% correctly identified the use of tobacco as a high-risk factor.<br>• Identification of SCC as the most common form of oral cancer.<br>• More than 90% mentioned that early oral cancer lesions are asymptomatic.<br>• 10% mentioned erythroplakia and leukoplakia to be associated with oral cancer.<br>• More recently graduated expressed greater knowledge levels. | • 91% believed that dentists were more qualified to perform an oral examination.<br>• 67% felt that physicians were qualified to perform the examination for oral cancer.<br>• 46% believed that they were adequately trained to examine patients for oral cancer.<br>• 5% strongly agreed that their oral cancer knowledge was current. | • Proficient in assessing the risk factors for oral cancer when taking the medical history of patients. | 62.5%; A |
| 14 | Reed *et al.* 2010 (65); USA | Questionnaire; *n* = 165 | • More than 88% identified tobacco use (smoking, chew or snuff) to be associated with oral cancer.<br>• Alcohol use (>37%) and HPV (45%) were mentioned as medium risk for oral cancer.<br>• More than half were aware of tobacco cessation sources. | • 38–58% were interested in receiving training in oral cancer screening.<br>• 49% were interested in receiving training in tobacco cessation. | • 14–20% conducted a routine oral cancer examination.<br>• 84–87% reported assisting patients regarding smoking counselling.<br>• Older practitioners (>60 years) were more likely to provide oral cancer screening. | 50%; B |
| 15 | Morse *et al.* 2011 (60); Puerto Rico* | Interviews; *n* = 2 | • Most of the participants reported a lack of knowledge regarding early signs and symptoms of oral cancer.<br>• Many identified some previous professional training related to oral cancer prevention, identification and treatment as part of a course.<br>• Had not received any training in conducting oral cancer examinations<br>• Acknowledged lack of coordination during referrals behind delayed diagnosis | • Felt impact of socio-economic status of patients on their wait prior to seeking health care<br>• Felt delayed diagnosis largely attributed to bureaucratic complexities<br>• Perceived dentist with greatest responsibility to provide oral cancer examinations<br>• The majority of participants had concerns regarding the quality of oral cancer examinations. | • All reported conducting oral cancer examination only on high-risk patients or in case of patient's specific concern for abnormality.<br>• One stated conducting only visual oral examinations.<br>• Considerable confusions regarding referral pathways. | 90%; A |
| 16 | Ismail *et al.* 2012 (67); USA | Questionnaire; *n* = 274 | • 21.3% identified the tongue as a common site for oral cancer.<br>• 87.4% mentioned the correct sequence of examination and areas to be checked for oral cancer. | | • 23% routinely screened patients for oral cancer.<br>• 31.5% never conducted a routine oral cancer examination.<br>• 43.9% usually screened patients (aged >40 years) for oral cancer. | 75%; B |
| 17 | Hertrampf *et al.* 2014 (62); Germany (Europe) | Questionnaire; *n* = 327 | • More than 90% knew about tobacco and alcohol use as a major risk factor for oral cancer.<br>• 88–90% said early detection improves survival rates.<br>• More than one-third identified SCC as the most common form of oral cancer.<br>• Half of the participants identified the tongue as a common site.<br>• More than 70% never attended any CME course regarding oral cancer. | | | 62.5%; B |



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**Table 2. Continued**

| S.N. | Author, year of publication and country | Method and sample size | Findings | | | Quality scores and quality rating[a] |
|---|---|---|---|---|---|---|
| | | | Knowledge | Attitudes | Practices | |
| 18 | Shanahan *et al.* 2018 (48); Ireland (Europe) | Questionnaire; *n* = 221 | • Tobacco smoking (94%), alcohol use (63%) and viral factors (29%) were identified as major risk factors.<br>• Ulceration (67%), leukoplakia (35%), exophytosis (31%) and erythroplakia (15%) were considered to be associated with oral cancer. | • 60% felt unsure about diagnosing oral cancer based on clinical appearance.<br>• 84% requested further education on oral cancer. | • 81% mentioned not conducting a routine examination of oral mucosa of patients.<br>• 5% informed their patients of risk factors for oral cancer.<br>• The majority indicated that they would prefer to provide referrals of suspected oral cancers to ENT surgeons (53%), while others preferred OMFS (42%). | 50%; B |
| 19 | Shimpi *et al.* 2018 (66); USA | Questionnaire; *n* = 43 | • All identified one or more symptoms of oral cancer correctly.<br>• 98% could recognize the visual-based image of aphthous ulcer lesion.<br>• Less than half could identify the tongue as the most common site for oral cancer.<br>• 56% reported limited training on oral cancer examination. | • 52% felt comfortable in educating patients about oral cancer.<br>• 61% perceived responsibility in screening patients for oral cancer annually.<br>• 53% were comfortable in performing oral cancer screening. | • 78% indicated not performing oral cancer screening on all patients.<br>• Practitioners with more than 10 years of experience were more comfortable performing oral cancer examination. | 62.5%; B |
| 20 | Gelažius *et al.* 2018 (19); Lithuania (Europe) | Questionnaire; *n* = 42 | • 61.3% reported low knowledge after university studies.<br>• 83.3% reported minimal familiarity with oral cancer.<br>• 16.7% mention the five most common carcinogens.<br>• 69.9% could answer the most frequent type of oral cancer.<br>• 33.3% picked up oral cancer symptoms correctly. | • 87.7% had patient's carcinophobia during visitations.<br>• 50.9% wanted to have an annual week of oral cancer prevention at their workplace.<br>• 45.2% agreed that POCD should be an individual procedure done at primary appointments. | • 76.2% gives information to patients about the negative influence of tobacco.<br>• 28.3% had dealt with patients with oral cancer.<br>• 17% usually checked the oral cavity of patients. | 25%; C |
| 21 | Lechner *et al.* 2018; UK (63) | Questionnaire; *n* = 376 | • 19.4% rated their oral cancer knowledge very good.<br>• 17.7% reported less knowledge about HPV-associated oral cancer.<br>• More awareness about well-established risk factors like smoking (99.4%), chewing tobacco (96.6%) and alcohol use (94.3%)<br>• 32.9% recognized oral cancer risk related to areca nut chewing. | | | 50%; B |

ENT, ear, nose and throat specialty; OMFS, oral and maxillofacial surgery; POCD, Primary Oral Cancer Diagnostics; SCC, squamous cell carcinoma.

[a]A or good quality (80–100%); B or fair quality (50–79%); C or poor quality (<50%).

[b]Puerto Rico is an unincorporated territory of the USA.





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### Data synthesis

Since the studies to be included were heterogeneous, a meta-analysis was not possible for this review. Therefore, outcomes of all studies were reported through narrative synthesis. This unfolding narrative synthesis with connecting themes is more appropriate to 'tell a story' (57) than the comprehensive categorization of all the individual studies. It aims to provide a relatively complete picture regarding knowledge, attitudes and practices of GPs concerning oral cancer risk in this review.

### Definition of terms

For the purpose of this review, the following terms have been modified and used: 'developed countries' denotes nations that have developed economies with high income like the USA, UK, Canada, Australia and New Zealand (58). 'Knowledge' signifies one's understanding and level of information regarding oral cancer risk (59). 'Attitudes' refers to one's inclinations, perceptions and beliefs associated with the oral cancer risk (59). 'Practices' denotes the habits and actions of oral cancer identification and prevention (59).

## Results

The search of databases identified 132 records; 23 were duplicates and subsequently removed. An additional nine records were found through a manual search of reference lists of identified studies, which resulted in a total of 118 records. The process of initial screening based on title and abstract resulted in the exclusion of 75 articles, leaving 43 for full-text screening. After full-text review, a further 22 articles were excluded as they were literature reviews ($n$ = 10), did not focus specifically on oral cancer-related knowledge, attitudes and practices ($n$ = 11) and data regarding GPs could not be elicited from studies involving multiple health care providers ($n$ = 1). This left 21 studies for inclusion in the review: 3 were qualitative (46,51,60), 16 were quantitative (19,35,38,40,41,45,47–50,61–66) and 2 were mixed-method designs (67,68) (see Fig. 1 for the study selection process).

### Study characteristics

The 21 studies included in this review were published between 1995 and 2018 and were conducted in the USA ($n$ = 11), UK ($n$ = 4), Europe ($n$ = 5) and Puerto Rico (US-owned territory; $n$ = 1). Sample sizes ranged from 2 (60) to 376 (63) with a total of 3409 GPs. The age of the participants ranged from 19 to 79 years and consisted of mostly males (see Table 1 for study characteristics).

The quality of the studies was rated as good ($n$ = 3; score ≥ 80), fair ($n$ = 13; score 50–79%) and poor ($n$ = 5; score < 50%; see Table 2 for findings and quality rating of studies). Due to limited literature in this area, irrespective of their quality, all studies were included in this review to allow the reader to make their own judgement.

### Study findings

The narrative synthesis facilitated the categorization of the study findings into three domains.

#### Domain 1: oral cancer knowledge

All 21 studies explored the knowledge of GPs about oral cancer risk. These studies assessed the level of information and awareness of participants regarding oral cancer risk factors, diagnosis and treatment strategies. Most studies indicated sound knowledge among GPs about oral cancer causative factors like smoking (88–99.4%) (19,40,48,61,63–65,68) and tobacco use (87.6–99%) (19,38,41,48,49,62,65). However, considerable variability in knowledge levels was noted among participants regarding other risk factors, including alcohol consumption (37–94.3%) (19,40,41,47–49,61–65,68), viral infections (23–73.8%) (48,63,65,68), old age (2.8–83%) (41, 45, 47, 68) and betel nut/quid chewing (0.8–50%) (40, 61, 63, 64). The uncertainty regarding alcohol as a risk factor for oral cancer was also evident in a qualitative study (68):

'Trauma, probably smoking, denture wear causing ulceration… I don't know about the alcohol factor, although I see no reason why it shouldn't be a factor as it affects your health in lots of other ways'. (p. 278) (68)

Other oral cancer risk-related factors correctly identified by GPs included prior oral lesions (31.5%) (41), trauma (43%) (68), fungal infections (20%) (68) and poor oral hygiene (20.7%) (64). GPs were generally knowledgeable about squamous cell carcinoma being the most common type of oral cancer (60.9–80%) (19,38,41,47,62) but were less sure about the most common sites for this cancer, such as floor of mouth (25.8–77%) (41,49,50,66) and tongue (21.3–55%) (41,50,66,67) or associated symptoms like ulceration (33.3–72%) (19,40,48,64) and premalignant lesions (10–72%)(19, 38, 40, 48, 61, 64, 68).

Participants had a mixed understanding (60–92%) about how early detection improves 5-year survival rates (35,45,47). Some studies though reported a lack of awareness (46,51) and limited understanding (46,60) among GPs concerning the prevalence of oral cancer. These findings were also reflected in the following statement:

'Honestly, very poor [referring to early oral cancer detection in Puerto Rico] because realistically, it [oral cancer] is not discovered as much because people [health practitioners] do not perform oral exams on patients. They do not open their mouths. Sometimes people arrive with something they have had for months, and no one [checks the mouth]' (p. 4) (60)

The main source of information regarding oral cancer for GPs were Continuing Medical Education/CME (10.6–52.1%) (41,62,64), professional meetings/colleagues (16.5%) (41), scientific journals (85.1%) (41) and professional mailings (85%) (50).

#### Domain 2: oral cancer attitudes

The attitudes of GPs towards oral cancer risk were reported in 16 studies. The attitude items were mainly related to the perception and inclination of participants towards oral cancer awareness. Few participants (5–32.6%) felt their oral cancer risk-related knowledge was current (38,40,45) and several GPs (38–94%) were interested in receiving further information and education on this topic (40,41,48,50,64,68). Some studies also revealed a lack of confidence (15–60%) (35,48,64,68) among GPs in undertaking oral cancer screening and prevention due to inadequate training (46–64%) (45). This lack of training was reiterated in qualitative studies:

'I would be unhappy if [physicians] didn't do a rectal exam. But I was not trained to routinely put my finger in someone's mouth and feel around. I was trained to look'. (p. 375) (46)

Participants acknowledged that they learned 'a bit [to examine the mouth] but there was little emphasis on cancers of the mouth and throat. The emphasis was on looking for swollen glands'. (p. 6) (51)

In some studies, GPs (91–100%) believed that dentists were more specialized than them to perform oral examinations (38,68). As one study highlighted:

'It's all down to the training of doctors and dentists, because dentists are the ones that know the mouth. They tend to know the mouth a lot better than the doctors because they're seeing mouths every day. Doctors are looking at the whole body'. (p. 279) (68)

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Some GPs felt that they could play a role in raising awareness about oral cancer particularly in patients with low health literacy who may often see a doctor first (46,51,60):

'People associate dentists with teeth first and maybe gums. But when you talk about the tongue and buccal mucosa, they think of [a] doctor. The more educated might go to a dentist, but the average or poorly educated would probably seek out a physician'. (p. 375) (46)

GPs also felt that socio-economically disadvantaged patients may wait to seek oral health care resulting in delayed diagnosis, further reinforcing the crucial role they could play (60). In the context of the role of GPs in oral cancer prevention, some participants were also interested in receiving more information (46,51) on this topic:

'It's an important topic. . . I would like to see CME on that—maybe not a whole course, but as part of course on primary care review'. (p. 375) (46)

**Domain 3: oral cancer practices**

A total of 19 studies explored GPs' oral cancer diagnostic and clinical practices. Ten studies (19,40,41,45,47,49,61,65,67) highlighted significant variability (7–70%) in routine oral check-up/screening practices among GPs. Such findings were also evident in two qualitative studies:

'If the problem is below the neck, I rarely check for oral cancer'. (p. 6) (51)

'Almost never do I spend much time looking [in the mouth] unless there is a complaint...'. (p. 375) (46)

Two studies reported that oral cavity examination was conducted by GPs only in case of complaints of soreness (94%) and prior history of pre-existing oral condition (81%) (60,68), while four studies reported that between 15% and 50% of GPs undertook oral cavity examination in older-aged patients (41,47,50,67). In four studies, 31.5–81% of GPs reported never conducting a routine oral cancer examination (40,48,66,67). Macpherson *et al.* (68) and Sohn *et al.* (50) identified lack of training (64–70%) and lack of time (15–47%) as key barriers in undertaking routine oral cancer examination by GPs. This was also reflected in the qualitative findings:

'I do not recall having been taught how to perform an oral exam in any moment' (p. 4) (60)

'I think it's a time issue. Ideally, we'd like to do it, but we don't have the time or the resources'. (p. 280) (68)

Despite differences in oral cancer screening practices, 82.5–90% of GPs reported asking patients about risk practices, including alcohol and tobacco use while taking their medical history (38,41,47,48,65,68). However, counselling and educating patients regarding ill effects of risk habits of tobacco and alcohol use were not consistent (5–87%) among the GPs (40,48,51,65).

Several studies explored GPs' referral practices for patients with oral cancer (40,46,61,64). GPs usually preferred to refer oral cancer cases to oral and maxillofacial surgeons (42–74.2%)(48, 61), followed by ear, nose and throat specialists (24–53%)(48, 61, 64) and dentists (9.3%) (64). This was also reflected in qualitative findings by Canto et al:

'If I see leukoplakia or [other] suspicious lesion, I send [the patient] to [an] ENT first for biopsy ... [I]Rarely start with an oral surgeon'. (p. 375) (46)

## Discussion

This is the first integrative review to identify and appraise the research literature on the knowledge, attitudes and practices of GPs regarding oral cancer in developed countries. The quality of included studies was varied and there was diversity in designs, samples and results. The majority of studies were conducted in the USA, UK and Europe reflecting the changing trends of oral cancer incidence globally (23).

Overall, this review revealed limited oral cancer-related knowledge of GPs in developed countries. They had little information about emerging causative factors, including viral infections (48,63,65,68) and betel nut/betel quid use (40,41,63,64). An important finding from this review was the mixed understanding of GPs relating to the importance of early diagnosis of oral cancer for its prevention and treatment. These findings are perhaps not surprising given a lack of awareness among undergraduate medical students concerning oral cancer risk factors (57), suggesting there is not much information on oral cancer and associated facts in medical curricula. In addition, this inadequate oral cancer knowledge among GPs could also be a result of limited information gained through sources, such as scientific journals and continuing education courses (41,50,62,64). Given the increasing numbers of people migrating from developing countries where betel nut/betel quid chewing is endemic, GPs in developed countries will increasingly play an important role in preventing oral cancer through early detection. This will require education and awareness campaigns (34) that address both traditional and emerging oral cancer risk factors (23,69). This review also supports the suggestions of the inclusion of oral health education in the undergraduate medical curriculum (70) and implementation of continuing education courses (71) for GPs in order to recognize oral premalignant and malignant lesions to aid in obtaining an early diagnosis of oral cancer.

This review identified positive attitudes of GPs regarding their role in oral cancer prevention. However, their attitude about oral cancer-related knowledge was unclear as only a few of the GPs believed their knowledge to be current and updated (38,40,45). This belief of being equipped with limited knowledge could have played a role in shaping their self-confidence regarding oral cancer clinical practices. This review echoes the exploration by Wade *et al.* (72) regarding the influence of attitude on GPs' intention to perform oral cancer examination. These findings are also consistent with a review by Florian *et al.* (73), which highlighted the mixed attitudes of GPs about facilitating discussions about risk factors with routine patients and subsequently suggested that identification of specific beliefs underlying such attitudes is essential to influence judgements of GPs. The findings from this review indicate the need for further oral cancer-related training for GPs (72) to enhance their confidence and comfort to do oral cancer screening and formulation of a universal approach to facilitate patient counselling (34) regarding the common, as well as emerging, risk factors like betel nut use.

It was evident that the knowledge and attitude of GPs towards oral cancer had an influence on their practices in this area. Their unclear attitude with limited oral cancer knowledge and training came up as a major deciding factor behind their practice of not conducting routine oral cancer screening until the patient complains (50,68). These findings echo the inadequate training of GPs regarding oral cavity examinations reported in previous literature (72,74). This review supports oral cancer screening in the medical curriculum (74) to increase the confidence of GPs to promote oral health.

The exact relationship of the length of experience in general practice with practitioners' knowledge, confidence and intention to practice oral cancer screening procedures could not be assessed through this review since a very limited number of studies reported this link (38,47,65); this area needs to be explored through further research. This review also indicated the lack of clear oral cancer-related referral guidelines for GPs (40,46,61,64) as the

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differences were apparent in their opinions for the preferred specialty for suspected oral cancer cases (48,61,64). These findings complement the previous literature (75–77), which highlights gaps in oral cancer referral systems and unclear guidelines regarding referrals. Interestingly though, the UK does have oral cancer referral guidelines requiring GPs to refer patients first to dentists for further assessment (78,79). However, these guidelines have been challenged by researchers due to the lack of accessible and affordable dental referral pathways for patients (80–82) in the UK, which could lead to further delays in diagnosis. Further, a recent systematic review of patient journeys in the diagnosis of oral cancer found no evidence to suggest that GPs performed less well than dentists in terms of referrals to specialists (81). Our findings along with previous research (75,81) suggest the need to also design and include a standard referral pathway globally for definitive care and management of oral cancer to reduce any further delays in initializing the treatment.

### Implications of the findings

The findings from this review have significant implications for training, clinical practice and research. The inclusion of specific education in the medical curriculum for a better understanding of oral cancer causative factors and pathogenesis could be beneficial. Although the general practice is already overburdened, further oral cancer-related training (e.g. online resources and continuing education courses) aimed at GPs could be undertaken to help them in identifying signs and symptoms of oral cancer. The short training modules for medical practitioners regarding emerging oral cancer risk factors like betel nut are needed considering the changing migration patterns and oral cancer trends in the world.

Furthermore, strategies to encourage the prompt identification of oral cancer through opportunistic screening of high-risk patients (e.g. those >45-years old, who engage in tobacco and/or alcohol consumption over the recommended limits or chew betel/areca nut (69,83)) could assist GPs to improve the poor oral cancer survival rates. Likewise, routine visual inspection of the oral mucosa of patients (using a torch and dental mirrors) can be incorporated in general practice as a more feasible and affordable method than expensive dental check-ups for early diagnosis of oral malignancies. Moreover, GPs could also be motivated to provide one-to-one health advice to high-risk patients during risk factor counselling (such as tobacco and alcohol cessation), which can be effective if tailored to individual needs and circumstances.

Lastly, in light of the limited number of studies in this area, future research regarding oral cancer-related practices of GPs must be undertaken in other developed countries like Australia and Canada, where there has been a great influx of South Asian immigrants in recent years, particularly from India.

### Limitations

The literature search for this review was limited to four databases and did not include any grey literature nor unpublished studies or articles in other languages. Therefore, all studies in this area may have not been retrieved in the literature search. The diversity in methodology and quality of included studies may have compromised the reliability of the findings. The studies reviewed were undertaken in the context of oral cancer only; hence, the findings cannot be generalized to other cancers. Additionally, the review was limited to studies conducted in developed countries and the findings may not apply to GPs practicing in developing countries, particularly those with high rates of oral cancer.

## Conclusion

This integrative review is first of its kind to provide valuable insight into GPs' perspectives and clinical practices regarding oral cancer. The pivotal role of GPs in developed countries is universally seen as the first point of contact in primary health care and a gateway to access secondary health care services. However, this review has identified gaps in their oral cancer-related knowledge, attitude towards oral cancer risk and screening practices. The limited knowledge of GPs is apparent as they are not updated regarding emerging oral cancer risk factors like betel nut/quid use and identification techniques to detect oral malignancy. Furthermore, GPs present mixed attitudes with inconsistent clinical practices relating to routine oral cancer screening, patient counselling and referrals, which is concerning for oral cancer prevention. These findings suggest the need for further education and training of GPs regarding timely diagnosis and referral of oral cancer cases in association with patient guidance to promote oral cancer awareness.

## Supplementary material

Supplementary material is available at *Family Practice* online.
Additional file 1: Example of search strategy
Additional file 2: Full text screening (table)
Additional file 3: Critical appraisal of articles (table)
Additional file 4: Data extraction tool

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# Chapter 4: Research Gaps, Aims and Conceptual Model

## 4.1 Overview

The previous two chapters provided a comprehensive literature review around the knowledge, attitudes, and practices of South Asian immigrants and GPs in developed countries regarding oral cancer. This chapter will present the research gaps identified in the reviewed literature, as well as reiterate the study aims and research questions. The chapter will conclude with a description of the conceptual model that was adopted to inform the various aspects of this study.

## 4.2 Research Gaps

The review of the literature identified several gaps regarding oral cancer-related knowledge, attitudes and practices of South Asian immigrants and GPs in developed countries. Despite high numbers of South Asians, particularly Indians, migrating to Australia, there is no information on whether these individuals have sufficient knowledge about oral cancer and if they are engaged in related risk practices in the Australian setting given the dire consequences of oral cancer in their country of origin. Their attitudes towards relevant health care practices and prevention policies also need to be determined. Although GPs are well-positioned in key tasks of early identification and raising awareness of oral cancer, this role has not been fully explored in the Australian background. Similarly, there is a paucity of information on the current knowledge, perspectives, and practices of GPs regarding oral cancer in Australia which could highlight barriers in this area. Considering the existing challenges of accessing dental care in Australia, this information would be helpful to inform possible oral cancer preventative strategies managed by GPs in the primary health care

setting. The research gaps identified reinforce the rationale for this PhD study and justify the study aims (detailed in Chapter 1).

## 4.3 Research Aims and Questions

The overall aim of this study was to explore oral cancer risk behaviours of Indian immigrants and identify preventative strategies to raise oral cancer awareness. The specific research objectives were to:

- Review and synthesise evidence on the oral cancer-related knowledge, attitudes, and practices of South Asian immigrants residing in developed countries (Chapter 2).
- Review and synthesise evidence relating to the knowledge, attitudes, and practices of general practitioners in developed countries regarding oral cancer (Chapter 3).
- Explore self-reported oral cancer knowledge, attitudes, and practices of Indian immigrants residing in Australia, along with their engagement in health services and perceived barriers/facilitators in accessing preventative oral cancer strategies (Chapters 6 and 8).
- Explore the oral cancer-related knowledge, attitudes, and clinical practices of General Practitioners (GPs), along with their perspective towards risk behaviours of Indian immigrants in Australia and perceived barriers/facilitators in engaging in preventative oral cancer strategies (Chapter 7).
- Integrate study findings to inform preventative strategies for raising oral cancer awareness among Indian immigrants in Australia (Chapters 9 and 10).

Table 4.1 outlines the study objectives and questions, and where these are addressed in the thesis publications.

***Table 4.1*** *Aligning the Study Objectives with Research Questions and Published Results*

| Objectives | Research Questions | Thesis Papers |
|---|---|---|
| **1. Review and synthesise evidence on the oral cancer-related knowledge, attitudes, and practices of South Asian immigrants residing in developed countries.** | • What are the oral cancer-related knowledge, attitudes and practices of South Asian immigrants residing in developed countries? | **Paper 1:** Knowledge, attitudes, and practices of South Asian immigrants in developed countries regarding oral cancer: an integrative review |
| **2. Review and synthesise evidence relating to knowledge, attitudes, and practices of general practitioners in developed countries regarding oral cancer.** | • What are the oral cancer-related knowledge, attitudes, and practices of GPs practicing in developed countries? | **Paper 2:** Knowledge, attitudes, and practices of general medical practitioners in developed countries regarding oral cancer: an integrative review |
| **3. Explore the self-reported oral cancer knowledge, attitudes, and practices of Indian immigrants residing in Australia along with their engagement in health services and perceived barriers/facilitators in accessing preventative oral cancer strategies.** | • What are Indian immigrants' knowledge and attitudes about oral cancer?<br>• What are the oral cancer-related risk practices and healthcare behaviours of Indian immigrants residing in Australia?<br>• What are the perceived barriers and facilitators for Indian immigrants living in Australia to access oral cancer information and related healthcare programs? | **Paper 3:** Oral cancer risk behaviours of Indian immigrants in Australia: A qualitative study<br><br>**Paper 5:** Oral cancer knowledge, attitudes, and practices of Indian immigrants in Australia: A cross sectional survey |

| | | |
|---|---|---|
| 4. **Explore the oral cancer-related knowledge, attitudes, and clinical practices of General Practitioners (GPs), along with their perspectives towards risk behaviours of Indian immigrants in Australia and perceived barriers/facilitators in engaging in preventative oral cancer strategies.** | • What are the oral cancer-related knowledge, attitudes and clinical practices of GPs in Australia?<br>• What is the perspective of GPs towards emerging risk factors and practices among Indians living in Australia?<br>• What are the perceived barriers according to GPs regarding oral cancer risk assessment and counselling of patients (particularly Indian immigrants)? What are GPs' recommendations to promote oral cancer awareness specifically among high-risk populations such as Indians in Australia? | **Paper 4:** Perceptions and Practices of General Practitioners towards Oral Cancer and Emerging Risk Factors among Indian Immigrants in Australia: A Qualitative Study |

## 4.4 Conceptual Model

Conceptual models serve as a map to aid in the design of the study and provide structure for the research (Premkumar et al., 2017). When logically developed and employed in research, such a model presents a skeletal framework to outline the possible course of action and delivers rigor to the research process (Elangovan & Rajendran, 2015). A schematic presentation of relevant key concepts was developed from the literature to address the main aim of this study, which was to explore the oral cancer risk behaviours of Indian immigrants and identify preventative strategies to raise oral cancer awareness.

The conceptual model for this study was informed by both the knowledge, attitude, and behaviour (K-A-B) model and Health Belief model (HBM). A similar type of integrated model has also been used in other international studies (Hsieh et al., 2021; Rimpeekool et al., 2016). The KAB model, which is also called the knowledge, attitudes, and practices (K-A-P) model is based on the premise that correcting the lack of one's knowledge with change in attitude can influence overall behaviour (Xu et al., 2010). The HBM is another dominant model in health promotion (Roden, 2004) and was developed in the 1950s by social psychologists working in the U.S. Public Health Service to explain the insufficient participation by people in public health programs which were initiated to prevent or detect disease (Maiman & Becker, 1974). HBM employs social-psychological variables to explain preventive health behaviour and has been modified many times over the years (Janz & Becker, 1984; Maiman & Becker, 1974; Roden, 2004; Tan et al., 2001).

HBM is based on the concept which considers that an individual's perceived susceptibility about the health problem combined with their perceived benefits of

preventive action and barriers to action can explain engagement in preventive health behaviours. In addition, inculcating positive attitudes into individuals through other external factors like engagement in health services and interaction with health professionals – referred to as cues to action, is likely to impact the behaviour (Xu et al., 2010). Studies focusing on oral cancer have also used the HBM model to assess the beliefs of populations in this area (Tan et al., 2001). Thus, being informed by both models allowed the ALARRM study to capture the oral cancer knowledge, attitudes, and practices of the Indian immigrants as well as GPs within the same research project.

In the current conceptual model (*Figure 4.1*), knowledge, attitudes, and practices are shown as inter-dependent variables that are informed by each other and play a key role in deciding the resultant behaviour towards oral cancer risk. Here, knowledge refers to one's ability to acquire, retain and use information (Badran, 1995) regarding oral cancer risk, while attitude is an inclination to react in a certain way to specific situations (Bano et al., 2013) in relation to oral cancer risk. Attitude is also influenced by one's perceived susceptibility regarding oral cancer risks and perceived benefits and barriers to preventive actions (Ajzen, 1985, 1991). Practices relate to the application of knowledge that leads to action (Badran, 1995) guided by attitudes regarding oral cancer risk. However, it has been found that knowledge alone is not sufficient to instigate a change in behaviour because a direct relationship must first be established among knowledge, attitudes, and practices; attitudes do not alter the behaviours, as there is a lack of consistency within the different factors affecting attitudes; and practices do not display any impact towards behaviour, as several factors can hinder behavioural modification (Aceret et al., 2021). Thus, knowledge, attitudes, and practices are co-related.

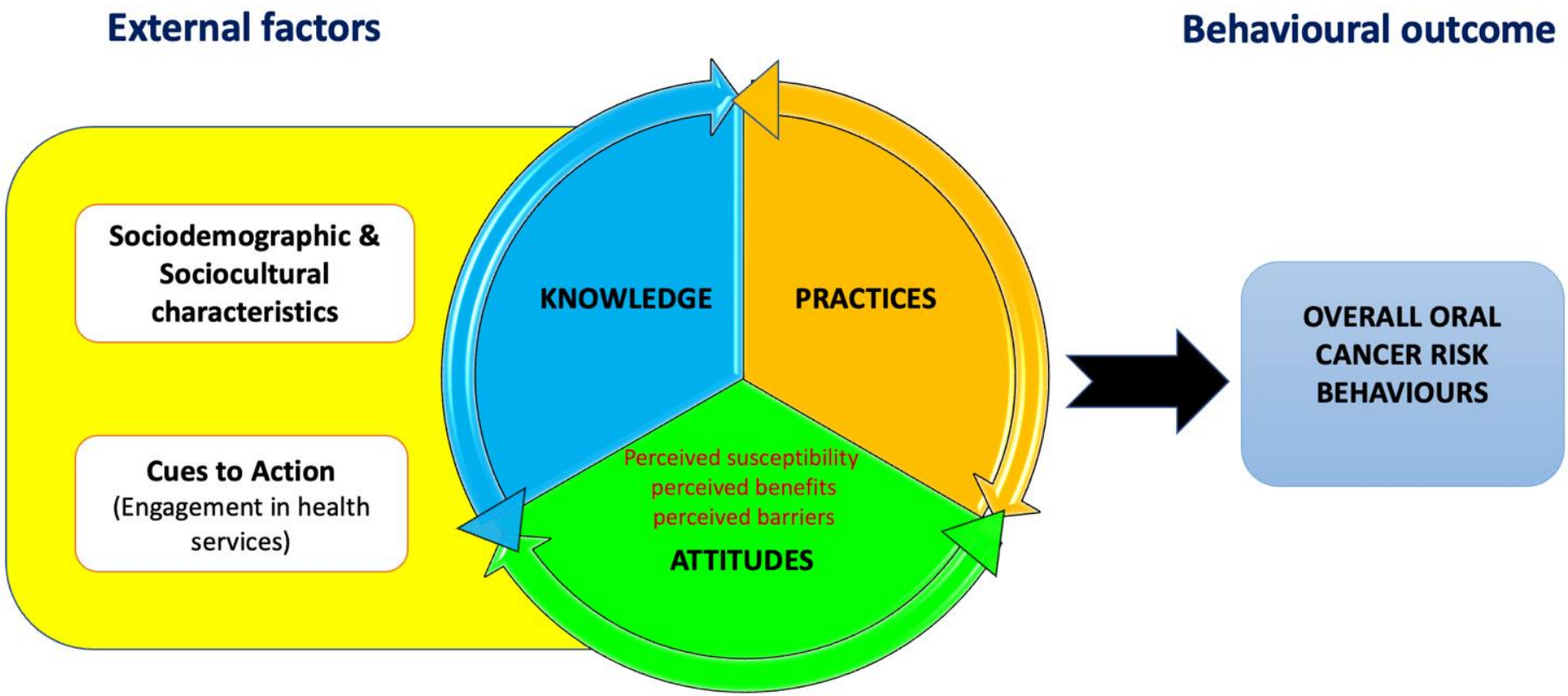
Several studies have also shown that external factors like socio-demographics (e.g., age, education, income) and sociocultural aspects (e.g., cultural beliefs, religion, ethnicity) of an individual's life play a crucial role in shaping perceptions regarding particular health-related behaviours (Aceret et al., 2021; Braun et al., 2018; Huang et al., 2008; Perumal et al., 2013; Rosa-Díaz, 2004; Simon et al., 2010) (such as oral cancer risk behaviours). These perceptions can affect knowledge and attitudes, which in turn influence the practices and finally the overall behaviour of a person towards oral cancer risk (Maiman & Becker, 1974; World Health Organisation, 2012). This has been further highlighted in our review (Paper 1) around the oral cancer-related knowledge, attitudes, and practices of South Asian immigrants which identified strong inter-play of these factors and overall risk behaviours. Exploring these variables is important in the context of this study, as Indian immigrants have different demographic and cultural backgrounds compared to the general Australian population, which can influence their perceptions and overall health behaviours.

Another external factor is engagement with health services (cues to action). Health promotion and motivation by health professionals (such as GPs) through health services are predictors of preventive health behaviour (Roden, 2004). This engagement is necessary to keep individuals consciously informed and aware of their perceptions about a particular health problem and is responsible for their desire and actions to avoid a state of illness (Graffigna & Barello, 2018). Several studies (Barello et al., 2017; Coulter, 2012; Graffigna et al., 2016; Kennedy et al., 2005; Thompson, 2007; Zolnierek & DiMatteo, 2009) have also highlighted the role of health care professionals in determining the willingness of patients to become more active towards their health care. In particular, factors such as healthcare providers' communicative skills and their attitude toward the concept of patients' active

participation in shared decisions about their care have been identified as potential factors affecting a person's choice to engage actively in their own health management (Graffigna & Barello, 2018).

In summary, the conceptual model for this study (see *Figure 4.1*) proposes that a person's overall behaviour towards the prevention of oral cancer is determined by the mutual interaction of their knowledge, attitudes, and practices related to this disease as well as external factors like sociodemographic, sociocultural and engagement with health services.

***Figure 4.1*** *Conceptual Model of the Study*



## 4.5 Conclusion

This chapter presented the research gaps in the study area and detailed the specific aims and objectives of this research. Thereafter, the conceptual model for this study was elaborated and explained. A description was provided on how the key components of the conceptual model address the overall aims and specific objectives of the study. The next chapter presents the research methodology and methods.

# Chapter 5: Research Methodology and Methods

## 5.1 Overview

The previous chapter presented the research gaps, aims, and conceptual model of the study. This chapter discusses the research paradigm and methodology adopted for the study followed by a detailed description of the research methods used to address the study aims. The chapter concludes with a discussion of the ethical considerations.

## 5.2 Research Paradigm

The term 'paradigm', in social research, refers to the basic set of beliefs or the philosophical assumptions that guide the actions and define the worldview of the researcher (Lincoln et al., 2011). Essentially, all paradigms that structure modern research are philosophical in nature and encompass the common elements of axiology (beliefs about the role of values in research), ontology (ideas about the nature of reality); epistemology (assumptions about how we gain knowledge), methodology (shared understanding of best means for gaining knowledge of the world), and rhetoric (shared understanding of the language of research) (Creswell & Poth, 2016; Lincoln et al., 2011). The researcher's stance and interpretation about each of these elements shape the approach to undertake research in a particular area (Creswell & Poth, 2016).

### *5.2.1 Adopting a pragmatic paradigm for research*

Pragmatism is a research paradigm that is not committed to any one system of philosophy but rather focuses on the 'what' and 'how' of the research problem (Creswell & Poth, 2016). This worldview accepts that there can be single or multiple realities that are open to empirical inquiry rather than getting involved in the metaphysical concepts such as

truth and reality (Kaushik & Walsh, 2019). In practice, this paradigm accepts the use of multiple methods of data collection to answer the research question in the best way (Creswell & Poth, 2016). This paradigm lets employing mixed methods approaches which allow the research question to determine the data collection and analysis methods (Mackenzie & Knipe, 2006). Adopting a pragmatic paradigm was appropriate for the current study, as it provided the opportunity to use a variety of methods to answer the research questions, which was crucial for this under-researched topic in Australia.

## 5.3 Research Methodology

Methodology is the overall approach to research linked to the paradigm (Mackenzie & Knipe, 2006). A mixed methods approach was selected to address the overall aim of this study, which was to explore oral cancer risk behaviours of Indian immigrants in Australia and identify preventative strategies to raise awareness in this area.

Mixed methods research has emerged as a dominant methodology in recent years among health care researchers (Doyle et al., 2009). It allows for a variety of ways to address the research questions which are best answered through both qualitative and quantitative approaches (Doyle et al., 2009). The flexibility of this approach is helpful to resolve complex and layered problems faced during research (Doyle et al., 2009). Mixed methods represent the pragmatic perspective of employing “what works”, using different approaches while giving prior importance to the research problem and question (Creswell et al., 2011). It values both objective and subjective knowledge gained from qualitative and quantitative methods (Creswell et al., 2011). Mixed methods work by employing rigorous qualitative research to explore the understanding of constructs and thorough quantitative research to

assess the magnitude of constructs (Creswell et al., 2011). Hence, this type of research purposefully employs both qualitative and quantitative data collection and analysis (Shorten & Smith, 2017) while integrating the findings at an appropriate stage (Ivankova et al., 2006).

Under-mixed methods, qualitative research methodology can assist in exploring and providing an in-depth understanding of a social phenomenon, particularly when little is known about the topic of research (Fossey et al., 2002; Pope & Mays, 1995). Chapters 2 and 3 have shown that there has been little or no research regarding oral cancer risk behaviours of Indian immigrants in Australia and this qualitative exploration was necessary to understand the current scenario. On the other hand, the quantitative research methodology aids in measuring the variables of interest and facilitates the comparison and statistical data analysis (Holton & Burnett, 2005). In the context of this study, the intent of employing a quantitative aspect was to conduct the same investigation in an objective manner, where more specific information regarding risk behaviours could be collected on a larger scale among Indian immigrants in Australia.

Mixed methods research can be categorised based on different designs (Creswell et al., 2011) as follows:

I. Explanatory Sequential – Quantitative data collection and analysis is conducted prior to qualitative data collection and analysis to help explain quantitative data.

II. Exploratory Sequential – Qualitative data is collected and analysed before the quantitative data collection and analysis to help gain insight into an under-researched phenomenon.

III. Parallel – Concurrent process of qualitative and quantitative data collection and analysis.

IV. Nested (embedded) – Either Qualitative or Quantitative can be the main design with the alternative paradigm embedded within the study to answer a complementary question.

A sequential exploratory mixed-methods design was chosen for this study which commenced with a qualitative exploration followed by a quantitative follow up (Creswell et al., 2011). In such exploratory studies, where the concepts are mostly unclear, equal priority can be given to qualitative and quantitative elements (Kroll & Neri, 2009).

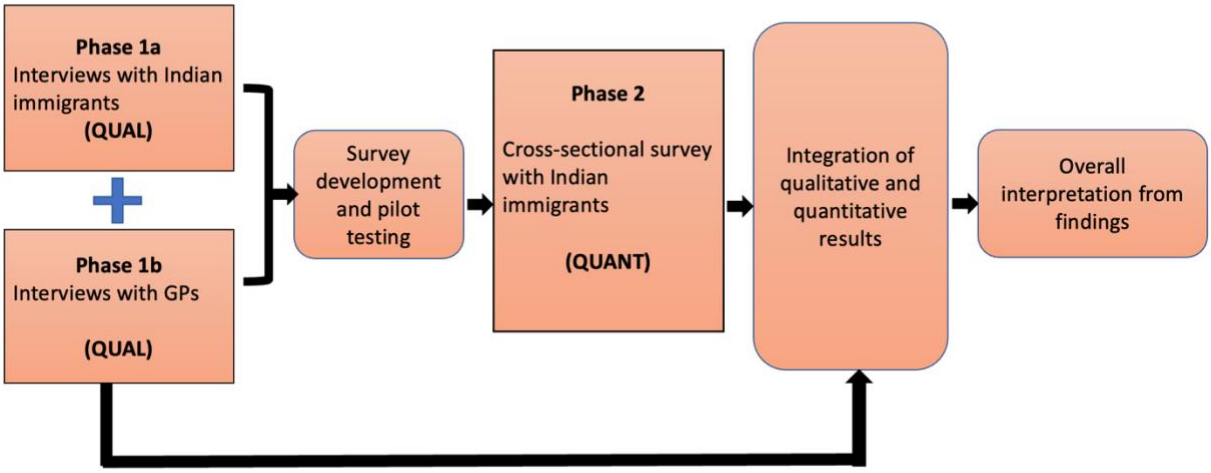
### 5.3.1 Rationale for a sequential exploratory mixed-method design

A sequential exploratory design is mainly beneficial in research where qualitative findings help in designing and develop a quantitative instrument which can then be used to collect data from a sample population (Creswell et al., 2011). It was applicable in this study (*Figure 5.1*), as there is very limited literature available about oral cancer risk-related behaviours of Indian immigrants as well as perspectives and practices of GPs regarding oral cancer in Australia. Thus, a qualitative phase was first employed to explore these areas further, followed by a quantitative phase to test generalisability of initial findings among Indian immigrants.

Undertaking the qualitative data collection and analysis as the first phase of the research was necessary (Creswell et al., 2011) to help understand the knowledge, attitudes, and practices of Indians and GPs regarding oral cancer in Australia. The findings from this phase, complemented by the literature review (Chapter 2) also helped inform the design of

the survey instrument (in the subsequent quantitative phase) to assess the oral cancer related knowledge, attitudes, and practices of Indian immigrants in Australia. The findings from both phases were then integrated (Onwuegbuzie & Combs, 2010) (Chapter 9) to inform preventative strategies for oral cancer specifically among Indian immigrants (Chapter 10). Thus, the sequential exploratory mixed-methods design was best suited for this study.

***Figure 5.1*** *Exploratory Sequential Design of the Study*




## 5.4 Research Methods

### 5.4.1 Phase 1 Qualitative – Indian Immigrants and General Practitioners (GPs)

Phase 1 employed a qualitative approach to explore the knowledge, attitudes, perceptions, and practices of Indian immigrants as well as GPs in Australia towards oral cancer. This phase also sought to identify the perceived barriers and facilitators to promote oral cancer awareness among at-risk migrant populations in Australia. Methods relating to

recruitment, setting and data collection are presented separately for Indian immigrants (Phase 1a) and GPs (Phase 1b). Phase 1a and Phase 1b were conducted concurrently so that the findings could inform each other. Further details of the methods for this qualitative component of the study are presented in the published thesis Papers 3 and 4 (Chapters 6 and 7).

#### *5.4.1.1 Phase 1a – Indian immigrants*

This component included gathering qualitative data in relation to oral cancer-related knowledge, attitudes, and practices of Indian immigrants in Australia. The details regarding sample, recruitment and data collection are provided below.

##### *5.4.1.1.1 Sampling, setting and recruitment*

Indian immigrants (aged 16 years and above) residing in New South Wales (NSW) and Victoria (VIC), states of Australia, were eligible to participate in this study. In Australia, the states of NSW and VIC are preferred places to settle among Indian immigrants, with an inclination towards the cities of Sydney and Melbourne respectively (Department of Home Affairs, 2014). As previous literature identified oral cancer risk practices (e.g., betel quid chewing) popular among all age groups of Indians including younger groups, the minimum age to participate was set at 16 years (Auluck et al., 2009; Chandra & Mulla, 2007). Likewise, evidence from a recent systematic review suggested oral cancer risk-related behaviours were prevalent across a number of sociodemographic groups and therefore, no exclusion criteria were set based on age, gender, residency status, place of origin in India or number of years living in Australia (Saraswat et al., 2020). Both purposive and snowball sampling techniques (Hancock et al., 2001) were used to recruit participants for interviews. Purposive sampling is a non-probability sampling technique used to generate a sample according to

specific selection criteria (in this case, Indian immigrants) that answers research questions during investigation/research (Teddlie & Yu, 2007). Snowball sampling aids the researcher in accessing participants through contact information provided by other informants and/or participants (Noy, 2008). This type of sampling can be useful in cases where the sample population is hard to reach, for example, ethnic minority groups or immigrants (Petti & Warnakulasuriya, 2018).

The recruitment strategy included the distribution of the study flyers (Appendix-1) advertised at various Indian/Asian grocery stores and restaurants in suburbs which were known to be densely populated with Indians (Department of Home Affairs, 2014). In addition, an invitation to participate was sent to two Indian associations in Australia (the United Indian Association and Australian Hindi Indian Association). Social media (e.g., Facebook, WhatsApp, Instagram) was also used by requesting the respondents to forward study information to their network and friends who might be interested in this study. All participants were provided with an information sheet (Appendix-2) and a consent form (Appendix-3) prior to conducting the interviews.

*5.4.1.1.2 Data collection*

A semi-structured interview process was followed for data collection. These types of interviews are very common in qualitative research and frequently employed in health services research because of the feasibility to conduct these even with limited resources (DeJonckheere & Vaughn, 2019). This approach consists of a dialogue between the researcher and participant, directed by an interview protocol and supplemented by follow-up questions/probes (Ford & Farah, 2013). This method is useful to collect open-ended data and allows the researcher to explore participants' deep thoughts and beliefs about a particular topic (Ford & Farah, 2013). Furthermore, migrants (Indians in Australia in this context) might feel vulnerable after moving into new social or cultural environments and be reluctant to share their experiences. In such cases semi-structured interviews can allow interviewers to establish a general direction for the conversation while still ensuring flexibility for the interviewee to direct the part of the conversation (Sánchez-Ayala, 2012).

An interview topic guide (Appendix-4) was developed based on the literature review (Paper 1) and further refined by the multidisciplinary team involved in this study. The guide included questions about oral cancer-related knowledge, attitudes, and practices of Indian immigrants in Australia. The interviews were conducted face-to- face and over the telephone at a time/place convenient to the participants. The principal researcher [NS, PhD candidate], who was trained in undertaking qualitative research interviews and had no prior relationship with any of the participants, conducted all interviews. Data collection commenced in August 2019 and was completed in January 2020. Interviews were conducted in English and were audio recorded. The duration of each interview was estimated at 30-45 minutes and all the participants were given a gift voucher (AU$50) as reimbursement for

their time. Participants were also given an opportunity at the end of the interview to add any further comments relating to the research topic.

Written informed consent for face-to-face interviews or verbal consent for the telephone interviews was obtained from all participants. Demographics of the participants including age, gender, occupation, and educational qualification were collected at the end of the interview (Appendix-3).

Simultaneous discussion sessions with the supervisory team were organised to seek patterns and identify any new areas to explore in subsequent interviews. Recruitment and data collection continued until data saturation was reached where no further new information emerged from the interviews (Hancock et al., 2001).

#### *5.4.1.2 Phase 1b – General Practitioners (GPs)*

This component of Phase 1 included collection of qualitative data in relation to oral cancer-related knowledge, attitudes, and practices of GPs in Australia. This stage also dealt with exploring GPs' perspectives and clinical practices related to oral cancer risk behaviours of Indian immigrants. The details regarding sample, recruitment and data collection are provided below.

##### *5.4.1.2.1 Sampling, setting and recruitment*

These interviews were conducted concurrent to Phase 1a interviews (with Indian immigrants). All GPs working in medical practices in New South Wales (NSW) and Victoria (VIC), Australia were eligible to participate. The suburbs of Sydney and Melbourne were preferred recruitment sites for practicing GPs since these cities are densely populated with Indian communities (Department of Home Affairs, 2014). No exclusion criteria were

established. Purposive and snowball sampling was used to enhance recruitment (Kuzel, 1992). These two types of sampling are often combined in qualitative research to aid in identification of additional informants or events that deserve investigation and thus are more likely to yield the desired diverse sample (Sofaer, 1999). Purposive sampling is usually employed to identify the participants initially while snowballing helps in increasing the participation of similar members to ensure diversity (Valerio et al., 2016). Adopting this combined approach has been found beneficial for more participation and to engage hard-to-reach populations (Valerio et al., 2016). In this study, the email contacts of medical practices across all suburbs of Sydney and Melbourne were retrieved from publicly available sources on the internet. These practices were then further screened for gender and ethnic diversity along with history of practice of the clinicians (where available). A letter of invitation (Appendix-5) and study flyer (Appendix-6) were then emailed to the practice managers of these medical practices across these suburbs. A follow-up reminder email was sent after a week in case of no response. A participant information sheet was provided to those GPs who expressed interest in the study (Appendix-7) outlining the purpose of the study and afterwards interviews were scheduled as per their convenience.

*5.4.1.2.2 Data collection*

Data were collected through semi-structured interviews, as the conversation during such interviews can delve into totally unforeseen issues rather than just adhering to verbatim or standardized questions (Adams, 2015). Given GPs have busy schedules, more flexible telephone interviews were offered to those unable to attend in-person. These types of interviews allow GPs to talk freely at a convenient time while providing detailed information on the topic (Novick, 2008).

A literature review (Paper 2) and concurrent interviews with Indian immigrants which comprised aspects of their routine healthcare practices, informed the development of the GP interview guide (Appendix-8). This was further refined with a multidisciplinary team involved in this research. The principal researcher [NS, Ph.D. candidate] conducted all interviews between August and November 2019. Written or verbal consent was obtained (Appendix-9), and interviews were audio-recorded. The interview duration was estimated around 20-30 mins. The researcher encouraged participants to speak openly on each question during the interviews with the use of open questions and follow-up probes. Demographic details of participating GPs including age, gender, highest level of qualification, and years of clinical practice in Australia were recorded. In addition, all GPs were asked for information about where they received medical training. Just like the interviews with Indian immigrants, all GPs were provided a gift voucher (AU$50) as reimbursement for their time. Participants were also given an opportunity at the end of the interview to add any further comments relating to the interview questions or the overall research topic.

De-briefing sessions were held with the principal supervisor [AG] following each interview to discuss completeness of data and any new areas to explore in subsequent interviews (McMahon & Winch, 2018). Recruitment and data collection continued until data saturation was reached (Bowen, 2008).

#### *5.4.1.3 Data analysis – Indian immigrants and GPs*

The audio recordings of the interviews were professionally transcribed and then checked for accuracy by the principal researcher [NS] against the original audio recordings. Member checking was done with willing participating Indian immigrants and no changes in transcripts were requested from their side. This step of participant verification is an

important quality control process primarily used in qualitative inquiry and helps the researcher seek to improve the accuracy, validity, and credibility of recordings done during a research interview (Harper & Cole, 2012). A prior decision was made by the research team that transcripts would not be returned to GPs considering their time constraints. The final transcripts were then imported into the QSR NVivo (Version 12) qualitative data management software (Dhakal, 2022). The data were analysed using qualitative content analysis (QCA), which is very commonly used in health care research for the description and interpretation of textual data by the systematic process of coding (Assarroudi et al., 2018). Directed (deductive) type of QCA was used for data analysis, which is a comprehensive method that allows the comparison of the findings of different studies and yield practical results (Assarroudi et al., 2018). The analysis with a directed (QCA) approach begins with a theory or relevant research findings as guidance for initial codes (Hsieh & Shannon, 2005). The existing research or theory can provide predictions about the variables of interest or about the relationships among the variables, and thus can help determine the initial coding scheme or relationships between codes (Hsieh & Shannon, 2005). The directed (QCA) approach is guided by a more structured process (Hsieh & Shannon, 2005), which was the case in the current study.

A formative categorisation matrix, based on the themes identified from an integrative review of oral cancer-associated knowledge, attitudes, and practices of South Asian immigrants (Saraswat et al., 2020) guided the initial coding in analysis. All members of the research team [Ph.D. candidate (NS), two practicing/academic dentists (AG and NP), and two nurse academics (RP and BE)] undertook the initial coding by reading two transcripts each. Over the course of further meetings, consensus was reached regarding a coding

structure, and this was used by NS to code the remaining transcripts. A codebook (Appendix-10) was developed by NS as a reference guide for further coding by the research team. After the initial analysis was completed, NS went back through the coded excerpts and identified subcategories, which were then presented to two other researchers in the team (AG and RP). These subcategories were then reviewed by all the members of the team until consensus was achieved. Any discrepancies were resolved through discussions. The analysis led to the development of the main categories and subcategories depicting the knowledge, attitudes, and practices of Indian immigrants and GPs in relation to oral cancer risk in Australia.

#### *5.4.1.4 Study rigour*

Rigour was maintained at every stage of data collection and analysis in the qualitative phase to ensure the trustworthiness of the study findings. Several strategies were employed to address the credibility, transferability, dependability, and confirmability of the findings.

Credibility of the research was achieved by conducting preliminary telephonic conversations with Indian immigrants and GPs (prior to interviews) to disseminate the information about the study and to establish trust. All the interviews were conducted by a skilled qualitative researcher [NS]. Debriefings were organised with the principal supervisor [AG] after each interview session to discuss completeness of data and identify new areas to explore in subsequent interviews (Shenton, 2004). Member checking of transcripts was carried out for participant verification (Indian immigrants) to improve the accuracy and promote credibility (Harper & Cole, 2012).

Dependability was attained when all members of the research team carried out individual coding which also raised credibility (Shenton, 2004). Regular consensus meetings were organised with the team to minimise discrepancy.

Confirmability and accuracy were accomplished by employing a professional transcription company for verbatim transcriptions of the interview audio recordings. The anonymity of the participants was ensured by de-identification throughout transcription.

Transferability was maintained by collecting detailed information about the study settings, participants, and data collection process. Furthermore, the categories and subcategories were directly supported by direct excerpts/quotes from interviews to ensure correct data interpretation (Fereday & Muir-Cochrane, 2006; Shenton, 2004).

## 5.4.2 Phase 2 Quantitative – survey with Indian immigrants

A quantitative approach using a cross-sectional survey was used to further explore the oral cancer risk behaviours of Indians residing in Australia through investigation of their oral cancer-related knowledge, attitudes, and practices. The survey also sought to explore the perceptions of Indian immigrants regarding GPs' capability to provide oral cancer preventative education, screening, referrals, and their intention to participate in such services. An overview of the methods for this quantitative component of the study are also presented in Chapter 8 (Thesis Paper 5).

### *5.4.2.1 Sampling, setting and recruitment*

Indian immigrants (who themselves or their parents were born in India) aged 16 years and above, and residing in Australia were eligible to participate in the survey. The minimum age was set at 16 years, as literature suggests that practices like betel nut/quid

chewing are popular even among younger generations in India (Chandra & Mulla, 2007). Considering the spike in immigration from India in the last few years (Department of Home Affairs, 2019, 2020), no specific recruitment sites were chosen to ensure diversity in terms of geographical location of Indians across Australia. No exclusion criteria were placed in terms of maximum age, gender, religion, socio-economic background, occupation, residency status, place of origin in India or number of years living in Australia, as current evidence internationally has shown oral cancer risk behaviours to be prevalent across these variables (Paper 1).

The recruitment for the survey was affected by the coronavirus pandemic (COVID-19), which also had unprecedented impacts on health systems and public health globally (Chu et al., 2020). Following the outbreaks, many countries implemented physical distancing measures, national lockdowns and travel restrictions in order to control the spread of COVID-19 (Chu et al., 2020). In response to these measures, like many other public health researchers, we had to switch from standard face-to-face data collection methods to remote data collection to support the continuation of the survey research. Remote data collection means the collection of data via the phone, online or other virtual platforms, with researchers and study participants physically distanced (Hensen et al., 2021). Attempts were initiated aiming to recruit a convenience sample (Teddlie & Yu, 2007) through online social networking sites and other virtual platforms.

The study flyer (Appendix-11) was made available online through a webpage (link: https://cohortaustralia.com/oralcancerinimmigrants/) consisting of links to the participant information sheet (Appendix-12) and the survey. The details in the study flyer allowed interested candidates to contact the principal researcher in case of any query. Advertising to

promote recruitment was also done through media by posting on various social platforms comprising WhatsApp™ (Facebook Inc., Mountain View, California, USA), Facebook (Facebook Inc., Menlo Park, CA, USA), and Twitter (Twitter Inc., San Francisco, California, USA). In addition, Indian associations in Australia including the United Indian Association and Australian Hindi Indian Association were emailed to seek assistance in reaching a wider audience. Word of mouth was employed to enhance recruitment. Recruitment continued from December 2020 to February 2022.

#### *5.4.2.2 Data collection*

The study questionnaire was initially developed using existing survey items identified from the literature reviews (Papers 1 and 2) and the findings from the qualitative phase with Indian immigrants and GPs (Papers 3 and 4). The questionnaire (Appendix-13) consisted of 88 items guided by the conceptual model of the study (Figure 4.1) which were categorised into six domains. These domains sought information from the participants' perceived oral health status, oral cancer risk-related knowledge, attitudes toward oral cancer risks, practices relating to oral cancer risk, general/oral health care access, and sociodemographic (with sociocultural) variables. The survey items were displayed using a combination of multiple choice, Likert scale and open-ended response formats. To ensure content validity, the preliminary draft of the study questionnaire was reviewed with the help of an expert panel consisting of academic and clinical experts in the field of oral cancer, dentistry, and public health (*n*=5).

The expert panel had members from the research team and an external reviewer Prof. Saman Warnakulasuriya (Professor Oral Med and Experimental Oral Pathology/Cons, WHO Collaborating Centre for Oral Cancer King's College, London, UK), who provided

guidance on the survey tool/questionnaire. Minor revision of items was undertaken following comments from the panel. Afterwards, the revised survey was pilot tested with Indian immigrants (*n*=7) from the earlier qualitative interviews who had provided consent (Phase 2). Participants were asked for feedback on the flow and clarity of the questions as well as estimated completion time. The study questionnaire was then modified according to suggestions, and the final version of the survey was used for data collection through the online platform Qualtrics (Experienced management company, Seattle, USA). Qualtrics offers a cloud-based subscription software platform and is simple to use as a web-based survey tool for conducting survey research, evaluations, and other data collection activities. The average time to complete the survey was estimated at 10-15 mins. No incentive was offered to participants. Submission of a completed online questionnaire implied consent to participate.

The measures which formed part of the study questionnaire (Appendix-13) are listed below (and in Table 5.1). The standardised questions which were previously validated to assess oral health status and oral cancer risk behaviours were used where available and are referenced in Table 5.1.

***Table 5.1*** *Description of the Study Questionnaire and Alignment to Conceptual Model*

| Domain | Description | Constructs from KAP and HBM model |
|---|---|---|
| **Perceived oral health status** | • 4 items<br>• A single item question widely used in the previous studies (Poudel et al., 2018; Sanchez et al., 2019) to assess overall oral health status (excellent, very good, good, fair and poor).<br>• A single item question to describe teeth, gum and mouth problems (yes, no), with a list of most common oral health problems/concerns found in people (Saraswat et al., 2020). | |
| **Knowledge regarding oral cancer and associated risk factors** | • 27 items<br>• Sourced from previous studies and included some validated items (Merchant et al., 2016). | Knowledge |
| **Attitudes toward oral cancer risks** | • 19 items<br>• Sourced from previous studies and included some validated items (Merchant et al., 2016). | Attitudes<br>Perceived Benefits<br>Perceived Susceptibility<br>Perceived Barriers |
| **Oral cancer risk-related practices** | • 9 items<br>• Sourced from previous studies and included some validated items (Merchant et al., 2016). | Practices |
| **Health care access** | • 13 items<br>• Sourced from previous studies and included some validated items (Merchant et al., 2016). | Practices<br>Cues to action |
| **Socio-demographic and Socio-economic questions** | • 16 items | Modifying Variables |

#### *5.4.2.3 Sample size*

The sample size was initially calculated based upon the expected proportion of the population that could engage in risk behaviours for oral cancer (e.g., betel nut/quid chewing). Based on international studies which reported a range between 34%-69% in this population group (Indians in this context) (Changrani et al., 2006; Khan et al., 2000; Merchant et al., 2016; Petti & Warnakulasuriya, 2018; Siddique & Mitchell, 2013), similar range was predicted in the Australian context. Following the completion of the first 100 surveys by the participants, we reassessed the population at risk to be 20%. Using G-power calculation software (Faul et al., 2009), in order to estimate a population proportion of approximately 20% with 95% confidence and allowing for a 5% margin of error, a total of 246 participants were required. Assuming a roughly 80% response rate (Changrani et al., 2006; Petti & Warnakulasuriya, 2018; Siddique & Mitchell, 2013), a total of 308 participants were needed to be approached.

#### *5.4.2.4 Data analysis*

Data were analysed using IBM SPSS (Statistical Product and Service Solutions) Version 27 software [v.27, IBM, New York, NY, USA]. Descriptive statistics (mean and standard deviation for continuous variables and frequency counts and percentage for categorical variables) were used to summarise socio-demographic, socio-economic and health specific characteristics, self-reported oral health status, and oral cancer-related knowledge, attitudes, and practices. Pearson's Chi-square tests were calculated to determine the associations between categorical variables, including oral cancer-related practices and attitudes. Group differences in continuous variables, e.g., knowledge, were

either assessed using independent samples T-tests if normally distributed, otherwise the Mann Whitney U tests. The significance level for all analyses was set at $p<0.05$.

#### *5.4.2.5 Study rigour*

Rigour in quantitative research is achieved through the measurement of validity and reliability (Heale & Twycross, 2015). Several techniques were undertaken to ensure the rigour in this phase of the study. The questionnaire used available standardised items which were already validated in previous research. Content validity of the questionnaire was assessed by an expert panel consisting of clinicians, academics, and educators in the field of cancer, dentistry, public health, and nursing ($n$ = 5). Their feedback and suggestions on the survey items were sought through qualitative feedback, and based on their comments, minor revision of items was undertaken. The modified questionnaire was then piloted with seven Indian immigrants in Australia to assess readability and face validity. The comments received from pilot testing were addressed and the survey questionnaire was revised accordingly.

## 5.5 Integration of the Qualitative and Quantitative Results

Mixed methods research relies on utilising strengths of both qualitative and quantitative approaches to emphasise the significance of the overall findings. Thus, the integration or linking of available sets of data in an appropriate way is pivotal in defining mixed methods research and highlighting its value (Berman, 2017). Integration can occur during various stages of the research process, mainly at the study design, methods and data interpretation levels (Kroll & Neri, 2009). For the ALARRM study, data integration was done at the following levels:

## 5.5.1 Integration at study design level

Integration was done at the study design level by employing an exploratory sequential design (detailed in 5.3.1) (Fetters et al., 2013). The qualitative data collected and analysed from semi-structured interviews with Indian immigrants and GPs helped in the identification of key concepts, which in turn informed the development of the quantitative questionnaire for data collection. Oral cancer risk behaviours of Indian immigrants were initially probed through concurrent interviews with participants (Indian immigrants and GPs), which included questions around emerging risk factors (e.g., areca nut use). The emerging findings were then further explored in the cross-sectional survey of the Indian community in Australia. In addition, provision of oral cancer preventative services in the primary care settings came up as a new concept during the qualitative phase, which was further explored in the quantitative questionnaire by asking Indian immigrants if they had received any kind of oral cancer information during routine medical visits in Australia.

## 5.5.2 Integration at methods level

Integration at this level was achieved by the linking of data collection and analysis methods. The 'building' approach was used for this type of integration (Fetters et al., 2013). The data collection method of the qualitative phase informed the data collection method for the quantitative approach. The items for the study questionnaire were extracted from the findings of the qualitative data. For example, the health care practices and preferences (in terms of health professionals) of Indian immigrants were identified in interviews and further

explored in the survey by asking them about their perceptions of the capacity of GPs regarding oral cancer prevention services and willingness to participate in such services.

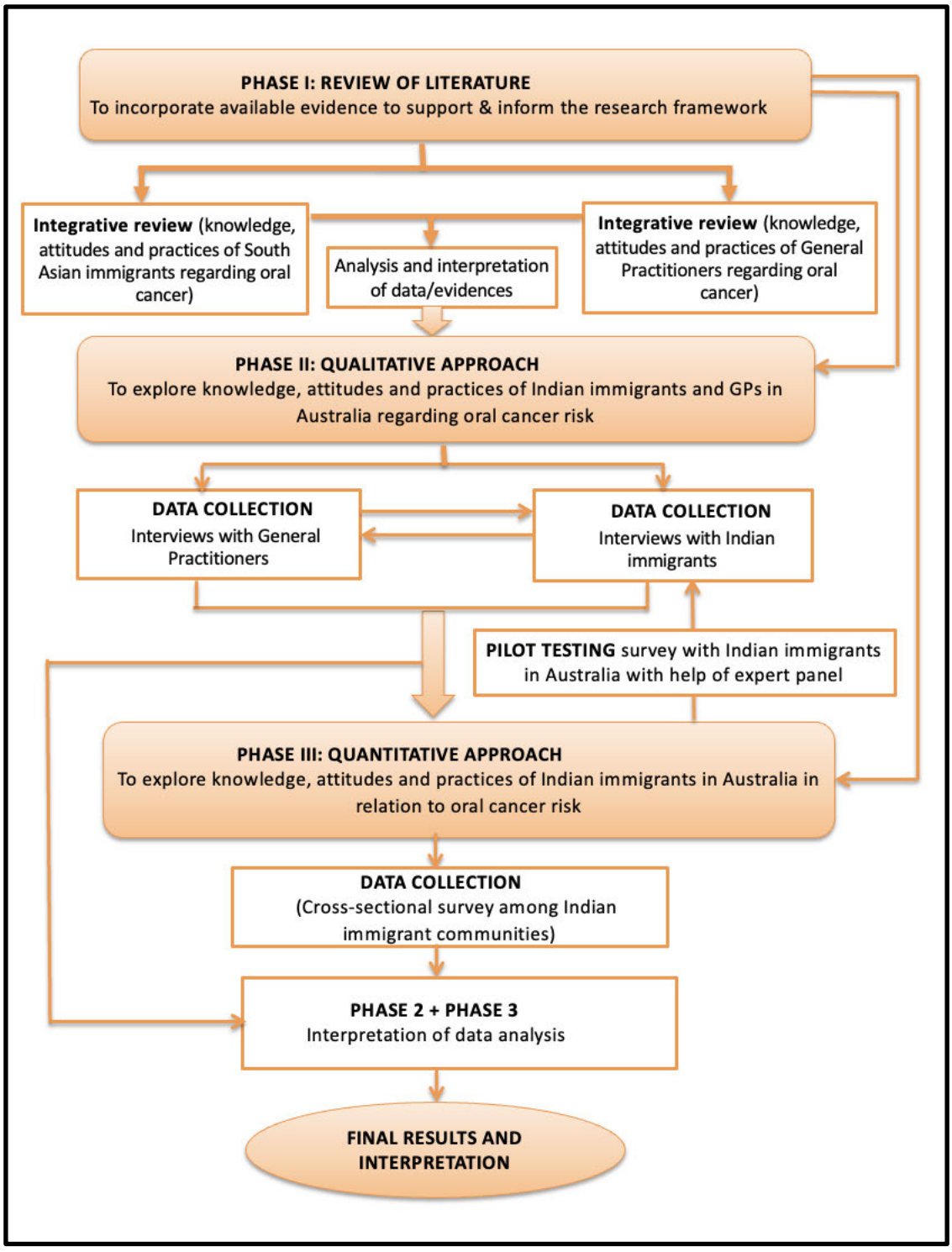
### 5.5.3 Integration at the interpretation and reporting level

A 'narrative' approach was employed to achieve integration of data at the interpretation and reporting (discussion) levels (Fetters et al., 2013). Though the findings from the qualitative and quantitative phases were published separately, integration was done while interpreting and discussing the overall results. This integration was attained by the weaving style, where both qualitative and quantitative results were discussed on concept-by-concept basis. The findings from the interviews and surveys with Indian immigrants were discussed together, then other concepts were discussed including oral cancer preventative strategies and recommendations. An intense search of existing literature was conducted seeking additional information to inform strategies to raise oral cancer awareness, particularly among Indians in Australia.

Figure 5.2 provides a schematic diagram of the study and shows the methods of data collection, analysis, integration, and interpretation during the different phases:

***Figure 5.2***

*Schematic Diagram of Study*



## 5.6 Ethical Considerations

In Australia, Human Research Ethics Committees (HRECs) have the overall responsibility of reviewing research proposals involving human participants. Ethics approval for the ALARRM study was obtained from Western Sydney University HREC (approval ref: H13203), which is one of the certified reviewing HRECs in Australia. The approval letters are provided in appendix (Appendix-14).

This PhD study was conducted in compliance with the values and principles outlined in the National Statement on Ethical Conduct in Human Research (NHMRC, 2018) for ethical design, conduct and dissemination of results. The National Statement was developed jointly by the National Health and Medical Research Council, the Australian Research Council and Universities in Australia (NHMRC, 2018). The core values provided in the National Statement include research merit and integrity, justice, beneficence, and respect. The Australian Code for Responsible conduct of Research also outlines eight principles for the ethical conduct of research, which includes: honesty, rigour, transparency, fairness, respect, recognition, accountability and promotion (NHMRC, 2018). These are embedded in the values of the National Statement, and are reflected in the design, review and conduct of this PhD study.

### *5.6.1 Research merit and integrity*

Research that has merit should be justifiable by its potential benefits and be appropriately designed or developed to meet the aims of the research proposal, based on the thorough review of the literature and ensuring that respect for the participants is not compromised by the way research is carried out (NHMRC, 2018). Research conducted with integrity should be committed to its contribution to the search for new knowledge and

understanding. In addition, researchers should follow the recognised principles of research, conduct and honesty throughout the process of designing, conducting research and dissemination of the results, whether favourable or unfavourable (NHMRC, 2018).

The design, data collection, analysis, and dissemination of the results of this study were undertaken in accordance with the values and principles summarised in the National statement. A prior comprehensive literature search was conducted to synthesise the current evidence and identify gaps regarding oral cancer risk-related behaviours of the Indian immigrants as well as the perceptions and practices of GPs in this area. To further support research merit, the current PhD project was peer reviewed by an expert panel as part of the confirmation of the candidature (CoC), which is a formal requirement of the Western Sydney University for PhD candidates. The CoC was a meticulous review process of the research progress and plan, which is usually completed within the first year of starting the candidature.

Strict confidentiality was maintained while treating all the information or data collected, and the privacy of the participants was carefully protected. For the qualitative data collection and analysis process, participating Indian immigrants and GPs were de-identified throughout transcription to ensure anonymity of participants. Pseudonyms were used when direct statements and quotes from individuals were used to represent the findings. Similarly, online submission of the survey questionnaire was anonymous. Electronic data were stored on a password protected computer and hard copies of data were stored in a locked filing cabinet at Australian Centre for Integration of Oral Health (previously known as COHORT–Centre for Oral Health Outcomes & Research Translation), at the Ingham Institute for Applied Medical Research. The data were only accessible by the supervisory

team. All data will be stored securely for seven years, after which all electronic files will be erased, and paper copies shredded. Dissemination of the results included publications in peer reviewed journals and presentation at national and international conferences.

### *5.6.2 Justice*

Research that is just should ensure fair selection and inclusion of research participants, and research participation should not be a burden on any population groups. Similarly, the research should ensure that there is fair access to its benefits. In addition, a fair distribution of benefits of participation in the research, without exploitation of participants in the conduct of research, should be ensured. The outcomes of the research should be accessible to the participants, in a timely and clear way (NHMRC, 2018).

All participants (Indian immigrants and GPs) in this study had equal opportunities to participate. The inclusion/exclusion criteria for the qualitative and quantitative phases were clearly identified and specified in the research protocol as well as participant information sheets, according to which the participants were recruited. Participant information sheets also provided information regarding the estimated time to complete the interviews and survey. The interviews with Indian immigrants were conducted at a place and time convenient for them. Likewise, interviews with GPs were scheduled on the day and time as per their availability. The study provided a $50 (AUD) voucher to Indian immigrants and GPs as a token of appreciation for participating in the research. The online survey was anonymous and completely voluntary with an option to leave the survey if participants wanted to quit.

The participant information sheet also included information regarding an option to

access the study results. Participants could select to receive results of the study or contact the investigator (via email/phone) to obtain the same if interested.

### *5.6.3 Beneficence*

Research should be designed to minimise the risks of harm or discomfort to participants and the likely benefit from research must justify any such risks (if any) to the research participants. Researchers should clarify the potential benefits and risks of the research to the participants while being responsible for the welfare of the participants in the research context (NHMRC, 2018).

The study participants (Indian immigrants and GPs) were informed that there were no anticipated risks of participation in the research, nor would their non-participation interfere with their relationship with the researcher or organisation (Western Sydney University) in any way. Steps were taken to minimise the risks which included collecting data in a respectful and sensitive manner. In addition, information was provided (verbally in interviews and in participant information sheets) about the available counselling services if participants felt uncomfortable or distressed and wished to receive support.

### *5.6.4 Respect*

Respect is recognition of human beings' intrinsic value and in research it includes abiding by the values of research merit, integrity, justice, and beneficence (already discussed in the preceding sections). The research should regard the autonomy of participants to make their own decisions. Respect in research requires the recognition of the welfare, beliefs, perceptions, customs, and cultural heritage of participants involved in the research (NHMRC, 2018).

The participants in this study were informed about the study aims and objectives. Furthermore, any benefits and/or risks of their participation in research were described in the participant information sheet. During qualitative data collection it was ensured that participants were all mature adults and were able to make an informed choice to participate or decline participation in the study. The option to withdraw was available to all the participants at any stage of the study without any negative consequences. All participants also had an opportunity to ask questions and seek clarification regarding the research prior to providing informed consent. The significance of participation in the research was explained by stating that the information collected would assist in developing strategies for oral cancer preventative strategies and help raise awareness in Australia, particularly for at-risk populations like Indian immigrants.

## 5.7 Conclusion

This chapter has presented the research methodology and methods employed in the ALARRM study. The chapter also outlined the process of the integration of the qualitative and quantitative phases and explained ethical considerations in the design, review, and conduct of the study. The following three chapters will present the study findings from the qualitative and quantitative phases, which comprise three published papers.

# Chapter 6: Qualitative Results

# (Indian immigrants – published)

## 6.1 Overview: Thesis Paper 3

The previous chapter presented the research methods and ethical considerations of this study. This chapter presents the findings from the qualitative phase, which explored the oral cancer knowledge, attitudes, and practices of Indian immigrants residing in suburbs of Sydney and Melbourne in Australia. This information is related to the external factors, cues to action, oral cancer-related knowledge, attitudes, and practices as per the conceptual model (*Figure* 4.1). The findings are published (Thesis Paper 3) in the Australia and New Zealand Journal of Public Health (Reference below).

Saraswat, N., Prabhu, N., Pillay, R., Everett, B., George, A. (2021). Oral cancer risk behaviours of Indian immigrants in Australia: A Qualitative Study. *Australian and New Zealand Journal of Public Health*, *46*(1), 87-94. Doi: https://doi.org/10.1111/1753-6405.13183

## 6.2 Aim: Thesis Paper 3

The overall aim of the paper was to explore the oral cancer risk-related knowledge, attitudes, and practices of Indian immigrants in Australia (Table 4.1; study objective 3). The specific research questions were as follows:

- What are the oral cancer-related knowledge, attitudes, and practices of Indian immigrants in Australia?
- What are the perceived barriers for Indian immigrants to access oral cancer information and related health care programs?
- What are Indian immigrants' suggestions to promote oral cancer awareness

among Indians in Australia?

## 6.3 Conclusion: Thesis Paper 3

The sample of Indian immigrants reported limited oral cancer-related knowledge with varying attitudes in this area, particularly around the adverse effects of areca nut preparations. Participants also revealed a limited availability of information around oral cancer risks in primary and community health care settings in Australia. Financial and time constraints were reported as the main barriers to accessing routine oral cancer check-ups. Potential strategies suggested by interviewees to increase oral cancer awareness included GP counselling, advertising through pamphlets/brochures, educational seminars during social gatherings and public events. The next chapter (Chapter 7) will present the findings of the qualitative interviews with GPs.

# Oral cancer risk behaviours of Indian immigrants in Australia: a qualitative study

Nidhi Saraswat,[1,2] Neeta Prabhu,[3,4] Rona Pillay,[2] Bronwyn Everett,[1,2] Ajesh George[1,2]

## Abstract

**Objective**: Oral cancer is widespread in South Asia, particularly India. In Australia, Indians are one of the fastest-growing communities. This study aimed to explore the oral cancer-related knowledge, attitudes and practices of Indian immigrants in Australia.

**Methods**: Fourteen semi-structured interviews were conducted with Indian immigrants residing across New South Wales and Victoria. Purposive and snowball sampling were used for recruitment. Data were analysed through a directed content analysis approach.

**Results**: All participants were knowledgeable of oral cancer risks associated with tobacco and alcohol, but few were familiar with the harmful effects of areca nut preparations. Varied attitudes were evident with most participants acknowledging the importance of oral cancer check-ups, yet very few followed this practice. All participants admitted engaging in oral cancer risk practices including areca nut use at least once or more in their lifetime.

**Conclusion**: Oral cancer risk practices are common among Indian immigrants in Australia who possess limited knowledge with varying attitudes in this area.

**Implications for public health**: Preventative strategies are needed to limit the use of oral cancer risk products among Indian immigrants. General practitioners and community organisations can play a key role in raising awareness in this area.

**Key words**: Oral cancer, Indian immigrants, risk behaviours.

Migration has been a key factor impacting social and economic transformations globally. In 2019, about 272 million international migrants were estimated worldwide, which is approximately 3.5% of the total population.[1] Although migration is a global phenomenon, a significant number of the immigrants reside in developed and high-income countries including the US, the UK, Australia, Canada, New Zealand and Switzerland.[2] Of all international immigrants, more than 40% come from Asia, primarily from South Asian countries such as India, Pakistan and Bangladesh.[1,3] Australia is a major 'immigration nation' with overseas immigration being the main driver of population growth.[4] More recently, India was reported as the largest source country of immigrants with 25,698 places (approximately 18.3%) in Australian immigration followed by China (18,587 places) and the UK (10,681 places).[5] Immigration at such a large scale has brought with it a unique blend of diverse cultures and beliefs from different parts of the world.

Migration generates great opportunities yet it can also be challenging for immigrants to integrate into new settlements with different norms and customs.[6] Almost all immigrants are believed to bring with them their native cultural behaviours, practices, and oral health beliefs, which modifies the patterns of oral diseases in destination countries.[7] Among such oral diseases, oral cancer has become a serious public health concern.[8] The prevalence of oral cancer is increasing worldwide[9] and the rise of cases in high-income countries over recent decades coincides with increased immigration from South Asia.[7] Oral cancer is widespread in South Asia[10] and is a leading cause of cancer-related mortality in India,[8,10] ranking among the top three cancers and accounting for over 30% of all cancers reported in India.[11] The seriousness of this health burden can be interpreted from a GLOBOCAN report which estimated approximately 119,992 new lip and oral cavity cancer cases in the year 2018.[12] This high prevalence of oral cancer among Indians is mostly attributed to the widespread use of tobacco products, especially smokeless tobacco and culturally embedded customs of areca (betel) nut preparations along with alcohol consumption and poor dietary habits.[13] The well-established practices of areca nut use and betel quid ('pan') chewing are so well-accepted in the Indian subcontinent as a custom that Indians are well known for sustaining this cultural practice long after emigrating to other countries.[14]

The continuation of cultural practices of South Asians after immigration has been speculated to be linked with the rise in oral cancer cases in destination countries.[7,10]

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Furthermore, a recent review has confirmed that South Asian immigrants lack adequate knowledge regarding oral cancer risk with a strong inclination towards negative oral cancer risk practices including the habit of areca nut chewing.[15] Given oral cancer is prevalent in India,[13] this elevated risk with associated habits is suspected to be carried by Indians to other countries[7] as it is the largest source country of immigrants.[1]

Historically, oral cancer has received little attention in Australia because of its relatively low prevalence and incidence.[16] However, an increase in registration of new cases over recent decades presents a serious health threat.[17] More than 4,000 new cases of head, neck and lip cancers are diagnosed each year in Australia with more than 600 of these cancers comprising oral cavity cancers.[18,19] Furthermore, the mortality rate has remained almost the same in the past decade even with fluctuations in the number of oral cancer reports,[17] which is more alarming. This increase in oral cancer cases could be explained by the rise in the population[20] in recent decades and can be connected with the increasing immigration from South Asia, particularly India.[21] In Australia, Indians are one of the fastest-growing communities forming about 2.6% of the total population.[22] Since tobacco consumption is linked to the development of oral cavity cancers,[20] an increase in such cases may be linked to Indians continuing to indulge in tobacco and areca nut use in Australia.[23,24]

The potential link between cultural risk practices of Indian immigrants and oral cancer cases has already been investigated in major developed countries including the UK,[25,26] the US,[27,28] Italy[29] and New Zealand[30] with a view to raising cancer awareness among these populations. Unfortunately, very little is known about oral cancer-related risk among Indians residing in Australia.[16,31-33] Gathering this information can help identify communities at risk for developing oral cancer in the country. The overall aim of this study was to explore the oral cancer risk-related knowledge, attitudes and practices of Indian immigrants in Australia.

### Research questions

The following research questions guided this study:

- What are the oral cancer-related knowledge, attitudes and practices of Indian immigrants in Australia?
- What are the perceived barriers for Indian immigrants to access oral cancer information and related healthcare programs?
- What are Indian immigrants' suggestions to promote oral cancer awareness among Indians in Australia?

## Methods

### Approach

A qualitative approach[34] was chosen for this study to help explore the perceived knowledge, attitudes and practices[35] of the Indian immigrants regarding oral cancer risk. The data for this paper were collected through interviews with Indian immigrants from two large states in Australia: New South Wales and Victoria. This study was conducted as part of a broader mixed methods study.

### Sampling and recruitment

The inclusion criteria for this study consisted of Indian immigrants over the age of 16 years residing in suburbs of New South Wales and Victoria. In Australia, the states of New South Wales and Victoria have been very popular places for Indian immigrants to settle, who often have a preference for the capital cities, Sydney and Melbourne, respectively.[36]

The minimum age to participate was 16 years, as previous literature has revealed that risk practices (e.g. betel quid chewing) are prevalent and popular among all age groups of Indians.[7,37] No exclusion criteria were set based on age, gender, residency status, place of origin in India or number of years living in Australia, as current evidence internationally has shown oral cancer risk-related behaviours to be prevalent across these variables.[15] All attempts were made to ensure the recruited participants had representation across all these variables. Both purposive and snowball sampling techniques[34] were used to recruit participants. Recruitment was also undertaken through flyers advertised at various grocery stores and restaurants in suburbs which were known to be densely populated with Indians.[36] A participant information sheet was provided to candidates who contacted the principal researcher (NS) directly or expressed an interest in this study through other participants by word of mouth.

### Data collection

An interview topic guide (See Supplementary File 1) was developed based on our review of the literature[15] and refined by the multidisciplinary team involved in this research. This guide broadly included questions about oral cancer-related knowledge, attitudes and practices of Indian immigrants in Australia. A total of 25 participants were identified for recruitment and 14 were interviewed, giving a response rate of 56%. These 14 interviews were conducted face to face and over the telephone at a time/place convenient to participants. The principal researcher (NS) who was trained in qualitative research and had no prior relationship with any of the participants conducted all the individual interviews. Another researcher (RP) from the research team was present during the first interview (conducted face to face) for support. Data collection commenced in August 2019 and was completed in January 2020. Interviews were conducted in English and a semi-structured interview process was followed by the researcher to ensure that participants spoke freely on each question with the use of open-ended questions and follow-up probes. Each interview lasted 30–45 minutes. Participants were also given an opportunity at the end of the interview to add any further comments not addressed in the interview.

All participants provided either written informed consent for face-to-face interviews or verbal consent for the telephone interviews. Recruitment and data collection continued until data saturation where no new information emerged from the interviews.[34] Demographics of the participants including age, gender, occupation, and educational qualification were collected at the end of the interview (see Supplemenary information).

### Data analysis

All interviews were audio-recorded by the principal researcher and then transcribed by a professional transcription service. Transcripts were checked against the audio for accuracy and imported into qualitative data management software (QSR NVivo 12). The transcripts were analysed for categories using directed qualitative content analysis (QCA).[38] This commenced with immersion in the data by reading and re-reading transcribed interviews to gain familiarity with the data and to record initial ideas. A formative categorisation matrix based on the findings from an integrative review of knowledge, attitudes and practices of South Asians regarding oral cancer[15] directed the


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initial coding of the transcripts. All authors (PhD candidate [NS], two practising/academic dentists [AJ and NP] and two nurse academics [RP and BE]) undertook the initial coding by reading three transcripts each. Over the course of two meetings, a coding structure was developed by the researchers, and this was used to code the remaining transcripts. After the initial analysis was completed, the first author (NS) went back through the coded excerpts and identified sub-categories that were then discussed with the other researchers in the team until consensus was achieved.

### Ethical considerations

The study received ethics approval from the Human Research Ethics Committee of Western Sydney University (H13203). All participants were given a gift voucher (AU$50) as reimbursement for their time. The audio recordings and transcripts were stored on a password-protected computer as per institutional and ethics committee requirements. All participants were de-identified throughout transcription to ensure the confidentiality and anonymity of the participants. Pseudonyms (*P1*, *P2*, *P3*, *P4*……*P12*, *P13*, *P14*) were used to present statements by participants.

### Rigour

A number of methodological strategies were used in this study to address trustworthiness – the criteria for robust qualitative research (credibility, transferability, dependability and confirmability).[39] All interviews were conducted by a researcher trained in qualitative research to develop a relational focus with the interviewee for active engagement while also establishing trust and rapport. Debriefings were organised with another researcher (AG) to discuss the completeness of data and any new areas to explore in subsequent interviews. A professional transcription service was used to improve the accuracy of the verbatim transcriptions of the audio recordings as it allows reference to the exact words of participants during the analysis. Member checking of the transcripts was undertaken with five participants who indicated they wished to review their transcripts; however, no changes were requested. To promote credibility and reflexivity, individual coding was done by all researchers in the team confirming their active involvement and then consensus was achieved with numerous team meetings. Detailed information about the participants, study settings, and data collection process are provided to ensure transferability and findings are supported by direct quotes of the participants. Reporting of this qualitative research has been undertaken using the Consolidated Criteria for Reporting Qualitative Studies (COREQ): 32- item checklist (See Supplementary File 2).

### Definition of terms

The terms 'knowledge', 'attitudes' and 'practices' have been used widely in this paper. For the purpose of this paper, the definition of 'knowledge' refers to one's awareness, level of information and understanding regarding oral cancer risk.[15] 'Attitudes', in this context, has been used to depict the inclinations, perceptions, and beliefs of the people associated with oral cancer risk.[15] The 'practices' of the participants relates to a person's oral cancer risk-related habits and the actions regarding initiation, continuation or quitting of these habits.[15] The reference to 'risk products' has been used to depict commonly consumed tobacco and areca nut preparations.[40] 'Immigrant', in this paper, refers to a person who moves into a country other than that of his/her nationality.[41]

## Results

### General characteristics

Fourteen Indian immigrants (10 males and 4 females) residing in different suburbs of New South Wales (*n*=12) and Victoria (*n*=2), were interviewed. Participants ranged in age from 25 to 59 years, with most (*n*=13) being Australian residents for more than five years. Most participants (n=10) were university graduates and were employed (n=11) at the time of interviews. Participants originated from all parts of India, but the majority (n=9) were from Northern and Western India. The main religion reported among participants was Hindu (n=10). Supplementary Table 1 displays detailed demographics of the participants.

Three main categories and nine subcategories were identified from the interviews. These included:

**1. Knowledge about oral cancer:** *Signs/ symptoms and related risk factors; Availability and accessibility of oral cancer risk products; Sources of oral cancer information.*

**2. Attitudes towards oral cancer:** *Perceptions of oral cancer in Australia; Reasons for engaging in oral cancer risk behaviours; Views about oral cancer prevention and early risk assessment.*

**3. Oral cancer risk practices:** *Frequency and types of oral cancer risk product use; Initiation and continuation of oral cancer risk practices; Preventative healthcare practices.*

### Knowledge about oral cancer

#### *Signs/symptoms and related risk factors*

All 14 participants had heard about oral cancer, yet only four were aware of its signs and/or symptoms. As one young male participant stated: "I heard about the oral cancer, but I don't know how it happens". (P5, Male, 25-29 years)

There were varying levels of knowledge among participants regarding the causes of oral cancer. While the effects of tobacco and alcohol consumption and their relation to oral cancer were commonly known, less than half (*n*=5) were aware of the effects of areca (betel) nut preparations (supari/gutkha). This lack of knowledge was evident irrespective of the age, sex and education level of the participants. For example:

> *Betel nuts, I didn't have much idea that this must be causing cancer, because that's a common thing being used in India for occasions.* (P10, Female, 35–39 years)

> *I don't have much information about the betel nut, but I know about tobacco for sure.* (P14, Female, 25–29 years)

> *…Betel nuts, actually, I am hearing this word first time.* (P1, Male, 55–59 years)

> *…there is a chance of oral cancer, if it relates to the smoking. I don't know if it is related to the smoking only or related to the supari or gutka [referring to areca/betel nut preparations].* (P5, Male, 25–29 years)

#### *Availability and accessibility of oral cancer risk products*

Several participants (*n*=10) reported being familiar with the selling of commercial areca (betel) nut preparations in Asian/Indian grocery stores and restaurants in Australia. For instance:

> *They're [products] available if you look for it, you can find them.* (P7, Male, 45–49 years)

Many (*n*= 6) recalled that tobacco preparations were readily available while areca (betel) nut products were often acquired through relatives or friends travelling from India. As one middle-aged male interviewee stated, "They bring bulk


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quantity from India and here also they purchase, local market". (P9, Male, 45–49 years)

Five participants were unaware of the legal requirements concerning procurement and selling of these products in Australia:

*I'm not sure illegally or legally they are selling, but possibly yeah, you know, they're selling some items here…* (P11, Male, 30–34 years)

Four participants indicated that these products are expensive in Australia and most people tend to buy them from India for a lower price.

### *Sources of oral cancer information*

The major source of information about oral cancer was through the media, either print (e.g. newspaper, posters) or multimedia (e.g. TV commercials, advertisements during movies) though it was largely obtained from India:

*Usually when I watch the movies or when I watch the TV shows or something, I see the advertisements…sometimes by reading some magazines or something, I have seen what oral cancer is.* (P10, Female, 35–39 years)

Three participants mentioned receiving information about oral cancer from general practitioners (GPs) or dentists in Australia, but the rest of the participants expressed the contrary:

*I never seen any, much awareness information available on normal GP or normal medical centre in Australia.* (P11, Male, 30–34 years)

## *Attitudes towards oral cancer*

### *Perceptions of oral cancer in Australia*

There was overall agreement that oral cancer could be an emerging health concern in Australia as more Indians have migrated in recent years, although participants felt currently it was not an issue when compared to India. Participants explained the potential seriousness of the situation as:

*It is a problem but it's not a dominating one at this stage. But it could get to a level because there is too much immigration, there is too much import of everything…So it can spread.* (P6, Female, 25–29 years)

### *Reasons for engaging in oral cancer risk behaviours*

There were diverse beliefs about why Indians continued to indulge in the use of tobacco or betel/areca nut products after migrating to Australia. Just over half the participants (*n*=8) commented that such habits were a result of addiction:

*… But people who have addiction and they are migrating here, I think 90% or I think 80% they continued that.* (P1, Male, 55–59 years)

Lack of awareness about oral cancer and related health hazards was brought up by half the participants (*n*=7) as a major factor for persistent oral cancer-related risk habits of Indian immigrants.

*People are using it from ages. I'm pretty sure 90% of the people, they are affected by it. After they get affected, then is the time when they actually know that, oh, it was bad for health.* (P6, Female, 25–29 years)

Some believed lifestyle (*n*=4) and social network (*n*=2) coupled with easy access to tobacco as other reasons for Indian immigrants to continue indulging in these risk behaviours:

*Maybe some may feel that, my friends are having [the products], so why can't I have it? So, that may be a reason.* (P10, Female, 35–39 years)

*… so there are lots of people who are used to tobacco in India before they came here, so after they came here it might be easy to get those products, so it can happen.* (P11, Male, 30–34 years)

In contrast, few (*n*=4) remarked that Indian immigrants continue consuming tobacco and areca nut products despite being aware of the potentially fatal consequences:

*Though they know it is going to kill them, yet they are consuming that. They know it is dangerous product, yet they consume.* (P9, Male, 45–49 years)

### *Views about oral cancer prevention and early risk assessment*

A consistent viewpoint among participants was the need to raise oral cancer awareness among all Australians including immigrant communities.

*I think the awareness is needed. I feel not just Indians, I feel it should be spread among Australians as well…* (P13, Female, 30–34 years)

All participants acknowledged routine oral cancer check-ups as a crucial measure for early detection and management, yet nine of the participants did not have check-ups at the time of the survey.

*… definitely prevention is better than cure, so you should check it out, so … I never thought about it. So probably I will go this time for myself.* (P11, Male, 30–34 years)

Several participants reported barriers to oral cancer check-ups including financial constraints (*n*=4) and lack of time (*n*=5).

*I think so because some people who are not permanent residents and they worry about the fees [for doctors consultation fees] and everything …* (P12, Male, 35–39 years)

*Most of the migrants over here are super busy with settling down … So they don't have time [for oral health check-ups].* (P13, Female, 30–34 years)

Some participants (*n*=5) believed Indians would not prioritise preventive check-ups,

*Indians will only approach you if they're actually sick. Otherwise they have a treatment for anything called Panadol".* (P6, Female, 25–29 years)

Nearly all (*n*=11) believed their GP was the best person to assist with further information and diagnosis and three participants suggested dentists could also play a role.

*Because I think the initial stage if you are having any issues, you would firstly go to a GP in Australia … and then the GP would guide you to any specialist …* (P14, Female, 25–29 years)

Participants (*n*=7) also believed that Indians would be more receptive to receive an oral cancer risk assessment through a GP since they are comfortable talking to their GPs in Australia: "Now, in coming to this culture, Australian culture, they [Indians] are a little bit Australian as well. So, I don't think they are scared or they hide something. They are open to the GP". (P1, Male, 55–59 years)

However, some (*n*=5) indicated Indians might be shy or reluctant to consult a GP for oral cancer:

*Indians have a mentality they think they are very superiorly intelligent. So, they will not go to the GP to ask that because they will think they are looking dumb doing that …* (P6, Female, 25–29 years)

Potential strategies to increase the awareness of oral cancer included GP counselling (*n*=11), advertising through pamphlets/brochures (*n*=7), and educational seminars (*n*=5) during social gatherings and public events. A belief reflected by a middle-aged female participant: "When we have such awareness programs, then we can pass to our generations, to our children and kids so that they might live in a healthy environment…". (P10, Female, 35–39 years)

A small number of participants (*n*=4) questioned the impact of oral cancer awareness campaigns and seminars:


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*Campaigns will only help the people that are already affected. Why do you want to spend 50 minutes on a seminar which has nothing to do with you?…* (P6, Female, 25–29 years)

### Oral cancer risk practices

#### *Use of oral cancer risk products: frequency and type*

All participants admitted being involved in oral cancer risk practices at least once or more in their lifetime with betel quid/'pan' chewing being reported as the most widely used product. The habit of consuming areca (betel) nut products was found to be more popular particularly among participants who belonged to the Western part of India (Gujarat state); (*n*=6).

Hindu participants (*n*=7) also appeared to be more inclined towards occasional/frequent use of areca (betel) nut preparations especially during their festivals and social gatherings. As one Hindu female participant mentioned:

*So they [pan] are usually available on celebrations … Could be a wedding. Could be a birthday party. They've got specific stalls for it and people who want to take it, take it.* (P6, Female, 25–29 years)

Some practised frequent smoking (*n*=5) and use of smokeless tobacco preparations (*n*=4) e.g. *gutkha, khaini*. The dependence on these products was evident in the following quotes:

*Every day. Not only every day, I think 10 times a day. It's a very small quantity I am keeping inside between my teeth and chin [referring to tobacco chewing].* (P1, Male, 55–59 years)

*How many a day? It's like how many glasses of water did you drink, you know! [referring to smoking]* (P4, Male, 30–34 years)

Two participants discussed their addiction to tobacco chewing and expressed difficulty in quitting the habit: "So from college I think I started taking tobacco. So until now it's continued. In between these 35, 40 years, a lot of time I tried to leave that addiction…. After coming Australia as well I have tried a lot for time". (P1, Male, 55–59 years)

Furthermore, a handful (*n*=6) acknowledged being involved in occasional smoking, alcohol consumption and betel quid chewing:

*Smoking I can do alone, alcohol mostly I go with the friends like that, and pan also if there is someone there that wants to eat, then I eat.* (P3, Male, 30–34 years)

Five Indians reported transitioning to occasional use after moving to Australia because of costs and lack of easy access to the products. This was reflected in the following statement:

*Here I am taking less because it's not easily available … Because it's I think 10 rupees to 500 rupees [Currency in India]. So, it's 50 times costlier here …* (P1, Male, 55–59 years)

#### *Initiation and continuation of oral cancer risk practices*

Most frequently reported reasons (*n*=8) for initiation and continuation of risk practices for this behaviour were associated with social and family gatherings:

*Yeah, whenever we go for marriage parties, or something … we do get a chance to have those [betel quid/pan, supari] because they are being served, so we just have it.* (P10, Female, 35–39 years)

Other factors identified were cultural norms (*n*=5), pleasant smell and/or taste (*n*=4) of the risk products. Few participants felt a connection to their country of birth (*n*=3) while consuming tobacco or betel quid/'pan'.

#### *Preventative healthcare practices*

There was a wide variation reported in the preventative healthcare practices of participants with some (*n*=6) visiting their GP regularly while others (*n*=8) accessing this service only when they were unwell. The older participants (*n*=3) seemed to be more irregular in routine visits to health professionals:

*I never have to go GP or dentist because I am very healthy person. I don't think in five years, except one, this ulcer, I went to the GP.* (P1, Male, 55–59 years)

*No, I'm very irregular. It's more than a year I've been to the GP now.* (P7, Male 45–49 years)

Three participants preferred consulting a GP from a similar cultural background to help in better understanding some of their diseases:

*… some of the Indian diseases or maybe sickness is not popular in Australian GPs or Australian-born GPs or they've studied here …* (P3, Male, 30–34 years)

Dental visits were less frequent among participants, with some interviewees (*n*=5) reporting their last dental visit several years ago: "Not once a year. In 13, 14 years here in Australia, just once." (P4, Male, 30–34 years)

## Discussion

This is the first study to explore oral cancer-related knowledge, attitudes and practices of Indian immigrants in Australia. The majority of study participants were recruited from New South Wales and had diverse characteristics in terms of age, sex, religion, place of origin in India, educational backgrounds and number of years residing in Australia. Having this diversity was important in this exploratory study as oral cancer risk-related behaviours have been previously linked to these characteristics among Indian immigrants.[15] Further, since a greater proportion of Indian immigrants settle in New South Wales,[22,42] the sample recruited did represent the population of interest.

Overall, there was adequate knowledge among participants around oral cancer and associated common risk factors like tobacco and alcohol. However, there was limited understanding of the signs/symptoms of oral cancer and the harmful health effects of areca nut use. A clear agreement on oral cancer as an emerging health concern was apparent with diverse views about oral cancer risk behaviours and conflicting attitudes towards preventative oral cancer risk assessments. Furthermore, oral cancer risk practices were evident among participants along with limited preventative healthcare practices.

The lack of knowledge around regular consumption of areca nut products and oral cancer is consistent with previous studies which show high-risk communities are generally less aware of this causal relationship.[43,44] These findings mirror past studies from the US,[27,28,45] the UK,[46] Italy[29] and New Zealand,[30] where more than half the Indians assessed were unaware of oral cancer risk associated with the use of areca nut. Similar to previous literature,[15] the age, sex and education level of the participants did not appear to contribute to the poor knowledge relating to the role of areca (betel) nut as an oral cancer risk product. Although this finding needs to be further explored, it could stem from the fact that areca nut use has always been deeply rooted in cultural and social customs of Indian communities.[7] It has also been suggested that this lack of understanding around areca nut may be contributing to delays in the presentation and diagnosis of oral cancer cases.[45] An added factor that may be exacerbating the situation is the limited information on oral cancer being provided by general practitioners as cited by participants. This finding is in line with recent studies investigating oral cancer-related diagnostic practices of GPs in other developed countries,[47,48] which has highlighted their limited knowledge in the


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context of emerging oral cancer causes and its early identification.

Similar to previous qualitative research,[27,30] our study participants had good knowledge about the easy availability and accessibility of the risk products through many Asian/Indian grocery stores in Australia. Similar findings were reported in a recent study in the US,[49] which found areca nut products were readily available and easily purchased without appropriate health warnings from South Asian retailers in Texas. Another notable finding in our study was the confusion among participants over the legality of obtaining areca nut preparations in Australia despite the standard prohibitions on its sale and use.[50,51] These issues raise concerns as to whether proper monitoring is occurring at points of importation and distribution.

Despite concerns that oral cancer could be an emerging health issue in Australia and the importance of raising oral cancer awareness in the community, it is clear that the varying risk behaviours perceived by participants pose additional challenges. Like past studies,[7,52] participants cited the health benefits of deeply rooted cultural customs of areca nut chewing and social influence played a key role in engaging immigrants in these risk behaviours. Adding to this is the psychotropic nature of areca nut which leads to addiction following frequent consumption.[53] These varied attitudes coupled with limited knowledge and misconceptions seem to have influenced the practices of immigrants with all participants reporting to have engaged in at least one or more oral cancer risk practices (for instance, betel quid/'pan' chewing and tobacco use) in their lifetime. These findings highlight the popularity of such products among Indians and echo the results of a recent review which found such risk practices were popular across almost all age groups and generations of South Asians including Indians.[15] Similar to an older study conducted in the UK,[46] there appeared to be more inclination among the Hindu participants to engage in areca (betel) nut use, although there was more representation of this religion in our study sample. A possible explanation behind this could be the areca nut-related religious connotations and health beliefs that prevail among the followers of the Hindu religion.[7] Another interesting trend in the findings was the popularity of areca nut preparations among participants who originated from the western part of India. This finding complements earlier literature which found Indians from particular regions[54] of India such as Gujarat are more involved in areca nut use and likely to continue these habits after migration to other countries.[52] Further, as documented previously,[7,14] the initiation and continuation of these risk habits were found to be linked to social networks which can increase the tendency of Indians to continue these practices even after emigration.

The findings from this study are of concern and suggest the need for actions at the community, organizational and policy levels to curtail the use of oral cancer risk products among Indian immigrants.[55] One of the key areas is to increase awareness may be through culturally sensitive programs with various community groups. Considering Indian immigrants from certain parts of India may be more inclined in following oral cancer risk habits like areca nut/betel quid chewing, specifically tailored awareness programs for this population group might be useful.[26] Other strategies such as the use of posters raising awareness of oral cancer risks associated with betel quid/'pan' use could be displayed in Asian/Indian grocery stores, restaurants, places of worship, and at cultural events where high numbers of Indians usually gather. Social media like Facebook, Instagram and WhatsApp could provide an effective platform to spread relevant public health messages in addition to local Indian radio and television channels. Since different population subgroups with various ethnic origins and religious backgrounds present differences in the level of knowledge and health-related behaviours,[56] a clear understanding of their cultural practices might help to improve oral cancer awareness strategies and inform the development of effective preventative educational material. To our knowledge, no national resource is currently available in Australia for raising awareness of immigrants about areca nut use.

Additionally, it is vital for GPs, especially those serving large Indian populations, to play an active role in providing oral cancer information around emerging risk behaviours like areca nut chewing. This is particularly important as they are the first point of contact in primary health care in Australia and participants in this study were also receptive to the idea. Further, as seen in our study and confirmed by a previous study in the UK,[25] Indian immigrants were reluctant to see a dentist regularly which could stem from the fact that the concept of screening an otherwise healthy individual for an asymptomatic disease is not well understood by Indian immigrants.[7] Adding to this, older immigrants in our study appeared to be more irregular in visiting health professionals possibly because of prior dissatisfaction with health services or inconvenience in accessing services.[57] GPs thus have a narrow window of opportunity to raise awareness about oral cancer risk behaviours and the importance of early dental interventions among older Indian immigrants. For GPs to take up this role, it is important that additional training around emerging oral cancer risk factors and changing oral cancer trends is provided via continuing professional development programs and in undergraduate medical curriculum. Alongside this clinical practice, guidelines in this area need to be developed by health departments and professional organisations to ensure consistent practices.

Government agencies need to strengthen legislation around illegal buying and sale of areca nut products. Apart from this, the increased oral cancer burden highlights a growing need for opportunistic oral cancer screening[17] and effective monitoring systems to assess the oral cancer cases in immigrants in Australia. Finally, this study demonstrates the significance and need for continued research to understand more in-depth the behaviours of Indian immigrants regarding oral cancer. Targeted research with Indian immigrants based on the frequency of risk practices must be developed after examining existing beliefs and perceptions relating to the use of smokeless tobacco products so that appropriate counselling strategies can be established.

### *Limitations*

This study is not without limitations. The participants were mainly from New South Wales; therefore, the findings may not be representative of all Indian immigrants in Victoria and other parts of Australia. Although all attempts were made to ensure variety in the sample, future research should include second-generation Indian immigrants to understand their perspectives on oral cancer risk. As this study was limited to Indian immigrants it is also important to research other immigrant groups in Australia that may be engaging in similar oral cancer risk practices. Another potential limitation could be the researchers' influence on the participants' responses. Finally, the reported results are subject to information bias due


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to the self-reported data as well as social desirability bias, since the respondents may have under-reported their oral cancer risk behaviours and practices. Therefore, other methodological approaches for observational data like examining oral cancer risk behaviours at large scale community events (festivals, weddings etc) could minimise bias.

## Conclusion

This study has highlighted that oral cancer risk practices are common among Indian immigrants in Australia, and they have limited knowledge with varying attitudes in this area particularly around the adverse effects of areca nut preparations. There is limited information available in primary and community health care settings about the emerging oral cancer risk in Australia. Further research is warranted to confirm these findings and inform the development of culturally appropriate interventions involving general practitioners to raise awareness of oral cancer risk among Indian immigrants. Oral cancer is a global concern and is potentially a ticking timebomb in Australia due to immigration, and this research is a valuable first step in shedding some light on this topic.

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## Supporting Information

Additional supporting information may be found in the online version of this article:

**Supplementary Table 1**: Demographics of participants.


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# Chapter 7: Qualitative Results

# (GPs – published)

## 7.1 Overview: Thesis Paper 4

The previous chapter discussed the findings of the qualitative interviews with Indian immigrants. This chapter includes the findings of another qualitative phase involving interviews with GPs practicing in the suburbs of Sydney (NSW) and Melbourne (VIC) in Australia. These interviews explored the oral cancer-related knowledge, attitudes, and clinical practices of GPs. This aspect related to the external factors and cues to action constructs of the conceptual model (*Figure* 4.1). The findings are published (Thesis Paper 4) in the International Journal of Environmental Research and Public Health (Reference below).

Saraswat, N., Pillay, R., Prabhu, N., Everett, B., George, A. (2021). Perceptions and Practices of General Practitioners towards Oral Cancer and Emerging Risk Factors among Indian Immigrants in Australia: A Qualitative Study. *International journal of environmental research and public health*, *18*(21), 11111.

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## 7.2 Aim: Thesis Paper 4

The overall aim of the paper was to explore the oral cancer risk-related knowledge, attitudes, and clinical practices of GPs in Australia (Table 4.1; study objective 4). The following were the specific research questions:

- What are the oral cancer-related knowledge, attitudes and clinical practices of GPs in Australia?

- What is the perspective of GPs towards the emerging risk factors and practices among Indians living in Australia?
- What are the perceived barriers for GPs regarding oral cancer risk assessment and counselling of patients?
- What are GPs' recommendations to promote oral cancer awareness, particularly among high-risk populations like Indians in Australia?

## 7.3 Conclusion: Thesis Paper 4

This study identified good overall oral cancer-related knowledge of GPs but a limited awareness about emerging risk factors and habits, particularly among Indians in Australia. Varied beliefs of participants regarding the seriousness of oral cancer in Australia and inconsistent clinical practices relating to routine oral cancer check-ups were noted. The interviews also highlighted the lack of relevant oral cancer training for GPs. Suggestions made by GPs to address these barriers included Continuing Professional Development activities around oral cancer training. The next chapter (Chapter 8) will present the results of the quantitative survey with Indian immigrants.

International Journal of
*Environmental Research and Public Health*

MDPI

*Article*

# Perceptions and Practices of General Practitioners towards Oral Cancer and Emerging Risk Factors among Indian Immigrants in Australia: A Qualitative Study

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**Abstract:** Background: In Australia, Indian immigrants are one of the fastest-growing communities. Since oral cancer is widespread in India, the indulgence of Indians in customs of areca (betel) nut use in Australia may be linked to the recent rise in oral cancer cases. Since GPs (general practitioners) are primary healthcare providers, it is pivotal to ensure the oral cancer awareness of GPs. This study aimed to explore oral cancer risk-related knowledge, beliefs, and clinical practices of GPs in Australia. Methods: Fourteen semi-structured interviews were conducted with GPs practicing across New South Wales and Victoria. Purposive and snowball sampling were used for recruitment. Data were analysed through a directed content analysis approach. Results: All GPs were knowledgeable of major oral cancer causative factors including tobacco and alcohol, but some had limited understanding about the risks associated with areca nut preparations. Positive attitudes were evident, with all participants acknowledging the importance of oral cancer risk assessment. Most GPs recalled not performing oral cancer routine check-ups. Conclusion: GPs presented good oral cancer knowledge except for emerging risk factors such as areca nut use. Varied beliefs and inconsistent clinical practices relating to oral cancer screening is concerning. Accessible oral cancer training around emerging risk factors may benefit GPs.

**Keywords:** oral cancer; knowledge; awareness; beliefs; perceptions; clinical practices; general practitioners; Indian immigrants; Australia

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## 1. Introduction

Oral health is a fundamental component of general health and wellbeing. Poor oral health significantly impacts a person's quality of life [1] and poses a major health burden leading to pain, discomfort, infection, and even death [2]. Despite being largely preventable, oral diseases affect approximately 3.5 billion people worldwide and remain mostly neglected within general health policy [1]. Furthermore, several systemic diseases such as AIDS (Acquired Immuno-Deficiency Syndrome) are also present with early signs of lesions in the oral cavity [3]. These factors highlight the importance of routine oral examination as a vital step for the early detection of various diseases [4]. However, the widespread perception that oral diseases and lesions are limited to the scope of dental practice [5] has caused the marginalisation of oral health from mainstream developments in

healthcare systems [1]. Although dentists have a definitive and unique role in diagnosing oral cancer [6], the high cost of dental treatments deters patients from visiting dentists on a regular basis [7]. In addition, in most regions of the world including developed countries, access to affordable oral healthcare is limited and aggravated by poor awareness about oral diseases [8]. To address this, general practitioners (GPs) and many other non-dental health professionals (for example—physicians, physician assistants, nurses, nurse practitioners) may have potentially crucial roles to play in the prevention and management of oral diseases [8]. Importantly, GPs are often the primary contact for patients, and routine examination of the oral cavity by GPs could considerably reduce the morbidity resulting from serious oral diseases [4].

A particularly serious oral disease is oral cancer, which comprises 1–2% of all cancers that may arise in the body [9]. Oral cancer is among the top 15 most common cancers worldwide [1,10], and the global incidence of cancers of the lip and oral cavity had been estimated around 377,713 new cases for the year 2020 [11]. Oral cancers are generally chronic, and they are usually asymptomatic until an advanced stage [12]. They are generally associated with high mortality rates and expensive medical treatment [5]. When compared to other major types of cancers, oral cancer has one of the lowest five-year survival rates (50% or less in reported cases) [13]. However, survival rates of 70% to 90% can be achieved if this disease is diagnosed and treated at early stage [13]. Furthermore, oral cancer patients with early-stage disease often require less intervention [12]. This is also important because high-risk patients developing oral cancer, for example, the older, heavy tobacco and alcohol users are often irregular dental attendees and more likely to attend hospitals for medical needs [14]. Therefore, early detection in primary healthcare settings is a key to reduce diagnostic delay [15], and GPs can play a crucial role in the early identification of oral cancer through a mouth/oral cavity examination with basic equipment [16].

Oral cancer has a high prevalence in South Asia and is on the rise in other countries [10]. The leading risk factors for oral cancer are tobacco use, alcohol consumption, and areca (betel) nut chewing along with poor dietary habits [1,2]. In the past few decades, a rapid rise in incidence of HPV (Human Papilloma Virus)-associated oral cavity cancers has also been noticed in many developed countries [17]. It is a well-known fact that chronic alcohol and tobacco smoking can lead to delayed wound healing, which in turn increases the susceptibility to various infections, including oral cancer lesions [18]. On the other hand, South Asian countries including India, Pakistan, and Bangladesh have a long history of chewing areca nut preparations [10], which is also a socially accepted culturally-embedded custom in the Indian subcontinent [19]. Areca (betel) nut has carcinogenic potential, and areca nut chewing has been found to be significantly associated with poor prognosis in patients diagnosed with oral cancer [20]. India is considered the epicentre of oral cancer disease with the highest number of cases reported each year [21]. Given that India is the largest source of immigrants [22], the elevated risk associated with the above practices is suspected to be carried by Indians to other parts of the world through immigration [19,23,24]. It is also noteworthy that a sharp increase in oral cancer incidence has been reported in the past decade in several countries that are popular for new immigrants including Denmark, France, Germany, Scotland and to some extent in Australia, New Zealand, the United Kingdom, and the United States [3].

In Australia, oral cancer represents less than 3% of all cancer cases, yet it continues to pose a significant disease burden due to the poor survival rates [25]. Mortality associated with oral cancer has remained stable over the past three decades despite a decrease in incidence over the last two decades [25]. More than 4000 new cases of head and neck cancers, including lip, are diagnosed every year in Australia, and almost 600 of these cancers are oral cavity cancers [26,27]. Among other factors responsible, this rise in numbers has also been linked to tobacco chewing and cultural practices of areca nut chewing within the Indian immigrant communities in Australia [28,29]. This is concerning, since India is the top source country of immigrants with 25,698 places (approximately 18.3%) in Australian immigration [30], and Indians are one of the fastest-growing communities forming about

2.6% of the total population in Australia [31]. With the increasing oral cancer incidence rates [26] and changing immigration patterns [32], it becomes even more important to ensure oral cancer awareness of GPs to assist in early identification and public education. This is particularly important in Australia, as recent studies indicate that only half of all oral health professionals are performing oral cancer screening with their patients [33].

However, not much is known about GPs' oral cancer-related knowledge and clinical practices in Australia, especially around emerging oral cancer risk practices among new immigrants. Exploring this information is important as a recent review regarding oral cancer-related practices of GPs in developed countries revealed limited oral cancer knowledge around newly emerging causative factors and a lack of related clinical training for routine oral cancer screening and/or counselling [34].

Thus, this study aimed to explore the oral cancer-related knowledge, beliefs, and clinical practices of GPs in Australia. This study was part of a broader mixed-method study that investigated the knowledge, attitudes, and practices of Indian immigrants towards oral cancer, the findings of which are published elsewhere [35].

The following research questions guided this study:

- What are the oral cancer-related knowledge, beliefs and clinical practices of GPs in Australia?
- What are the perceived barriers for GPs regarding oral cancer risk assessment and counselling of patients?
- What are GPs' recommendations to promote oral cancer awareness particularly among high-risk populations such as Indians in Australia?

## 2. Materials and Methods

### 2.1. Design

This exploratory study used a qualitative research design involving interviews with GPs. Exploratory qualitative research has been identified as a suitable method to study areas (specifically within healthcare practice) that have previously received little or no attention [36]. Semi-structured interviews were chosen to provide scope to use prompts to draw out additional information and to clarify responses. This method of data collection was appropriate, as this study intended to explore oral cancer-related knowledge, beliefs, and clinical practices of GPs in Australia. The Consolidated Criteria for Reporting Qualitative Studies (COREQ): 32-item checklist [37] was used to report the qualitative aspect of this research (see Supplementary Materials File 1).

### 2.2. Sampling and Recruitment

All the GPs practicing in the suburbs of New South Wales (NSW) and Victoria (VIC), Australia were eligible to participate. A combination of purposive and snowball sampling was used to enhance participation. Since the larger study also investigated the oral cancer awareness needs of Indian immigrants, suburbs of Sydney and Melbourne were the preferred recruitment sites, as they are densely populated and represented the required Indian population [38]. No exclusion criteria were set based on age, gender, country of origin or number of years of clinical practice in Australia. The email contacts of medical practices in these areas were retrieved through information publicly available on the internet. An invitation to participate with contact details was emailed to all practices, and a follow-up reminder email was sent after one week in case of no response. Those GPs who expressed an interest in participating were provided with a participant information sheet outlining the purpose of the study, and interviews were scheduled at a convenient time. All attempts were made to ensure diversity in the sample in terms of gender, age, country of birth, and educational training. To become a general practitioner in Australia, one must either complete an undergraduate double degree or a bachelor's degree followed by a postgraduate degree to become registered with the Medical Board of Australia [39]. Overseas trained GPs have to go through a comprehensive assessment process before registration to ensure their qualifications (undergraduate or postgraduate) are comparable to the Australian

standards [40]. Once registered, GPs have the option of undertaking additional specialist training in general practice or other specialities through a fellowship [39].

### 2.3. Data Collection

A literature review [34] and interviews with Indian immigrants (conducted as part of a larger study) [35] informed the development of an interview guide, which was further refined with a multidisciplinary team involved in this research (see Supplementary Materials file 2—Interview focus areas and guiding questions). Recruitment and data collection continued until data saturation, where no new information emerged from the interviews ($n$ = 14). Previous studies have recommended that a minimum sample size of at least 12 is sufficient to reach data saturation in qualitative studies [41,42]. Furthermore, a recent systematic review of interview-based qualitative studies found eight to ten participants was appropriate in studies that were exploratory in nature [43]. The principal researcher (NS, female, Ph.D. candidate) was experienced in qualitative methods and conducted all 14 interviews between August and November 2019 with one interview face-to-face and the remaining 13 interviews conducted over the telephone. Written or verbal consent was obtained.

Due to time constraints and the busy schedules of GPs, the interviews varied in length ranging from 17 min (shortest interview) to 43 min (longest interview). The interviews were audio-recorded and then professionally transcribed. The transcripts were not returned for member checking due to the time constraints of participants. Demographics of the participants including age, gender, highest level of qualification, and years of clinical practice in Australia were recorded. Participants were also given an opportunity at the end of the interview to add any further comments not addressed in the interview.

### 2.4. Data Analysis

Transcripts were checked by the principal researcher (NS) against the original audio recordings for accuracy and then imported into qualitative data management software (QSR NVivo 12 (QSR International, Melbourne, VIC, Australia)). The data were analysed using directed qualitative content analysis (QCA). A formative categorisation matrix based on the themes identified from an integrative review of oral cancer-associated knowledge, attitudes, and practices of South Asian immigrants [24] guided the initial coding. All authors (Ph.D. candidate (NS), two practicing/academic dentists (AG and NP), and two nurse academics (RP and BE)) undertook the initial coding by reading two transcripts each. Over the course of two meetings, consensus was reached regarding a coding structure, and this was used by NS to code the remaining transcripts. After the initial analysis was completed, the first author (NS) went back through the coded excerpts and identified subcategories, which were then presented to two other researchers in the team (AG and RP).

### 2.5. Ethical Considerations

The study received ethics approval from the Human Research Ethics Committee of Western Sydney University (H13203). All GPs were given a gift voucher (AU$50) as reimbursement for their time. The audio recordings and transcripts were stored on a password protected computer as per institutional and ethics committee requirements.

### 2.6. Rigor

Rigor was maintained at every stage of data collection and analysis to enrich the study. Several methodological strategies were employed to address trustworthiness—the criteria for vigorous qualitative research (credibility, transferability, dependability and confirmability). An individual interview format was selected to facilitate participants' disclosure of relevant information without any confidentiality concerns. Debriefings were organised with another researcher (AG) to discuss the completeness of data. For accuracy, a professional transcription company was employed for verbatim transcriptions of the interview audio recordings. Participants were de-identified throughout transcription to

ensure their anonymity. To enhance credibility, all researchers in the team did individual coding, and then, consensus was achieved with subsequent team meetings. Codes and subcategories were robustly discussed and confirmed with two other researchers (namely, (RP) and (AG)). To ensure transferability, detailed information is provided about the study settings, participants, and data collection. Direct quotes by the participants have been used to support the findings. The implementation of these methodological strategies has ensured the rigor and trustworthiness of this research.

## 3. Definition of Terms

The terms 'knowledge', 'beliefs', and 'clinical practices' have been used widely in this paper. For the purposes of this paper, the definition of 'knowledge' refers to one's awareness, level of understanding, and information in relation to oral cancer [34]. The term 'beliefs' has been used to depict the perceptions, views, and attitudes associated with oral cancer [34]. The 'clinical practices' of the participants (GPs in this context) relates to clinical actions encompassing oral cancer identification, counselling, and prevention [34]. 'Risk products' has been used as a term to represent commonly consumed tobacco and/or areca (betel) nut preparations [44]. In this paper, the term 'Immigrant' refers to a person who moves into a country other than that of his/her nationality [45].

## 4. Results

Fourteen GPs practicing across Sydney South ($n$ = 6), West ($n$ = 3), North-West ($n$ = 2), and East ($n$ = 1), in New South Wales and Melbourne North ($n$ = 1) and South-West ($n$ = 1) in Victoria, Australia participated in this qualitative study. GPs originated from different countries with a handful from the Indian subcontinent ($n$ = 5). Of the 14 GPs, nine were male participants and seven were within the age range of 35–54 years (range 25–64 years). More than half had obtained their basic qualifications from overseas ($n$ = 9) and had undertaken specialist general practice training in Australia ($n$ = 9). Their clinical practice experience in Australia ranged from 3 to 35 years (mean 10.7 years) (see Table 1 for demographics, given below). These demographics were fairly similar to the trends observed among GPs in Australia. Recent workforce data indicate there are more male GPs than female GPs in Australia (60% vs. 40%), more than half (53%) are within the age groups of 35–54 years, and the majority (51–80% depending on speciality training) have their basic qualifications from overseas [46]. In addition, according to the Australian Bureau of Statistics, there has been a marked increase in the number of GPs and specialists from South Asia [47], and they represent the second largest group of GPs after Australian-born general practitioners [48].

**Table 1.** Demographics of participants.

| Age Range/Group | Gender | Country of Birth | Region/State | Medical Qualifications (Country) | Years of Clinical Practice in Australia |
|---|---|---|---|---|---|
| 25–34 | Female | Pakistan | South Sydney/NSW | Undergraduate (Pakistan) Fellowship (Australia) | 3 |
| 35–44 | Male | India | North Melbourne/VIC | Undergraduate (Russia) Post-graduate (Russia) | 4 |
| 35–44 | Male | Pakistan | South Sydney/NSW | Undergraduate (Pakistan) Fellowship (Australia) | 6 |
| 35–44 | Female | Philippines | South-West Melbourne/VIC | Post-graduate (Philippines) Fellowship (Australia) | 4 |
| 25–34 | Female | Australia | South Sydney/NSW | Undergraduate (Australia) Post-graduate (Australia) | 3 |
| 55–64 | Female | India | Western Sydney/NSW | Undergraduate (India) Fellowship (Australia) | 23 |
| 55–64 | Male | Afghanistan | Western Sydney /NSW | Undergraduate (Afghanistan) Post-graduate (Afghanistan) | 20 |
| 55–64 | Male | Malaysia | South-West Sydney/NSW | Undergraduate (Australia) | 35 |
| 35–44 | Male | Australia | South Sydney/NSW | Undergraduate, Fellowship (Australia) | 19 |
| 25–34 | Male | Australia | South-East Sydney/NSW | Undergraduate, Fellowship (Australia) | 3 |
| 25–34 | Female | India | Western Sydney/NSW | Undergraduate, Fellowship (Australia) | 3 |
| 45–54 | Male | India | Sydney-East/NSW | Undergraduate (India) Fellowship (UK) | 6 |

**Table 1.** *Cont.*

| Age Range/Group | Gender | Country of Birth | Region/State | Medical Qualifications (Country) | Years of Clinical Practice in Australia |
|---|---|---|---|---|---|
| 35–44 | Male | Pakistan | North-West Sydney/NSW | Undergraduate (Pakistan) Fellowship (Australia) | 16 |
| 35–44 | Male | India | North-West Sydney/NSW | Undergraduate (India) Fellowship (UK) | 5 |

Three main categories and nine subcategories were identified from data analysis (see Table 2 for categories and subcategories, given below).

**Table 2.** Categories and subcategories.

| Categories | Subcategories |
|---|---|
| Oral cancer-related knowledge | • Recognition of the symptoms and risk factors<br>• Availability of risk products<br>• Oral cancer training |
| Oral cancer-related beliefs | • Views towards oral cancer scenario in Australia<br>• Perceived role in oral cancer prevention<br>• Overcoming the barriers to oral cancer prevention and diagnosis |
| Clinical practices relating to oral cancer | • Routine check-ups and examinations<br>• Referral processes<br>• Preventative counselling |

### *4.1. Oral Cancer-Related Knowledge*

Overall, GPs demonstrated good knowledge and awareness about oral cancer risk.

#### 4.1.1. Recognition of Symptoms and Risk Factors

All participants were well informed about the main clinical signs—for example non-healing ulcer or an oral swelling—and knew the clinical symptoms such as bleeding or bad mouth odour commonly observed in oral cancer suspected cases. Major risk factors responsible for oral cancer such as tobacco and alcohol were also reported by every participant. However, varying levels of knowledge were apparent regarding the association of areca (betel) nut use and oral cancer. Three GPs were sceptical about the carcinogenicity of areca nut, while two had never heard of these products in Australia. As reflected from the following statements:

> *I don't think betel nut on its own is sufficient [to cause oral cancer]. You need all the other things in there that contributes to that . . .* (GP-8)

> *I haven't heard of betel quid, specifically. I do know—as I said I know about smokeless tobacco . . . which, yeah, is a big risk factor . . .* (GP-5)

More than half of the participants ($n$ = 9) had prior training and clinical experience from overseas, particularly South Asia ($n$ = 7) and were therefore more aware of areca nut usage as an emerging oral cancer risk factor as supported in the quote below:

> *Because I am from an Indian background . . . . In India, it was more common because I guess people used to chew paan and gutka. So basically, that was like a betel nut product to be more precise which were the major risk factors of oral cancer . . .* (GP-2)

Moreover, a larger proportion of GPs ($n$ = 9) also knew that some population groups such as South Asians and Indians were at high-risk for oral cancer owing to cultural practices:

> *Middle East is also high risk. Indians, I think Indian background is high risk. Chinese because of the smoking probably, they're also high risk.* (GP-6)

#### 4.1.2. Availability of Risk Products

Nearly all ($n$ = 12) remarked that tobacco preparations and alcohol were readily available in Australia. In contrast, only GPs from Indian ($n$ = 5) and Pakistani ($n$ = 3) backgrounds were familiar with the availability of areca nut preparations at Asian/Indian grocery stores in Australia. For instance:

*I know the paans [betel quid] are available in a lot of the restaurants and these products are available in Indian grocery stores*. (GP-14)

The majority of GPs ($n$ = 10) commented that areca nut preparations were more easily accessed in suburbs densely populated with Indian immigrants:

*I know that they're [areca nut/betel quid] available in certain very limited areas where the ethnic population is predominately Indian...* (GP-1)

There was some confusion though among interviewees ($n$ = 6) over the legality of areca (betel) nut use in Australia:

*I think it's legal. I don't think that's a—I don't think it's illegal in Australia*. (GP-8)

#### 4.1.3. Oral Cancer Training

All participants ($n$ = 14) admitted not receiving any type of formal oral cancer-related training in Australia.

Nonetheless, eight GPs had some knowledge on oral cancer identification from their undergraduate course and clinical internship training overseas particularly from countries such as India and Pakistan where such habits are prevalent as noted in the following quote:

*In Australia no . . . In India yes. I used to do my internship in a government hospital and we did have a campaign for the doctors [about] how to identify and what to look for*. (GP-2)

Furthermore, several participants ($n$ = 11) highlighted the lack of any specific resource related to oral cancer.

*I mean if someone has it [resource], there's things we download, but I mean they're not available unless I actually search for it...* (GP-9)

### *4.2. Oral Cancer-Related Beliefs*

Overall, positive beliefs and attitudes of GPs were recorded from the interviews.

#### 4.2.1. Views towards Oral Cancer Scenario in Australia

There were diverse views about the current oral cancer situation in Australia. Considering the low incidence and prevalence of oral cancer in Australia, six GPs were not sure if oral cancer could be a serious health issue in the near future:

*So, I guess cancer of the oral cavity in general in Australia is pretty low in terms of prevalence and incidents . . . even among the lower socioeconomic groups who are generally higher risk of smoking, and poorer oral hygiene, the numbers are still very small . . . I don't think [it is] an emerging problem*. (GP-8)

In contrast, eight GPs were of the opinion that increasing immigration and continuation of habitual practices in Australia might lead to increased oral cancer risks in the future. As a few GP explained:

*Well, there might be [increased oral cancer risk] because Australia is having a lot of immigrants. With that, they bring likely new type of diets, and habits, and stuff. So, maybe it might increase the overall cancer risk*. (GP-14)

*But the way the migration is there, say 10, 15 years down the track, with the number increasing, it's going to be more easy visibility of these paans and chewing tobacco which is sort of still available. Yes, I predict that [increased oral cancer risk] they will be*. (GP-13)

#### 4.2.2. Perceived Role in Oral Cancer Prevention

All participants believed that GPs have a crucial role in oral cancer prevention and early diagnosis as they are primary healthcare providers and generally the first to notice any suspicious oral lesions:

*I cannot stress enough the role of the GP, to be honest, as the GP is always the first point of contact. Because of the universal access to healthcare in Australia through Medicare, most*

*of the patients, more or less, end up with a GP. Even if they know this particular matter is not related to the GP, but they know that the GP can direct them to the right person.* (GP-1)

*The role of the GP is important because I think you need the biopsy or the referral to a specialist because sometimes the patient will come in and then they will, obviously they don't think it's a throat cancer . . . I think without seeing a GP it's very hard to diagnose it.* (GP-9)

Majority of the interviewees ($n$ = 11) perceived GPs to play a preventive role in oral cancer care:

*So preventative care is good with GPs in case they find that even if they don't have ulcers, but they are chewing tobacco, or they can be told about the risk factors and supported to quit.* (GP-11)

Many ($n$ = 9) were of the belief that all patients including Indian immigrants would be open to receive oral cancer risk assessment or referrals and preventive education. In contrast, two GPs suggested that Indians may be reluctant in accepting patient counselling:

*I think—I find that generally, the Indian population, especially the migrant ones, they don't—they're not comfortable in [oral cancer prevention counselling]—they'll only come when something is really bad. They won't—in terms of prevention, they're not very good with coming in for preventative stuff, they're more—if it gets really bad and the symptoms don't go away, they might come, they might be in a later stage.* (GP-9)

Another aspect highlighted by participants ($n$ = 6) was the preference of some migrants to consult a GP from a similar cultural background, which could be an additional barrier for preventative strategies in this area:

*I feel that's true, a lot of them, they do like to see—they say if you are an Asian you also want to see an Asian doctor, you know what I'm saying . . . I feel that it's—they're more open to that . . . Because there is cultural ethnicity factor.* (GP-4)

#### 4.2.3. Barriers to Oral Cancer Prevention and Management

Some participants ($n$ = 8) emphasised a gap in the existing knowledge for oral cancer prevention and diagnosis with many practitioners referring patients to other specialties for a definitive diagnosis and opinion:

*From the GP's point of view, I would say a knowledge gap; a lack of being able to do much except for refer. Probably a feeling that—I mean, the mouth is the area of either dentist or specialist in terms of our comfort to biopsy and comfort to manage oral changes and dental changes, and some uncertainty about where to send them I think.* (GP-10)

Limited time ($n$ = 10) was cited as a major hurdle in oral cancer risk assessment and counselling:

*I think when it comes down to barrier, there's no barrier, it's just that we focus, as I said earlier as well, we focus more on the smoking part, but we always forget about it—I do try my best to do it, but the barrier is the time. If you're running short of time and the waiting room is full of patients, so that's one of the barriers.* (GP-13)

A small number of GPs ($n$ = 3) highlighted the uncertainty while addressing oral concerns during check-ups owing to dentists having more expertise in this area as well as the high cost of dental treatments.

*The main barrier I have come across is sometimes there is a bit of overlap between dental and oral health issues. We recommend sometimes people do see the dentist and—because the dental assessment is quite often needed to make the better diagnosis. It could be an oral cancer issue. Sometimes people can't afford seeing a dentist. That is quite a good barrier, I think . . .* (GP-14)

Other obstacles identified were lack of awareness ($n$ = 3) and financial constraints ($n$ = 2) among patients. One GP addressed this in the context of Indian immigrants as:

*You can call it ignorant behaviour. Yeah, that's other way but that's how I see is like they don't see—they don't see through actually. So, they're not familiar with the health system . . . because most of the Indian patients I have to counsel them, they think why they are charging us the money . . .* (GP-3)

Various suggestions made by participants to address barriers in oral cancer prevention included oral cancer training endorsed by professional organisations such as the Royal Australian College of General Practitioners (RACGP), online Continuing Professional Development (CPD) activity ($n$ = 9), educational pamphlets for clinical practice ($n$ = 7), and raising awareness through social media and other advertisements ($n$ = 10). Additionally, one GP even recommended incorporating oral cancer-training as part of the undergraduate medical curriculum:

*. . . So, that needs to be incorporated in the undergrad training. In the fellowship training, personally, which I did over here, they're mostly focused on—they encourage GPs to identify population subgroups and then to know particular problems for them . . . but I've never received CPD activity for cancer. So, it's kind of lack of effort on both hands.* (GP-1)

However, three participants were not in favour of additional oral cancer-related training for GPs:

*Because we GPs get annoyed a lot now. Everybody wants you to have a six-month training done in something. So how come we can do six months in breast cancer, six months in cervical cancer, six months in this cancer. So, it's getting a bit cliché as well, like GPs are in the best position to have it so we usually laugh about it. So, I think if you publish your guidelines like GPs are best suited for that, we're not even going to look at it . . .* (GP-3)

### *4.3. Clinical Practices Relating to Oral Cancer*

A wide variation appeared in the clinical practices of GPs regarding oral cancer.

#### 4.3.1. Routine Check-Ups and Examinations

All GPs recalled asking about smoking and alcohol while taking medical history; however, only a handful ($n$ = 5) admitted to discussing areca nut products:

*We should be doing it, but we are not. We ask about, do you smoke? It's a part of our medical profession that we have to. But it's never been a software tick that you ask about betel use, any betel nut or any other thing.* (GP-13)

*No, not betel nut. I won't ask betel nut, but if they are chewing something constantly any addiction, anything else, they usually say on their own, so I wouldn't really particularly ask for betel nut as such.* (GP-11)

The majority of participants ($n$ = 11) acknowledged not talking about oral cancer during routine check-ups:

*We do generally discuss the risk factors . . . but I don't generally speak specifically about oral cancer, no.* (GP-10)

Seven GPs admitted conducting mouth/oral check-ups at some stage of routine examination only if necessary:

*Oral cancer is not—it's not something I routinely check for unless someone is a smoker and then I will do the check, I'll ask them some questions about any sore throat or hoarseness of their voice or any mass lesion or things about that but, if they don't smoke then I usually don't do it; don't screen for it.* (GP-9)

#### 4.3.2. Referral Processes

No clear or consistent oral cancer-referral pathways were followed by interviewees. The majority of GPs ($n$ = 9) were found to refer suspected oral cancer cases to an oral surgeon, while others ($n$ = 5) preferred ENT (Ear, Nose, and Throat) specialists:

*There is no specialist pathway that's what you do if you think it's oral cancer. I would probably send him to a centre . . .* (GP-12)

Few participants ($n$ = 3) identified dentists as their main referral choice for oral cancer diagnosis:

*It really depends on what the lesion is . . . if it's more on the gums or on the—yeah more on the gums area then I would just refer to a dentist . . .* (GP-4)

#### 4.3.3. Preventative Counselling

Almost all participants raised the issue of not having any educational resource for oral cancer counselling. Although many ($n$ = 9) accessed the internet, three GPs cited the 'UpToDate' website as a useful online resource:

*It's also we basically use the guidelines, therapeutic guidelines for oral cancer, but there's no like true resources, apart from online . . . I don't have any access to up to date and other such data. I wish, I'd like to, but I don't have, no.* (GP-13)

No one confirmed if any kind of standard screening tool is available for oral cancer risk assessment:

*Not particularly oral cancer, as there is no screening program available in Australia for oral cancer. Generally, it's dealt as one of the risks that you get from smoking. So, you just touch base . . .* (GP-1)

Most interviewees ($n$ = 10) were keen to know more about a quick oral cancer risk evaluation guide or tool for clinical examination.

On the other hand, three GPs expressed an interest in testing an assessment tool prior to employing it in clinical practice:

*I'd be interested to see how that [assessment tool] pans out. I'd be happy to give my comments on how usable it is in general practice.* (GP-8)

## 5. Discussion

This is the first study to explore the oral cancer-related knowledge, beliefs, and clinical practices of GPs in Australia, with a particular focus on the oral cancer risk behaviours of Indian immigrants. The diverse sample of participants recruited in terms of experience, ethnicity, professional training, and location of practice has provided a valuable insight into this under-researched yet emerging area of cancer care in Australia.

The findings revealed that GPs were well aware of the key factors contributing to oral cancer, including some of the common risk products such as tobacco and alcohol. However, their knowledge regarding the association of oral cancer with areca (betel) nut consumption and the availability of these preparations was variable. The lack of awareness among some GPs in this study regarding areca nut as an oral cancer risk factor has been observed in the UK and the USA, where there has been a long history of migration from the Indian subcontinent [49–51]. A recent systematic review [34] on this topic found variable knowledge (0.8–50%) of GPs on emerging risk factors, such as betel nut chewing. This finding is not surprising, as the current undergraduate medical curriculum and CPD programs in Australia [34] have limited focus on oral cancer and related emerging risk factors. This limitation is evident in other developed countries as well [52–54]. However, many developing countries [55–57] have placed more emphasis in this area through well-formulated training strategies due to the alarming rise in oral cancer cases. This was evident in our study findings, as the GPs who trained overseas in India and Pakistan were well-informed about oral cancer aetiology due to better access to training modules or prior undergraduate training [58,59]. It is usual for medical curricula to reflect current health trends and challenges in the country, but in light of increasing immigration from India [32] and reports of areca (betel) nut use becoming popular in Australia [28,29,60], it is important that medical students in Australia should be made aware of these new carcinogens [61]. Needless to say, the inclusion of new emerging oral cancer risk factors

in undergraduate medical curriculum [5] and continuing relevant education courses and training modules [62] for GPs would be beneficial for the early identification of oral premalignant or malignant lesions.

This study identified overall positive beliefs of GPs regarding their vital role in oral cancer prevention. However, their attitude on the current oral cancer scenario in Australia was varied, as more than half of the GPs did not consider it to be an emerging health problem. Although oral cancer has not gained much attention in Australia because of its low prevalence, recent data [26,27] indicate that oral cancer cases have increased, which interestingly aligns with a significant jump in immigration from India. Furthermore, GPs in this study who had dealt with Indian patients previously did acknowledge the continuation of typical risk habits such as betel quid chewing of Indian immigrants and thus were comparatively more concerned with this growing problem in Australia. These findings align with past studies that show the changing trends in oral cancer cases in response to cultural risk practices of Indian immigrants in other major immigration nations such as the United States, the UK, and Canada [19]. However, limited research has been undertaken to assess the oral cancer risk susceptibility of Indian communities in Australia, which may be the reason why many GPs were uncertain of oral cancer being an emerging health challenge in Australia. Mixed perceptions of GPs concerning the healthcare choices of Indian immigrants and the inclination of Indians towards healthcare providers of a similar cultural background in Australia was also noteworthy. The literature suggests that cultural factors influence beliefs, behaviours, perceptions, and emotions, all of which affect health and healthcare [63]. Therefore, the cultural background of GPs may play a role in how oral cancer risk is perceived. Culturally relevant counselling in primary care settings and the education of Indian immigrants can be useful here, as acceptance and satisfaction are high if the patient has been previously educated about oral cancer [64].

Limited knowledge of GPs regarding new oral cancer risk factors and varied beliefs towards the oral cancer scenario in Australia seems to have influenced their clinical practices in this area. The majority of GPs acknowledged rarely conducting oral cancer screening unless patients raised oral health concerns. Furthermore, there was variation in the preventative oral cancer counselling strategies among GPs with some hesitation about routinely discussing this topic with patients. This observation was expected given that GPs face many barriers including time constraints, lack of prior knowledge on this subject, and a paucity of oral cancer-specific resources for educating patients. Similar behaviours of GPs were observed in a previous review [34] that linked inadequate clinical oral cancer screening and counselling practices of GPs to their insufficient training in this area and limitations in terms of time for medical visits. The discomfort expressed by some GPs to initiate oral cancer linked discussions with patients could be one of the contributing factors in delayed diagnoses. This compliments the interpretations by Vogt et al. [65] that the hesitation of GPs about facilitating discussions about risk factors with routine patients can influence the diagnostic judgements.

The additional challenges for GPs as evidenced in the findings are the unavailability of an appropriate oral cancer screening tool and the lack of clear referral pathway to specialist services. These findings can be concerning, as earlier studies have described that gaps in oral cancer referral systems [66,67] are responsible for delays in the diagnosis. In a similar context, the absence of a national oral cancer screening program in the Australian healthcare system also adds up to the list of concerns [68]. This study supports the recommendation by Farah et al. [25] for opportunistic oral cancer screening of at-risk populations in Australia with the focus on risky health behaviours. Likewise, it is now vital for GPs serving large Indian populations to play an active role in delivering oral cancer information, after a recent study [35] has verified the involvement of Indian immigrants in risk habits in Australia.

It is also important to point out that communication about oral cancer risk factors can be complicated for both the clinician and the patient owing to many factors including health literacy, language, and cultural barriers. Additionally, sometimes, despite understanding the risk factors, clinicians find it hard to convey this information to patients from CALD

(Culturally and Linguistically Diverse) backgrounds. These issues raise the need for appropriate educational resources on emerging oral cancer risk factors not only for health professionals but also for the general population, which could be more informative if translated into key languages. A recent initiative by a state government in Australia to publish an online resource for health professionals about hazardous health effects associated with areca (betel) nut chewing among immigrant populations is a step in the right direction to increase health literacy in this area [69].

The findings from this study have significant implications for oral cancer-related research, policies, and clinical practices in Australia. Further large-scale quantitative research is fundamental to confirm the findings from this study by exploring the knowledge and clinical practices of all Australian GPs in this area. A formal targeted demographic pre-selection of participants in relation to the geographic distribution of various types of oral/head and neck cancer might help in obtaining more generalisable information in future research. From a policy point of view, the formulation of clinical guidelines is essential to ensure a single national strategy for oral cancer awareness and prevention. The inclusion of a qualified dental specialist accompanying GPs during oral cancer screening and check-ups could also be beneficial and should be investigated further. However, it is important to point out that although such shared models of care exist in other countries such as the UK [70], it will be more challenging in Australia due to the lack of a universal dental scheme. Additionally, the implementation of a system and/or protocols for screening while taking into account the different pathologies according to age could be helpful in the timely identification of oral cancer/lesions [71]. GPs may benefit from the inclusion of culturally appropriate risk factors in the medical curriculum for a better understanding of oral cancer causative factors. While the overload on general practice is explicit and understandable, it is possible that accessible oral cancer-related training such as short online learning resources and continuing education courses designed for GPs could be undertaken to aid their consultation process for oral cancer prevention [72]. These resources should focus more on new oral cancer risk factors such as areca (betel) nut use, which is required considering the changing global migration and oral cancer trends.

This study also implies that GPs could adopt patient-specific decision-making strategies in their clinical practices for the identification of oral cancer through opportunistic screening of high-risk populations such as Indian immigrants who are known to be engaged in tobacco and/or alcohol consumption or chew betel/areca nut [73,74]. Being the primary contact for accessing healthcare, it becomes more crucial for GPs to engage in duties of oral cancer prevention counselling, initial screening, and routine oral/mouth check-ups [75]. Moreover, as per the practice feasibility, one-to-one health advice by GPs to high-risk populations through preventive counselling can be very effective if tailored to individual cultures and circumstances.

The timely access to medical and dental facilities has become more critical for the general population under the current COVID-19 pandemic and could lead to oral cancer being a ticking time bomb in Australia [76,77]. This situation might be more exacerbated for Indian immigrants who are less frequent in their routine medical and/or dental visits in Australia [35] and, in general, have a limited understanding for the concept of screening healthy individuals [19]. Given the great influx of Indian immigrants in recent years, the need of the hour is to develop an evidence-based oral cancer awareness resource to support public health messaging in Australia, which currently does not exist. Additionally, the development of an appropriate screening tool and a clear referral pathway could help in early diagnosis and avoid delays in initialising timely treatment.

This study has some limitations. First and foremost, the GPs were mainly from NSW, and therefore, the findings may not be representative of the GP community in VIC and other parts of Australia. Future in-depth research is needed to understand the perspectives of GPs practicing in other states and territories in Australia. Given that some of the participating GPs were trained overseas, their responses regarding oral cancer awareness may have been influenced by their previous experiences; thus, the results reported here are

subject to information bias. Another limitation could be 'volunteer error', as some of the GP participants would have participated because they are highly motivated to learn more about the cancer problem and help their patients. Despite these limitations, this study has provided valuable insights into this under-investigated area in Australia.

## 6. Conclusions

This study has identified that GPs have good oral cancer-related knowledge with limited information about emerging risk factors, varied beliefs about the seriousness of oral cancer in Australia, and inconsistent clinical practices relating to routine oral cancer check-ups and screening as well as dental referrals. GPs play a crucial role as primary healthcare providers and are a gateway to access specialist services; however, the lack of relevant training is making it difficult for them to actively promote oral cancer prevention. Further research is warranted to confirm these findings and inform about the development of resources and/or training aimed at medical practitioners to raise awareness of oral cancer among high-risk populations such as Indian immigrants in Australia.

**Supplementary Materials:** The following are available online at https://www.mdpi.com/article/10.3390/ijerph182111111/s1. The COREQ checklist and interview focus areas can be located in Supplementary Materials File 1 and Supplementary Materials File 2, respectively.

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## Abbreviations

| | |
|---|---|
| NS | Nidhi Saraswat |
| AG | Ajesh George |
| NP | Neeta Prabhu |
| RP | Rona Pillay |
| BE | Bronwyn Everett |

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# Chapter 8: Quantitative Results

# (Indian immigrants – published)

## 8.1 Overview: Thesis Paper 5

The previous two chapters (Chapters 6 and 7) presented the qualitative findings from interviews with Indian immigrants and GPs respectively. This chapter presents the results of the quantitative study involving a cross-sectional survey of Indian immigrants residing across Australia. This phase built on the earlier qualitative phase to test the initial findings regarding the oral cancer knowledge, attitudes, and practices of Indian immigrants residing in Australia. The survey addressed various constructs of the conceptual model of the study including knowledge, attitude (perceived benefits, perceived susceptibility, perceived barriers), cues to action and practice (*Figure* 4.1). The results are published (Thesis Paper 5) in the International Journal of Environmental Research and Public Health (Reference below).

Saraswat, N., Everett, B., Pillay R., Prabhu, N., Villarosa, A., George, A. (2022). Knowledge, Attitudes and Practices of Indian Immigrants in Australia towards Oral Cancer and Their Perceived Role of General Practitioners: A Cross-Sectional Study. *International Journal of Environmental Research and Public Health*, *19*(14), 8596.
Doi: https://doi.org/10.3390/ijerph19148596

## 8.2 Aim: Thesis Paper 5

The overall aim of the paper was to explore the oral cancer risk-related knowledge, attitudes, and practices of Indian immigrants and their perceived role of general practitioners in Australia (Table 4.1; study objective 3). The following were the specific research questions:

- What are the oral cancer-related knowledge, attitudes, and practices of Indian immigrants in Australia?

- What are the perceived oral health status and self-reported mouth/dental problems among Indians in Australia?
- What are the general health and dental care practices of Indians in Australia?
- What are the perceptions of Indian immigrants towards general practitioners providing advice regarding oral cancer?

## 8.3 Conclusion: Thesis Paper 5

The survey revealed varying levels of knowledge about oral cancer among the sample of Indian immigrants, particularly around risk factors like alcohol and betel quid use (65-76%). Positive attitudes around preventative oral health practices were evident, though some were currently or previously involved in oral cancer risk practices such as alcohol consumption (42.4%) and chewing tobacco preparations (6-14%). The findings also highlighted a lack of adequate oral cancer-related information being provided in primary health care settings (12.3%). The receptiveness of the study sample (71.9%) to follow the advice of GPs around oral cancer prevention was very encouraging and highlighted the key role these health professionals could play in this area with adequate training and resources.

The next chapter (Chapter 9) will provide a summary by integrating the findings presented in Chapters 6 to 8 and discuss the new knowledge that has emerged from this study.

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*Environmental Research and Public Health*

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*Article*

# Knowledge, Attitudes and Practices of Indian Immigrants in Australia towards Oral Cancer and Their Perceived Role of General Practitioners: A Cross-Sectional Study

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**Abstract:** Oral cancer is highly prevalent in the Indian subcontinent. With the increasing immigration of Indians to Australia, a potential rise in oral cancer cases can be expected if they continue engaging in oral cancer risk practices. Unfortunately, little is known on this topic in the Australian context. This study aimed to generate new insights into this area by examining Indian immigrants' knowledge, attitudes and practices regarding oral cancer in Australia and their perceived role of general practitioners in raising oral cancer awareness. Exploring these aspects could determine the oral cancer risk behaviours of Indians in Australia along with any contributing factors which could help identify potential preventative strategies. A cross-sectional survey was undertaken of 164 Indians across Australia. Data were analysed using SPSS software with descriptive statistics. Respondents had varying levels of knowledge about oral cancer (mean total score 61%), particularly around risk factors such as alcohol and areca nut use as well as oral cancer-related signs/symptoms. The majority (87.7%) had not received any information about oral cancer in a health care setting but were receptive (71–90%) to general practitioners playing a more active role in this area. Respondents were engaging in positive preventative oral health care though few were currently (6.7%) or previously (14.7%) chewing tobacco preparations. Further research is needed through larger studies to confirm the study findings and inform the development of culturally tailored strategies particularly involving general practitioners, to raise oral cancer awareness and provide early screening for Indian immigrants.

**Keywords:** oral cancer; knowledge; attitudes; practices; perceptions; general practitioners; Indian immigrants; Australia

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## 1. Introduction

Oral cancer is a worldwide concern with an estimated 377,713 new cases and 177,757 deaths in the year 2020 alone [1]. The global five-year survival rate for this malignancy is still around 50% despite medical advances in the diagnosis and treatment of oral cancer [2]. Although the early identification of this disease has a critical role in improving overall survival rates, almost half of the oral cancer cases are not diagnosed until advanced stages [3]. Late detection is attributed to various factors including lack of oral cancer awareness, delay in seeking treatment from healthcare professionals and limited focus on at-risk groups [4]. One such at-risk group is the South Asian community comprising of people from countries such as India, Pakistan,

Bangladesh and Sri Lanka [5]. In India, oral cancer is a leading cause of cancer-related mortality, ranking among the top cancers [6] and accounting for more than 30% of all cancers reported [7]. It is estimated there were 135,929 new lip and oral cavity cancer cases with 75,290 deaths in India for the year 2020 [8]. Thus, India is considered an epicentre of oral cancer due to the record number of cases every year [9].

The high prevalence of oral cancer among Indians is mainly attributed to the extensive consumption of tobacco products including bidis, smokeless tobacco and areca (betel) nut preparations [5]. The areca nut is the dried seed of Areca catechu and is often mistakenly termed betel nut since it is commonly chewed along with the Piper betel leaf [10]. India is the largest consumer of areca nut where the nut is cut into small pieces and chewed on its own or wrapped in a "betel vine leaf" commonly known as betel quid/'paan' along with slaked lime and condiments for extra flavouring [10]. Chronic use of areca nut (with or without tobacco) among this community is linked with religious beliefs, cultural acceptability, addiction and perceived advantages [5,10]. Indian migrants are well known for sustaining practices of areca nut use and betel quid ('pan') chewing, since these habits are deeply rooted and well-accepted customs in the Indian subcontinent [11]. Given India is the largest source of immigrants [12] and oral cancer is widespread in this country [9], the elevated risk with associated habits is also suspected to be carried by Indians to different countries [5]. The possible link between oral cancer and cultural risk practices of Indian immigrants has been researched in developed countries including the United Kingdom (UK) [13,14], the United States (US) [15], and Italy [16] with a view to promoting awareness among these populations. A recent review of this evidence concluded that South Asian immigrants including Indians in developed countries, have a lack of knowledge about oral cancer risks and are inclined towards negative oral cancer risk practices such as areca nut/betel quid chewing [17].

Over the past decade, like many developed countries, Australia has become a major multicultural 'immigration nation' and witnessed a significant rise in immigration from India [18,19]. Indian immigrants have had a marked surge [20] and are one of the fastest-growing communities constituting over 2.6% of the total population in Australia [21]. More recently, India was identified as the leading source with 25,698 immigrants (approximately 18.3% of all Australian immigration) [22]. Coincidently, during the period of increased immigration from India, there have also been fluctuations in the number of oral cancer cases in Australia [23]. Over the period 1997 to 2008, an increase in cancers of the tongue has been observed [23]. Likewise, in recent years, the number of lip and oral cavity cancers has increased in the continent and were projected to increase to 2788 in the year 2020 [8]. This rise in oral cancer cases could be linked to the growth of Indians in Australia [24] and their accompanying habits such as tobacco and areca (betel) nut chewing [25,26].

The potential connection between cultural risk practices of Indian immigrants and rising oral cancer has been under-researched in Australia [27–30]. However, a recent qualitative study exploring the perceptions of Indians towards oral cancer in Australia highlighted their engagement in risk habits and poor knowledge regarding adverse health effects of areca nut use [31]. This emphasizes the importance of appropriate help-seeking behaviours (HSB) which can vary with available healthcare resources as well as patient demographics and thus a balance between self-care and professional care is necessary [32]. Trained health professionals, for example, general practitioners (GPs) can play a key role in promoting health-seeking behaviours in at-risk population groups [33–36]. Nonetheless, a study exploring the perspectives and clinical practices of general practitioners (GPs) in this area revealed the need to raise awareness about new evolving oral cancer risk factors such as betel quid use among at-risk populations such as Indian immigrants [37]. Considering these emerging findings, it is important to conduct further research to shed more light on this important area of cancer care in the Australian healthcare system.

The primary aim of this study is to explore the knowledge, attitudes and practices of Indian immigrants in Australia towards oral cancer and their perceived role of general practitioners. This study was part of a broader mixed-methods study that also explored

the oral cancer-related knowledge and clinical practices of GPs in Australia, especially among high-risk populations such as Indian immigrants [37]. This research was informed by both the knowledge, attitude and behaviour (K-A-B) model and the health belief model (HBM). A similar type of integrated behaviour model has been used in other international studies as well [38,39]. The KAB model, also known as knowledge, attitudes and practices (K-A-P) is an important model of health education and asserts that a behaviour change is influenced by knowledge as well as attitude [40]. Similarly, the HBM has been widely used to explain the association between attitudes and preventive health behaviours [40]. This model considers the vulnerability of the individual combined with belief that prevention is possible and can lead to actions to reduce risk. In addition, instilling positive attitudes into individuals through external avenues such as educators/health professionals—(cues to action) is likely to change their choice of action [40]. Thus, adapting both these models allowed for the perspectives and practices of both the Indian immigrants and GPs around oral cancer to be captured within the same research. The findings from this study will help identify any additional oral cancer risk behaviours in the Indian community and inform the development of culturally appropriate interventions and preventative strategies such as raising oral cancer awareness and providing oral cancer screening through GPs for early detection. This study was guided by the following research questions:

1. What are the perceived oral health status and self-reported mouth/dental problems among Indians in Australia?
2. What are the oral cancer-related knowledge, attitudes and practices of Indian immigrants in Australia?
3. What are the general health and dental care practices of Indians in Australia?
4. What are the perceptions of Indian immigrants towards general practitioners providing advice regarding oral cancer?

## 2. Materials and Methods

### 2.1. Design

A cross-sectional survey was conducted between December 2020 and February 2022 among Indian immigrants living in Australia.

### 2.2. Inclusion/Exclusion Criteria

Any person who self-identified as an Indian immigrant (were born or their parents were born in India), aged 16 years and above, and residing in Australia was eligible to participate in the survey. The minimum age of participation was set at 16 years as previous literature has shown that oral cancer risk practices such as betel nut/quid chewing are prevalent even among the younger generation in India [41]. The survey was open to Indians living in all states of Australia to ensure diversity. No restrictions were applied in terms of age limit, gender, religion, socio-economic status, occupation, residency status, place of origin in India or number of years living in Australia as international evidence in this area has revealed oral cancer risk practices to be widespread across all these variables [17].

### 2.3. Sample and Setting

The sample size was estimated on the basis of the expected proportion of the population that would engage in typical oral cancer risk practices (e.g., betel nut/quid use). Based on international published data (Indians in this context) [13–16,42] (range 34–69%), we predicted the proportion to be around 20% in Australia. A power calculation software [43] was employed to calculate the population proportion of approximately 20% with 95% confidence while allowing for a 5% margin of error. A total of 246 participants were required. Assuming roughly 80% response rate [14–16], 308 participants needed to be recruited.

Unfortunately, due to the coronavirus pandemic (COVID-19), the avenues of recruitment for this study were limited. The pandemic led to the implementation of physical distancing measures, national lockdowns, and travel restrictions in order to control the spread of the virus [44]. Taking these restrictions into account the survey recruitment strat-

egy was modified from a face-to-face data collection method to a remote data collection [44]. Remote data collection refers to the collection of data via the phone and online platforms, with researchers and study participants physically distanced [45]. Therefore, all attempts were made to recruit a convenience sample [46] through online social networking sites and other virtual platforms.

The recruitment flyer for the study was published online through a webpage (link: https://cohortaustralia.com/oralcancerinimmigrants/ (accessed on 10 January 2022)) including links to the participant information sheet and the survey. The contact details of the principal researcher were provided in the flyer so that interested participants could reach out for any clarification. The study was advertised through various social media platforms including WhatsApp™ (Facebook Inc., Mountain View, CA, USA), Facebook (Facebook Inc., Menlo Park, CA, USA), and Twitter (Twitter Inc., San Francisco, CA, USA), etc. In addition, Indian associations in Australia such as the United Indian Association and the Australian Hindi Indian Association were emailed for assistance in promoting the study. Word of mouth and snowballing sampling were also used to aid recruitment.

### 2.4. Data Collection

An anonymous web-based questionnaire in English was made available through a webpage (link: https://cohortaustralia.com/oralcancerinimmigrants/ (accessed on 10 January 2022)). The survey was created using QualtricsXM (Experience management company, Seattle, WA, USA). Qualtrics is a software platform that offers a web-based survey tool for conducting survey research, evaluations, and other data collection activities. These surveys were electronically answered, and the answers were linked to the institutional QualtricsXM account. The survey required approximately 10–15 min to complete.

### 2.5. The Questionnaire Development and Pilot Testing

The study questionnaire was initially developed using existing survey items identified from a comprehensive literature review [17,47] as well as preliminary exploratory work around oral cancer in Australia [31,37]. The questionnaire development was informed by the KAB model and Health belief model. The questionnaire consisted of 39 questions which were grouped into six domains that sought information on the participants' perceived oral health status, knowledge about oral cancer and associated risk factors, attitudes toward oral cancer risks, oral cancer risk-related practices, access to general health and oral health care, and demographic characteristics. These domains addressed various constructs of the KAB model (knowledge, attitude and practice) and HBM model (perceived benefits, perceived susceptibility, perceived barriers and cues to action) and have been detailed in Table 1. The survey items were presented as a combination of multiple-choice, Likert scales and open-ended questions. To establish content validity, the preliminary draft of the survey questionnaire was reviewed by an expert panel consisting of academic and clinical experts in the field of oral cancer, dentistry, nursing and public health ($n$ = 5). The comments from the panel were taken into consideration and minor revision of items was undertaken. Thereafter, the revised survey was pilot tested with seven Indians in Australia for face validity. These participants were asked for feedback on the readability and clarity of the questions and the duration of the survey. The survey was then modified according to their suggestions, and the final version of the survey was used for data collection through Qualtrics. The survey tool/questionnaire has been attached as Supplementary Material (see Supplementary File S1).

### 2.6. Measures

The measures which formed parts of the survey questionnaire and data analysis are listed below. Standardised questions that were validated to assess oral health status and oral cancer risk behaviours were used where available.

**Table 1.** Measures of questionnaire.

| Domain | Description | Constructs from KAP and HBM Model |
| --- | --- | --- |
| Perceived oral health status | • 4 items<br>• A single item question widely used in the previous studies [48,49] to assess overall oral health status (excellent, very good, good, fair and poor).<br>• A single item question to describe teeth, gum and mouth problems (yes, no), with a list of most common oral health problems/concerns found in people [17]. | |
| Knowledge about oral cancer and associated risk factors | • 27 items<br>• Sourced from previous studies and included some validated items [13]. | Knowledge |
| Attitudes toward oral cancer risks | • 19 items<br>• Sourced from previous studies and included some validated items [13]. | Attitudes<br>Perceived benefits<br>Perceived susceptibility<br>Perceived barriers |
| Oral cancer risk-related practices | • 9 items<br>• Sourced from previous studies and included some validated items [13]. | Practices |
| Access to health care | • 13 items<br>• Sourced from previous studies and included some validated items [13]. | Practices<br>Cues to action |
| Socio-demographic questions | • 16 items | Modifying variables |

### *2.7. Data Analysis*

Data were analysed through Statistical Package for the Social Sciences (SPSS) Version 27 software [v.27, IBM, New York, NY, USA]. Socio-demographic variables, health-specific characteristics, self-reported oral health status, and oral cancer-related knowledge, attitudes and behaviours were summarised using descriptive statistics. This included mean and standard deviation for continuous variables and frequency counts and percentage for categorical variables. Pearson's chi-square tests were used to test for associations between categorical variables, including oral cancer-related behaviours and attitudes. Group differences in continuous variables, such as knowledge, were either assessed using independent samples T-tests if normally distributed, or otherwise Mann–Whitney U tests. The significance level for all analyses was set at $p < 0.05$.

### *2.8. Ethical Considerations*

This study received ethics approval from the Human Research Ethics Committee of Western Sydney University (H13203). No incentive was offered to participants. The survey was online and completely anonymously. Participation was voluntary and submission of a completed questionnaire implied consent to participate. All responses were recorded in an online database and accessible by the research team only.

## 3. Definition of Terms

The terms 'knowledge', 'attitudes' and 'practices' have been used widely in this paper. For the purposes of this paper, the definition of 'knowledge' refers to one's level of information, awareness and understanding relating to oral cancer risk [17]. The term 'Attitudes' has been employed to depict the individuals' views, inclinations, perceptions,

and beliefs associated with oral cancer risk [17]. The 'practices', in the current context, relates to oral cancer risk-related habits and the actions regarding initiation, continuation or quitting of these habits [17]. The reference to 'risk products' has been provided to depict potential oral cancer causative products such as tobacco and areca (betel) nut preparations [50]. 'Immigrant' term, in this paper, refers to a person who moves into a country other than that of his/her nationality [51].

## 4. Results

### 4.1. Demographic Characteristics

A convenience sample of 164 Indian immigrants was recruited across Australia. A total of 192 Indians accessed the survey. Of these, 28 participants were excluded as they completed less than 50% of the questions offered to all respondents, leaving a total of 164 cases included in the analysis. Slightly less than half (47.2%) of the respondents were female, and the age ranged from 20 to 69 years, with an average age of 35.2 years. Participants had lived in India for between 2 to 60 years, and over three-quarters (87.1%) of the respondents spoke a language other than English at home. The majority (90%) had attended university, and more than half (69.3%) were working full time. Full demographic characteristics of the sample can be seen in Table 2.

**Table 2.** Demographics characteristics of included participants.

| Characteristic | *n* (%) |
|---|---|
| Gender † | |
| Male | 76 (52.8) |
| Female | 68 (47.2) |
| Age at last birthday (mean ± SD) † | 35.2 ± 7.40 |
| Years lived in India (mean ± SD) † | 8.2 ± 6.19 |
| Years since living in Australia (mean ± SD) † | 26.1 ± 7.87 |
| Country of birth | |
| Australia | 2 (1.4) |
| India | 142 (98.6) |
| State of residence ‡ | |
| NSW | 48 (47.5) |
| ACT | 1 (1.0) |
| VIC | 30 (29.7) |
| QLD | 2 (2.0) |
| SA | 15 (14.9) |
| WA | 3 (3.0) |
| TAS | 1 (1.0) |
| NT | 1(1.0) |
| Speaks English at home † | 18 (12.9) |
| Current religion ‡ | |
| Atheist/not religious | 2 (2.4) |
| Catholic | 4 (4.8) |
| Christian | 10 (11.9) |
| Hindu | 66 (78.6) |
| Islam | 1 (1.2) |
| Jain | 1 (1.2) |

**Table 2.** *Cont.*

| Characteristic | *n* (%) |
|---|---|
| Level of education † | |
| Primary school | 2 (1.4) |
| High school | 6 (4.3) |
| TAFE | 6. (4.3) |
| University | 126 (90.0) |
| Employment status † | |
| Full time | 97 (69.3) |
| Part time | 12 (8.6) |
| Casual | 18 (12.9) |
| Home/domestic duties | 4 (2.9) |
| Retired | 3 (2.1) |
| Not working | 6 (4.3) |
| Average household income † | |
| Less than AUD 40,000 | 14 (10.0) |
| AUD 40,000–59,000 | 13 (9.3) |
| AUD 60,000–79,000 | 15 (10.7) |
| AUD 80,000–99,000 | 12 (8.6) |
| AUD 100,000–120,000 | 13 (9.3) |
| More than AUD 120,000 | 37 (26.4) |
| Don't know | 1 (0.7) |
| Prefer not to answer | 35 (25.0) |
| Has private health insurance † | |
| Yes | 62 (44.3) |
| No | 70 (50.0) |
| Don't know | 8 (5.7) |
| Has family history of cancer/oral cancer † | |
| Yes | 13 (9.3) |
| No | 114 (81.4) |
| Don't know | 11 (7.9) |
| Prefer not to answer | 2 (1.4) |

† Number of missing cases for each item ranged from 20–39; ‡ number of missing cases for each item ranged from 63–80.

### *4.2. Perceived Oral Health Status*

Nearly two-thirds (65.8%, *n* = 102) of the respondents rated their oral health as excellent or good and almost a quarter (23.8%, *n* = 39) currently had problems or concerns with their oral health.

### *4.3. Oral Cancer-Related Knowledge*

Around three-quarters (73.8%, *n* = 121) of the respondents had heard about oral cancer and the mean total knowledge score was 12.8 out of a total of 21 possible points (SD4.06) with a range of 5–20. The lowest numbers of correct responses were seen in items regarding pain from oral cancer screening and the capacity of GPs to perform them (24.4–45.7%), symptoms of oral cancer such as painless ulcers red patches yellow patches discomfort and bleeding gums (14–48.8%), and family history as a risk factor for oral cancer (41.8%, *n* = 64). Participants were comparatively less knowledgeable about betel quid/nut and alcohol as risk factors for oral cancer compared to traditional factors such as smoking or chewing tobacco. Higher mean knowledge scores were reported among respondents who had heard about oral cancer compared to those who had not heard about oral cancer (13.1 vs. 11.2; Mann–Whitney U = 1595.5, $p = 0.012$) as well as among those reporting a family history of oral cancer compared to those who had no family history of oral cancer (76.9% vs. 47.2% Pearson chi-square = 4.155, 1df, $p = 0.042$). All knowledge items and number of correct responses are presented in Table 3.

**Table 3.** Knowledge items and correct responses.

| Item | Correct *n* (%) |
|---|---|
| A check up for mouth (oral) cancer is: | |
| Painless | 75 (45.7) |
| A way of finding mouth (oral) cancer at an early stage | 104 (63.4) |
| Helps in treatment of oral cancer if detected early | 129 (78.7) |
| Can be done by a GP | 40 (24.4) |
| The signs/symptoms of mouth (oral) cancer are: | |
| A white patch/discoloration in the mouth | 76 (46.3) |
| An ulcer (sore) that does not heal | 95 (57.9) |
| A painless ulcer (sore) in the mouth | 71 (43.3) |
| A red patch in the mouth | 76 (46.3) |
| A yellow patch in the mouth (correct response: false) | 23 (14.0) |
| A lump or swelling in the mouth | 103 (62.8) |
| A sore throat | 49 (29.9) |
| Discomfort or pain in the mouth | 68 (41.5) |
| Bleeding gums | 80 (48.8) |
| You are more likely to get oral cancer if you: | |
| Smoke tobacco, cigars or pipe | 141 (92.2) |
| Smoke hukkah (sheesha) | 133 (86.9) |
| Chew tobacco | 144 (94.1) |
| Drink alcohol heavily | 99 (64.7) |
| Chew gutkha | 142 (92.8) |
| Chew betel quid/'pan' | 116 (75.8) |
| Chew betel nut/'supari' | 119 (77.8) |
| If your family got it | 64 (41.8) |

Number of missing cases per item ranged from 0–11.

### 4.4. Oral Cancer-Related Attitudes

When asked to rate the importance of various activities in the prevention of oral cancer, more respondents rated a healthy diet (64.1%), brushing teeth twice daily (73.2%), and regular dental visits (65.4%) as very important. See Table 4 for ratings of all activities.

**Table 4.** Self-rated importance of various activities in the prevention of oral cancer.

| Preventive Activities | Not Important *n* (%) | Slightly Important *n* (%) | Fairly Important *n* (%) | Important *n* (%) | Very Important *n* (%) |
|---|---|---|---|---|---|
| Doing exercise regularly | 16 (10.5) | 16 (7.8) | 22 (14.4) | 35 (22.9) | 68 (44.4) |
| Eating a healthy diet (2 fruits and 5 vegetables per day) | 5 (3.3) | 3 (2.0) | 29 (19.0) | 18 (11.8) | 98 (64.1) |
| Brushing teeth twice a day | 1 (0.7) | 4 (2.6) | 14 (9.2) | 22 (14.4) | 112 (73.2) |
| Visit a dentist at least once a year | 2 (1.3) | 6 (3.9) | 25 (16.3) | 20 (13.1) | 100 (65.4) |
| Visit a doctor (G.P.) regularly | 2 (1.3) | 10 (6.5) | 30 (19.6) | 37 (24.2) | 74 (48.4) |

Number of missing cases per item was 11.

Almost half (45.8%, $n = 70$) of the respondents thought people of Indian background were at higher risk of oral cancer. When asked why they thought people used tobacco preparations and alcohol, the largest proportion of respondents indicated this was due to addiction (83.0%, $n = 127$) and leisure/lifestyle/enjoyment (69.3%, $n = 106$), and the smallest proportion of responses were regarding it being a cultural practice for some Indians (32.7%, $n = 50$).

Over half of the respondents indicated they would visit a dentist for a white or coloured patch in the mouth (55.6%, $n = 85$) that had lasted more than 3 weeks and a doctor for an ulcer or sore in the mouth that had lasted more than 3 weeks (56.2%, $n = 86$). More

than half (60.1%, $n = 92$) of respondents indicated they prefer seeing health professionals from their cultural background for regular check-ups.

### 4.5. Oral Cancer-Related Practices

Just under half (42.4%) of the respondents indicated consuming drinks that contain alcohol. Few reported currently smoking (6%) or chewing tobacco preparations (6.7%). Between 14 and 18% of participants reported previously smoking and chewing tobacco preparations (see Table 5 for full results).

**Table 5.** Self-reported behaviours with alcohol and tobacco preparations.

| | Yes *n* (%) | I Used to and Stopped *n* (%) | Never *n* (%) |
|---|---|---|---|
| Consume drinks that contain alcohol | 64 (42.4) | 21 (13.9) | 66 (43.7) |
| Smoke tobacco (including cigarettes, cigars, pipes or hukkah) | 9 (6.0) | 27 (17.9) | 115 (76.2) |
| Chew any tobacco preparations (tobacco, betel nut/supari, betel quid/pan) | 10 (6.7) | 22 (14.7) | 118 (78.7) |

Number of missing cases per item ranged from 13–14.

Smoking and chewing tobacco preparations were significantly associated with gender, whereby being male was associated with higher proportions of currently smoking ($p = 0.003$), ever smoking ($p < 0.001$), currently chewing ($p = 0.006$) and ever chewing ($p < 0.001$) tobacco preparations. See Table 6 for all associations.

**Table 6.** Associations between gender and use of tobacco preparations.

| | Male *n* (%) | Female *n* (%) | Pearson's Chi-Square (df) | *p*-Value |
|---|---|---|---|---|
| Currently smokes tobacco preparations | 9 (11.8) | 0 (0.0) | 8.589 (1) | 0.003 |
| Currently chews tobacco preparations | 8 (10.5) | 0 (0.0) | 7.579 (1) | 0.006 |
| Has ever smoked tobacco preparations | 29 (38.2) | 4 (5.9) | 21.164 (1) | <0.001 |
| Has ever chewed tobacco preparations | 25 (32.9) | 3 (28) | 18.588 | <0.001 |

### 4.6. Engagement in Health and Dental Care Services

Approximately three-quarters (72.8%) of the respondents reported having visited a doctor, community health clinic or practice nurse in the last 12 months; however, just over one-third (35.4%) had visited a dentist in the last 12 months. Only 12.3% ($n = 18$) of respondents recalled receiving information about oral cancer during any health care visit.

### 4.7. Perceived Role of General Practitioners

Roughly three-quarters of the respondents (70.5%, $n = 103$) agreed that a doctor could assist them in identifying oral health problems such as oral cancer. While just half of the respondents (50.0%, $n = 73$) thought doctors had sufficient knowledge to advise them regarding oral cancer, 71.9% ($n = 105$) would consider oral health advice given by their doctor and 90.4% ($n = 132$) would make an appointment to see a dentist if referred by a doctor.

## 5. Discussion

This descriptive cross-sectional study is the first to examine the oral cancer-related knowledge, attitudes and practices of Indian immigrants in Australia and their perceptions

of the role of general practitioners in this area. The study sample had diverse socio-demographic characteristics which were fairly representative of the Australian population data for Indian immigrants in terms of their median age (35.2 vs. 33.9 years) and proportion of Indian males (52.8 vs. 54.6%) [52,53]. Most respondents had a tertiary level of education and were employed full-time, which is consistent with recent immigration statistics showing Indian immigrants holding the highest number of skilled visas [52]. Similar to national data, most were followers of the Hinduism religion and were residing in either NSW or VIC as these two states are favoured by most Indian-born immigrants [53].

Overall, there was varying knowledge regarding oral cancer. In line with previous research [54], majority of the respondents were knowledgeable about oral cancer risks posed by smoking (92.2%) and chewing tobacco (94.1%). Unlike previous studies that demonstrate low levels of knowledge regarding the carcinogenic effects of areca (betel) nut [13,15,16], three-quarters of the respondents in our study reported they were aware of this as a risk factor. The higher level of knowledge could be due to the fact the Indians in our study were more highly educated (close to 90% graduates) and economically well-off when compared to the past literature (85% completed high school and 69% employed) [15] as there is clear evidence showing both these factors are linked to increased oral cancer awareness [55,56]. It was perhaps unsurprising that the demographic profile of the current study sample was different to other developed countries given Australia has had a selective immigration policy focusing primarily on highly skilled migrants [57]. Interestingly, consistent with past research involving Asian males in the UK [58], not all (64.7%) in the current study knew about the association of alcohol use with oral cancer. This finding may not be unique to immigrants from South Asia as studies across UK and Australia show that the general public are equally uninformed about alcohol being a risk factor for oral cancer [56,59].

The survey findings also reaffirm an earlier report [31] that Indian immigrants in Australia have limited knowledge of the potential signs and symptoms of oral cancer. Less than half (46.3%) of the respondents believed that a white or red patch/discoloration in the mouth could be a sign of oral cancer. A previous study in the UK comprising young South Asians also reported similar findings [13]. This lack of awareness could have serious implications as neglecting any discolorations in the mouth can lead to delayed oral cancer screening and diagnosis which can be detrimental due to the high mortality rates associated with this type of cancer [60]. Further exacerbating the situation is the fact that less than a quarter of the respondents were aware that screening for oral cancer can be carried out by a general practitioner. A possible reason for this could be that promoting oral cancer awareness among patients in general healthcare settings has often been neglected across developed countries due to various barriers [61,62]. This is clearly evident in the study findings as very few (12.3%) acknowledged receiving oral cancer information during medical appointments. This lack of knowledge may have influenced the attitudes of the respondents with more than half preferring to visit a dentist over a GP for patches or any discolorations in the mouth. This could have important clinical implications in developed countries such as Australia where access to affordable dental care is limited, resulting in infrequent dental visits among immigrants as seen in the study findings.

It was also encouraging to note that many respondents acknowledged the importance of preventive oral health activities such as brushing teeth twice a day (73.2%) and regular dental visits (65.4%). These positive views could have been influenced by socio-economic characteristics (such as education level and income) and the healthy immigrant effect [63] although this does deteriorate over time. A high education level, as seen in this study, has been shown to be positively linked to health behaviours such as physical activity, brushing and diet [63]. This finding also complements the observations from another study in the USA which reported very positive attitudes towards oral health among almost 80% of Indian immigrants [64]. Nevertheless, in line with qualitative findings [31], almost half of the respondents (45.8%) agreed that Indian immigrants in Australia were at higher risk for oral cancer due to their continued use of risk products (e.g., areca nut/tobacco preparations and alcohol) and linked this to addiction, leisure/lifestyle choices and cultural

customs. These views are not surprising as the burden of oral cancer in India [7,65] and the prevalence of risk practices among Indians has been well documented with research continuing to show that these practices tend to continue even after migration to new settlements [5,11,66]. This is particularly relevant in Australia with recent reports [25,26] suggesting the popularity of new risk products such as areca nut and the potential flow-on effect on future oral cancer cases.

Respondents' knowledge about key oral cancer risk factors and their positive attitudes toward preventive oral health may have had a positive impact on their practices with less than half (42.4%) indicating they consumed alcohol and even less reported smoking (6%). In addition, very few reported chewing tobacco and areca nut preparations (6.7%) which is in sharp contrast to previous studies which have shown higher prevalence rates of these practices (range 34–69%) [13–16,42]. This finding was also dissimilar to our earlier qualitative study [31] which showed indulgence (occasional/regular) of all Indian immigrants in one or more risk habits such as smoking, alcohol and betel nut/quid use; however, it is important to note that almost 15% of the respondents had previously used tobacco and areca nut products. As we did not assess the average period since cessation of these practices, we cannot be certain that the prevalence rates reported for chewing tobacco preparations in this study are accurate. Adding to this is the fact that the current study was undertaken during the COVID-19 lockdown in Australia and as a consequence respondents may have had limited access to tobacco preparations due to restricted domestic travel, limited supply of Indian groceries and their inability to travel overseas to India [67]. A pilot study in the USA [15] did find that difficulty in procurement/storage of tobacco preparations and being socially unacceptable were some of the reasons why respondents decided to switch or stop risk practices such as betel quid use. It is also possible that the number of years living in Australia could have influenced the oral cancer risk practices of Indian migrants. The respondents had been living in Australia for a long period (average of 26 years) and this could have affected their risk habits as a result of acculturation which is usually common in South Asian migrants [68]. Due to the very small number of people using areca nut preparations in the sample, a test of associations between length of residence and areca (betel) nut use was not possible. Nevertheless, this aspect should be considered in future research. Smoking or chewing tobacco and areca (betel) nut products were found more frequent in males as compared to females. This finding is supported by research from the US [15] which showed that men were larger consumers (61%) of betel quid/'pan' compared to women (26%). Interestingly, studies do show there is considerable use of areca nut preparations among women in India [69,70].

The study findings suggest the need for strategies to raise oral cancer awareness among this population group at the community, health services and policy levels. Although there was greater awareness around key oral cancer risk products such as smoking and tobacco chewing and few appeared to be engaging in such risk practices, the variable levels of knowledge around other risk factors such as alcohol and areca nut use as well as oral cancer-related signs/symptoms are concerning. Culturally appropriate programs and visual aids such as posters raising awareness of oral cancer risks associated with tobacco and betel quid/'pan' use could be displayed at avenues popular for Indian gatherings such as Asian/Indian grocery stores, restaurants, temples and cultural events. Social media such as Facebook, Instagram, WhatsApp, Twitter, and local Indian radio and television channels could also assist in spreading relevant public health messages. Although no relationship was found between religion and frequency of risk habits in this study (possibly due to the small sample), previous studies have shown differences in knowledge levels and health-related behaviours among South Asian subgroups with diverse religious backgrounds [71]. More research is thus needed from an Australian context to inform the development of preventive educational campaigns/resources that are evidence based and tailored to specific subgroups within the Indian community.

Another key strategy is to involve general practitioners in oral cancer prevention and awareness programs as they can play a pivotal role in this area. They have a trusting

relationship with their patients to address this issue by providing educational counselling relating to oral cancer risk and the importance of early intervention. This is supported by the fact that most respondents clearly engaged more with health services than dental care services and were very receptive to receiving oral health advice and referrals from general practitioners. However, there was a lack of clarity among respondents about the exact scope of practice of GPs and this is evident by the fact that many indicated they would see a GP for a nonhealing ulcer/sore and not a white/coloured patch in the mouth. A number of respondents also questioned the competency of GPs to advise them on oral cancer. These findings are not unforeseen as a recent qualitative study involving GPs in Australia raised similar concerns regarding their limited knowledge around new oral cancer risk factors, inconsistent clinical practices relating to routine oral cancer check-ups and referrals [37]. These views were supported by the findings of a review that explored the knowledge, attitudes and practices of general practitioners in developed countries regarding oral cancer [47]. Based on the current literature, it is evident that for GPs to take up this unique opportunity, additional training is required around emerging risk factors such as areca (betel) nut preparations, which could be provided via continuing professional development programs and online modules. One such resource targeted at health professionals in public health services has recently been launched in one state in Australia which offers great insights into the carcinogenic potential of areca (betel) nut use [72]. This is a step in the right direction, but more can be done in this field, particularly around consumer resources relating to oral cancer and betel nut which could be promoted in the waiting room of health care settings. To our knowledge, no national resource is currently available in Australia regarding areca nut use among immigrants and this is an area that needs urgent attention particularly given the ongoing influx of Indian immigrants to Australia [22].

It is important to note that many participants (60%) expressed their preference for health professionals of similar cultural backgrounds for routine medical/dental check-ups. This mirrors the observations from an earlier study which found that having GPs from similar ethnic backgrounds is preferable for Indian women due to a perceived better understanding of cultural issues and being able to communicate in the patients' own language [73]. Past research has also found that immigrants from the Indian subcontinent do not feel comfortable visiting doctors/dentists of different ethnic backgrounds as communication may be limited or sometimes ineffective and culturally insensitive advice from the healthcare provider may offend immigrant patients hindering healthcare delivery [5]. These points need to be taken into consideration when targeting and training GPs to raise oral cancer awareness among the Indian population.

To ensure consistent clinical practices in this area, guidelines need to be developed by health departments and professional organisations to ensure all medical and dental professionals engaging with Indian immigrants provide the same messaging regarding oral cancer risk practices. Apart from this, the rising oral cancer burden draws attention towards a growing need for opportunistic oral cancer screening and effective monitoring systems in Australia [23] to assess oral cancer cases in immigrants. Lastly, it is important to note that the key focus of the current study was on hypothesis generation to shed more light on this under-researched area. The findings have identified emerging areas that need continued research through larger studies. These areas include, confirming if Indians in Australia are engaging in oral cancer risk behaviours particularly chewing tobacco preparations, examining if the oral cancer risk behaviours are different between first- and second-generation Indian immigrants and confirming the perspectives and clinical practices GPs in Australia towards oral cancer, especially when interacting with high-risk populations such as Indian immigrants.

The results of this study should be interpreted with caution due to several limitations. Firstly, the sample size was small owing to recruitment challenges during the COVID-19 pandemic and thus more complex analysis was not possible. More importantly, due to convenience sampling, the study findings may not be reflective of the whole Indian

community living in Australia and therefore cannot be generalized. Further, most of the participants had been residing in Australia for a long period and so the findings may not reflect the current knowledge and practices of new immigrants. The majority of participants were also in their middle age and thus more research with younger and older generations could give further insights into this research area. In addition, the reported results are subject to information bias and due to the self-reported data as well as social desirability bias, the respondents may have under-reported their oral cancer risk practices. Despite these limitations, the survey has broadened our understanding of this under-researched topic in Australia and identified potential pathways to raise oral cancer awareness in this community.

## 6. Conclusions

This study has revealed varying levels of knowledge about oral cancer among the sample of Indian immigrants, particularly around risk factors such as alcohol and areca nut use as well as oral cancer-related signs/symptoms. Positive attitudes about preventive oral health practices were evident though some were involved in oral cancer risk practices. The findings have also highlighted the lack of adequate information regarding oral cancer being provided in primary health care settings and uncertainty around the scope of practice of GPs in this area. The receptiveness of the study sample towards GPs playing a role in raising oral cancer awareness looks promising and adequate training of these health professionals could be beneficial. With the growing influx of Indian immigrants to Australia, more strategies are needed to raise awareness in this community about oral cancer risk practices, particularly around tobacco/areca nut use which is highly prevalent in India. Further research through larger studies and a more representative sample is warranted to explore this area in Australia and confirm the study findings. Greater knowledge in this area will help inform the development of culturally sensitive and tailored strategies to raise awareness of oral cancer risk among Indian immigrants.

**Supplementary Materials:** The following supporting information can be downloaded online at https://www.mdpi.com/article/10.3390/ijerph19148596/s1, File S1: The survey tool (questionnaire).

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# Chapter 9: Summary

## 9.1 Introduction

The overall aim of this study was to explore oral cancer risk behaviours of Indian immigrants and identify preventative strategies in oral cancer. The specific aims of the study were then discussed extensively in the five thesis papers (Papers 1-5) that were published in peer reviewed journals.

The purpose of this chapter is to integrate and summarise the overall results described in Chapters 6 to 8 and discuss the new knowledge that has emerged from this study. This chapter will commence with a discussion of Study Aim 2 (oral cancer-related knowledge, attitudes, and practices of Indian immigrants in Australia and their perceived barriers/facilitators in accessing preventative oral cancer strategies) and Study Aim 3 (knowledge, attitudes and clinical practices of GPs regarding oral cancer in Australia, particularly among Indian immigrants and their perceived barriers/facilitators in engaging in preventative oral cancer strategies) in the context of current global evidence (Study Aim 1). Preventative strategies regarding oral cancer awareness among Indian immigrants in Australia (Study Aim 4) will be discussed in light of the study findings (Specific aims 2 & 4). The chapter will conclude with a reflection on the conceptual models that informed this research along with the strengths and limitations of the study.

## 9.2 Oral Cancer-related Knowledge, Attitudes, and Practices of Indian Immigrants in Australia

This aspect of the study was initially explored in an integrative review (Chapter 2, Paper 1), which synthesised global evidence on the knowledge, attitudes, and practices of South Asians residing in developed countries. The review, which was undertaken in 2019, found there were limited studies in this area (*n*=16) and even less (*n*=11) involving Indians. The findings revealed that South Asian immigrants, especially Indians in developed countries, have inadequate oral cancer risk-related knowledge, poor attitudes towards oral cancer risk and a strong inclination towards negative oral cancer risk practices (such as areca/betel nut chewing, alcohol consumption and tobacco use). This review also highlighted the consistent lack of information among South Asian Immigrants regarding the harmful health risks associated with the use of risk products like tobacco and areca nut preparations.

A key point from the integrative review was that none of the studies were conducted in Australia. Thus, our research with Indian immigrants (Papers 3 and 5) addressed this gap and provided an Australian perspective in the context of oral cancer risk behaviours. Our qualitative phase (interviews with Indians in NSW and VIC) found limited knowledge among Indian immigrants in relation to the signs and symptoms of oral cancer as well as emerging risk factors like areca nut. A similar situation was noted in the quantitative phase (cross-sectional survey with Indians across Australia) where less than half the sample (14-48.8%) were aware of oral cancer symptoms (e.g., painless ulcers, red patches, yellow patches, discomfort, and bleeding gums) and had varying levels of knowledge around alcohol as well as areca nut use as risk factors. Furthermore, the qualitative findings (Chapter 6, Paper 3)

revealed a scarcity of oral cancer-risk information being provided in primary health care settings, which was further confirmed in the survey with only 12.3% of participants receiving relevant information. These observations are not much different from that of Non-Indian Australians, as a survey reported that only half of this population were knowledgeable of oral cancer risks associated with alcohol consumption (F Dost et al., 2016). Further, another survey investigating awareness of oral cancer amongst adult dental patients attending regional university clinics in NSW (Australia) discovered that less than half of participants were aware about persistent painless ulcers being a sign of oral cancer (Zachar et al., 2020).

Taken together, the findings from the qualitative and quantitative study suggest that Indian immigrants are not receiving adequate information about oral cancer in primary health care settings in Australia which could explain why many (three quarters) of survey respondents were uncertain about the scope of practice of general practitioners in this area. These findings are similar to those reported in the integrative review (Paper 1). Consistently across both phases, Indians were found to have varied attitudes towards oral cancer. Many participants acknowledged the importance of routine preventative oral cancer check-ups and were engaging in preventative oral health care like a healthy diet, brushing teeth twice daily, and routine dental visits. While all participants in the qualitative phase had engaged in at least one or more risk practices (such as alcohol and betel quid use) on a regular or occasional basis and there was no difference across the gender, this was not reflected in the quantitative phase, with few Indians reporting smoking tobacco (6%) and chewing tobacco preparations (6.7%). Again, unlike the qualitative phase which found no gender difference in terms of oral cancer risk practices, the quantitative data identified more males engaging in these risk practices.

These findings are not supported by previous literature, which has found the use of smokeless tobacco (mainly chewable) popular across both genders in India while smoking prevalence has been lower in Indian women than men (Bhawna, 2013; Sreeramareddy et al., 2014). Although consumption of smokeless tobacco among women is well-accepted in some parts of India, this habit has been shown to be associated with low education levels and lower socio-economic status (Mishra et al., 2015). This might have been an influencing factor in the Australian context where due to immigration policies the majority of Indian women migrants have higher education and socioeconomic status (Costa-Pinto, 2014) leading to less female participation in smokeless tobacco use. It is important to note though (as discussed in Paper 5) that almost 15% of respondents had previously used tobacco and areca nut products, so the true prevalence rate need to be confirmed through larger studies. The limited access to risk products during the pandemic along with travel restrictions (Beck & Hensher, 2020) could also have resulted in the underreporting of risk practices in this study. Nevertheless, there was consensus across both phases that Indian immigrants were continuing to engage in these risk practices due to lifestyle, social networking, cultural practices, and a lack of awareness around the addiction of these products.

Since the thesis publications (Papers 1, 3 and 5), two more studies were conducted in this area (Tami-Maury et al., 2022; Yang et al., 2021) along with a review (Singh et al., 2020), but none were undertaken in Australia. The review reiterated the high incidence of areca nut use in the Indian subcontinent and emphasised the potential changes in the patterns of oral diseases due to globalisation and increased movement of Indians across borders. This publication further reinforces the importance of undertaking the current study, especially as India is now the third largest source of immigrants in Australia according to the latest report

(ABC News Australia, 2022). The additional new studies (Tami-Maury et al., 2022; Yang et al., 2021) were conducted in the USA and involved surveys of South Asian immigrants including Indians. The results of these studies again reported an association between Indian immigrants and areca/betel nut use with several respondents being unaware of the harmful effects caused by consuming such products (Tami-Maury et al., 2022; Yang et al., 2021). These new studies mirror the findings from our study.

Overall, the findings from our study and related literature suggest that Indian immigrants in Australia do not possess adequate knowledge around oral cancer and have some tendency towards involvement in risk practices. These behaviours seem to be more pronounced in males and are linked to socio-cultural practices. Even though our survey found only a small number of Indians engaged in risk practices, this could be an under-representation due to the convenience sampling used along with the impact of COVID on travel and availability of tobacco preparations. Furthermore, the uncertainty among Indians regarding GPs' roles in oral cancer screening and preventative practices is concerning. While this area needs to be researched more in-depth in future, the findings suggest more preventative strategies are needed to address the lack of oral cancer awareness in this community.

## 9.3 Knowledge, Attitudes, and Practices of General Practitioners in Australia Regarding Oral Cancer

This aspect of the study was initially addressed through an integrative review (Chapter 3, Paper 2), which synthesised current evidence on the oral cancer-related knowledge, attitudes, and practices of General Practitioners (GPs) in developed countries.

The review was conducted in 2019 and included 21 studies conducted globally involving 3,409 GPs. The review highlighted limited knowledge among GPs around emerging oral cancer risk factors like areca nut and betel quid use. Most GPs were unsure about identifying oral cancer and highlighted the need for further education/training in this area. There was also significant variation around their clinical practices relating to oral cancer such as routine mouth check-ups and preventative counselling.

A notable finding from the review was that none of the studies specifically focused on GPs' clinical practices relating to South Asian immigrants and there were no such studies from Australia. This research gap was thus addressed through our qualitative phase (Chapter 7, Paper 4), which explored the oral cancer-related knowledge, attitudes, and practices of GPs in Australia, along with their perspectives towards emerging risk factors among Indian immigrants. Similar to the integrative review (Paper 2), the study revealed sound knowledge among GPs about common oral cancer causative agents like tobacco and alcohol, but a limited understanding about the risks associated with areca nut use. Participant GPs also had varied beliefs about the seriousness of oral cancer in Australia and were inconsistent in clinical practices relating to routine oral cancer screening, counselling, and referrals. These findings were also reiterated among Indian immigrants (Chapter 6, Paper 3 and Chapter 8, Paper 5), with the majority reporting not receiving any kind of oral cancer-related information in a health care setting but were receptive to general practitioners playing a more active role in this area. Nearly all GPs highlighted the lack of oral cancer educational resources and raised the need for improvement in their knowledge around oral cancer prevention and early identification. This is particularly important since the majority of the Indians during the interviews (Paper 3) considered a GPs as the best person to assist with

oral cancer risk-related information and during the survey many (24.4–45.7%) were uncertain around GPs' skills to diagnose oral cancer.

Since the thesis publications (Papers 2 and 4), two additional studies have been conducted in this area (Demers et al., 2022; Tavakoli et al., 2021) which were both quantitative in nature. One of these studies (Tavakoli et al., 2021) assessed the levels of oral cancer awareness in healthcare staff (including GPs) at a district general hospital in the UK through 155 completed surveys. The other study was undertaken in the Netherlands (Demers et al., 2022) examining the knowledge of 207 GPs via postal surveys with questions related to HPV-associated oropharyngeal cancer. The results of these new studies showed gaps in GPs' oral cancer-related knowledge, especially regarding less common risk factors such as areca nut use. In addition, a recent systematic review (Langton et al., 2020) of studies that compared the referral practices of GPs and dentists highlighted the need for enhancement in GPs' skills of oral examination, lesion recognition and risk factor knowledge. Furthermore, a retrospective study exploring the self-perception and physician's awareness of early detection of tongue cancer in Italy (Gobbo et al., 2020) concluded that patients are not always aware of oral cancer risk, and relevant information regarding risk factors should be provided to patients as well as to other health professionals rather than just dentists. These additional studies echoed our qualitative findings and further reinforced the pivotal role GPs could play in this area.

Overall, the findings from our study and related literature suggest that GPs do not have optimum knowledge about oral cancer, especially around emerging risk factors like betel quid. They are also not regularly screening and providing counselling on this topic even to at-risk population groups like Indian immigrants. This is of concern, as an audit of referral

patterns for oral squamous cell carcinoma in the Australian state of Victoria (Kaing et al., 2016) revealed a significant shift of oral cancer initial presentations towards GPs in the last decades. The main reason behind this could be the structure of the Australian healthcare under which Medicare provides free or subsidised healthcare services and medications for all Australians (Gupta & Stuart, 2020). On the contrary, dentistry is generally not covered under the Medicare Benefits Schedule, with some exceptions, for example, cleft palate surgery and certain government-funded schemes (Gupta & Stuart, 2020). In addition, patients are also not entitled to a Medicare rebate for a specialist consult or treatment without referral from a GP (Kaing et al., 2016). It is likely that these factors have contributed to substantial increase in early presentations of suspected oral cancer to GPs as compared to dentists over the last 20 years (52% versus 24%) (Kaing et al., 2016). This further highlights the crucial role of GPs in the initial evaluation of oral cancer patients in the Australian population. Although our qualitative findings need to be confirmed through larger studies, it is evident that more strategies are needed to address the gap in the knowledge and practices of GPs in this area for timely oral cancer identification and referrals.

## 9.4 Preventative Strategies to Promote Oral Cancer Awareness in Australia

The findings from both the qualitative and quantitative phases of this study have highlighted the need to promote oral cancer awareness among Australian Indian immigrants and primary health care providers. The following section discusses various preventative strategies that could be employed to achieve this based on the study findings:

### 9.4.1 Community-centred oral cancer awareness

The findings from this study clearly suggest that there is the need for more awareness in the Indian community about oral cancer-associated risk factors, particularly alcohol and areca nut use. The latter aspect is important, as our study findings do indicate that a proportion of the community is engaged in risk practices of betel quid/ 'pan' chewing as a result of strong cultural practices. Furthermore, areca (betel) nut preparations are easily available in Asian/Indian grocery stores or supermarkets and as highlighted in the findings, some Indians bring these products in Australia while returning from overseas. Although Asian/Indian grocery stores are considered as primary venues to purchase smokeless tobacco and areca nut preparations in Australia (Hossain et al., 2014), it is important to point out that not all Indian immigrants may access these products owing to various factors like high cost to maintain the habit, disapproval by family/friends and restrictions at workplaces (Gupta et al., 2022). Furthermore, other factors like - limited access to such stores especially in regional areas and living in Australia for a longer time can also limit Indians from indulging in such practices (Spallek et al., 2011). However, the availability of and continued access to these products contributes to increased use, which is worrying, as betel quid constituent areca nut is the fourth-most frequently consumed addictive substance in the world, following tobacco, alcohol, and caffeine (Warnakulasuriya & Chen, 2022). The psychotropic nature of these risk products creates addiction among the consumers, which was highlighted in Paper 5, as one of the reasons why migrants continue such practices. It is equally important for people who are engaging in these practices to be familiar with the signs and symptoms of oral cancer, which are currently lacking according to the study findings.

The limited familiarity of Indian immigrants regarding oral cancer risk has been highlighted in other developed countries like the UK (Merchant et al., 2016), the USA (Changrani et al., 2006) and Italy (Petti & Warnakulasuriya, 2018). From these studies, promoting public health messages through awareness programmes has emerged as an effective recommendation to promote oral cancer understanding. In general, these awareness programmes can involve population-based campaigns, multi-faceted mass media approaches, community-based initiatives, and individual interventions. Owing to the high prevalence of oral cancer in South Asia, many population-based large-scale programmes have been developed with a view to raising awareness of the oral cancer disease and its risk factors. Past campaigns in India have involved the screening of high-risk individuals, encouraging oral self-examination and participation of village health workers to promote early detection and awareness (Mishra & Bhatt, 2017; Singh et al., 2017; The Oral Cancer Foundation, 2022). In the present era, the internet has become a popular source of knowledge for people, even for health information, and thus it could be a useful mechanism for providing relevant oral cancer awareness messages to the public (Cancer Research UK, 2021). Thus, mass media campaigns via news and entertainment outlets represent a promising strategy to convey public health messages related to oral cancer (Amarasinghe et al., 2023). In 2010, the Lancet published a review of the use of mass media campaigns to change health behaviour and concluded that these types of campaigns are effective in causing positive changes in health-related behaviours (Wakefield et al., 2010).

Some developed countries like the US and the UK have also introduced national mouth cancer awareness days on an annual basis (Oral Health Foundation, 2022; The Oral Cancer Foundation, 2022) to help engage with the general population and primary

healthcare professionals. Short-term evaluation of this approach has shown increased awareness of oral cancer and increased uptake of screening at secondary care centres (MacCarthy, 2012; Rafiq et al., 2013). In addition to the annual campaigns, other one-off mass media programmes have been used to raise awareness of oral cancer and encourage early detection through engagement with primary care services. One such successful example was the National lottery-funded West of Scotland Cancer Awareness Project in the UK (Rodgers et al., 2007), which involved key oral cancer messages conveyed via media/mail for the targeted at-risk population of adults over 45 years of age from lower socio-economic groups to boost their engagement with primary care services. Another successful oral cancer marketing campaign was in the USA (Ismail et al., 2012), aimed at African- American men, which included numerous media advertisements and multiple educational sessions with community groups and resources for health care professionals to increase oral cancer screening activity.

In addition to the population-based and media campaigns, individual or community-based interventions at local levels could be useful. Many smaller and more localised oral cancer awareness campaigns have been undertaken in developed countries with special consideration to the development of culturally sensitive approaches intended for high-risk ethnic minority communities (Croucher et al., 2011; Siddique & Mitchell, 2013). However, a systematic review examined the evidence of the effectiveness of community-based or individual interventions and found them of limited influence, as these could only endorse short-term knowledge and awareness (Austoker et al., 2009). The same review highlighted that more intensive or tailored interventions can be effective for a longer duration and more work is required to enhance the effect of awareness campaigns. Following this, the public

health law centre in the UK has developed one such resource emphasising risks linked with areca nut/betel quid use in migrants including Indians (Public Health Law Center, 2017).

From an Australian perspective, there have been some efforts to raise oral cancer awareness via general oral cancer information relating to risks and signs/symptoms which are available through online platforms by charity bodies such as Cancer Council Australia (Cancer Council, 2021b) and government funded services like Healthdirect (Healthdirect, 2020). State governments have also taken some steps in this direction, for example, the Victorian government has approved an online *Better Health Channel* to keep people alert of oral cancer risk along with other health ailments (BetterHealth Channel, 2022). In addition, a professional organisation (Australian Dental Association) has provided an informative piece on oral cancer on their website (Australian Dental Association, 2022). Annual awareness days like *World Head and Neck Cancer Day* have also been announced to promote oral cancer awareness (Head & Neck Cancer Australia, 2022b). However, there has been a lack of targeted information for high-risk populations like Indian or other migrant communities. This is perhaps unsurprising since oral cancer has a relatively low prevalence in Australia compared to some other parts of the world (Sung et al., 2021). However, given the fact that Indians have been migrating in record numbers and are now the third highest migrant group to Australia (ABC News Australia, 2022; Australian Bureau of Statistics, 2019; Department of Home Affairs, 2019, 2020), it is imperative to have a greater focus on this community.

Based on current international evidence, having a multi-component and tailored awareness campaign targeted at Indian immigrants in Australia may have greater potential to change behaviour. Supporting this is the encouraging study finding showing the engagement of Indians in preventative health activities and a willingness to receive oral

cancer information. However, facilitating behaviour change can be challenging even after imparting relevant knowledge and information (Heimlich & Ardoin, 2008; Kelly & Barker, 2016). Thus, promoting intrinsic motivation while providing extrinsic support and guidance is also vital to enhance engagement in health behaviour change (Yardley et al., 2015).

### 9.4.2 Capacity building of primary health care professionals for oral cancer prevention

This study has identified important gaps in the knowledge and clinical practices of GPs in relation to oral cancer. Though the findings need to be confirmed with a larger sample, the limited knowledge of GPs about new risk factors and inconsistent clinical practices relating to oral cancer screening and check-ups are noteworthy. Furthermore, the study highlighted a lack of relevant training and resources for GPs to assist in oral cancer prevention and diagnosis. This finding is concerning, as GPs are often the primary contact for patients with medical needs in developed countries and if they are not trained to undertake oral screening as part of a physical examination, they will lack the ability and skill required to identify oral cancer lesions that are usually symptom free, and as a consequence, many patients will never be referred in a timely manner for definitive care (Feierabend-Peters & Silk, 2022).

The need for capacity building of GPs in this area, particularly around less common oral cancer causative factors like areca nut, has been strongly advocated in the UK and the USA, where there has been a long history of migration from the Indian subcontinent (Carter & Ogden, 2007; Ismail et al., 2012; Riordain & McCreary, 2009). These studies have highlighted the need to address the oral cancer-related educational needs of GPs,

particularly regarding the emerging risk factors (e.g., areca nut) through undergraduate training and via professional development programmes for graduates. Given the association of areca nut consumption with increased incidence of oral cancers, the World Dental Federation has recently emphasised an explicit mention of betel quid and areca nut use as an oral cancer risk factor (FDI World Dental Federation, 2021). The FDI has also urged World Health Organisation to consider the addition of new strategies to support general health practitioners for oral cancer screening (FDI World Dental Federation, 2021). Likewise, the training of GPs has been recommended for the detection of oral cancer lesions to help upskill them in early identification and prevention counselling (Carter & Ogden, 2007).

Among developed countries that have attracted Indian immigrants, the UK has witnessed awareness campaigns like the West of Scotland Cancer Awareness Project, which included oral cancer training for primary healthcare professionals (Rodgers et al., 2007). This was beneficial in raising awareness of oral cancer while also encouraging individuals to consider consulting primary care professionals in case of related symptoms (Eadie et al., 2009). However, one of the criticisms of just raising awareness among these health professionals is the high number of inappropriate referrals that can occur which can place an additional burden on secondary care services (Rodgers et al., 2007). Having more structured and appropriate training of health practitioners could be more beneficial. The UK seems to have implemented such strategies through the inclusion of oral cancer education in the undergraduate medical curricula, although more needs to be done to address this health issue (Carter et al., 2011; McCann et al., 2005).

Due to the rise in oral cancer cases, many developing countries like India and Pakistan have well-formulated oral cancer related training modules for medical

undergraduates (National Centre for Disease Control, 2017; National University of Medical Sciences, 2018), which have been effective in implementing a screening program and managing oral cancer in primary health care settings. Opportunistic oral cancer screening has also been suggested as an important step in oral cancer prevention in medical settings, especially when people at-risk of developing oral cancer, such as smokers and tobacco users, are unlikely to have regular dental check-ups and are more likely to access primary medical care (Ford & Farah, 2013). To facilitate this, studies have suggested the use of specialist tutors, e-learning programmes and problem-based-learning sessions (Ahluwalia et al., 2016), some of which have been implemented in the UK. Though not exclusive to GPs, detailed information has been made available by the UK government relating to oral cancer risk, early detection and post-treatment prevention (Department of Health & Social Care, 2021). The introduction of an oral cancer recognition toolkit for identification of oral cancer is a good initiative which was created by the UK organisation-Cancer Research (Cancer Research UK, 2015b).

This study highlighted uncertainty among GPs regarding referral pathways and guidelines for oral cancer (Paper 4), which is worthy of attention. Appropriate referrals are essential in oral cancer diagnosis and timely treatment. Keeping this in context, the National Institute for Health and Care Excellence (NICE) in the UK has developed guidelines for oral cancer referrals (National Institute for Health and Care Excellence, 2015). This guidance states that patients with a lump on their lip or in their oral cavity, or with a red or red and white patch in their oral cavity, should be sent for potential oral cancer assessment by a dentist within two weeks of seeing their GP. However, it has been speculated that this guidance may expose patients to an increased risk of delayed referral, because there are no

clear referral pathways between GPs and dentists for suspected oral cancer (Grafton-Clarke et al., 2019). Furthermore, a small case-series trial modelling the impact of the updated NICE guidance revealed that the lack of clear referral pathways would result in delay of one in nine diagnoses of oral cancer (Grimes et al., 2017).

The NICE guidance is also not ideal because even if a GP decides to refer a patient with suspected oral cancer to a dentist, the emphasis is placed on the patient to attend, regardless of whether they can afford to pay for dental services (Grafton-Clarke et al., 2019). Following this, the Cancer Research organisation in the UK decided to take the unusual step of deviating from NICE guidelines by designing the Oral Cancer Toolkit to make a simpler recommendation that GPs and dentists should consider referring patients directly for further investigation if symptoms persist for more than three weeks (Cancer Research UK, 2015a). There is still the need for more efforts globally in this area considering delays in oral cancer referrals.

Unfortunately, there are limited oral cancer-related learning resources and training exclusively for general practitioners in Australia despite the rise in cases in recent years (Farah & McCullough, 2008; Wong & Wiesenfeld, 2018). Although there is some oral cancer-related information provided by organisations like Cancer Australia (Cancer Council, 2021b), the Australian Cancer Research Foundation (ACRF) (Australian Cancer Research Foundation (ACRF), 2017), and Head & Neck Cancer Australia (Head & Neck Cancer Australia, 2022a) which is accessible online in addition to the general resources discussed in the previous section, none are tailored for GPs. There has also been a limited focus on new risk factors like areca (betel) nut use (Cancer Council, 2021b; Head & Neck Cancer Australia, 2022a). Compared to other developed countries, a lot more work is needed to capacity build GPs in

this area, as dental visits are not covered by the Universal Health care system in Australia (Medicare) and medical specialists do not see patients without referrals from a GP. Thus, GPs remain the most affordable and approachable health practitioners for medical needs in Australia and this is probably why there has been a significant shift of initial oral cancer presentations towards GPs in the last 20 years (Kaing et al., 2016).

The lack of a national screening programme and standard referral pathways for oral cancer is also concerning (Cancer Council, 2021b). However, there is insufficient evidence to assess the balance of benefits and harms of oral cancer screening in asymptomatic adults (Warnakulasuriya & Kerr, 2021). Screening of high-risk populations and telemedicine consultations could be cost-effective in countries with low prevalence of oral cancer (Warnakulasuriya & Kerr, 2021). Some of the evidence-based educational strategies that have been found to be effective in other countries could also be trialled in Australia (Wee et al., 2016). Currently, most of the efforts have been on training the dental professionals to detect oral cancer and raise awareness about emerging risk factors. Recently, a learning resource (*The Oral Cancer Learning Hub)* was developed by the Victorian Oral Cancer Screening and Prevention Program with funding from the Department of Health, in response to the increase in oral cancer in Victoria (ADA Victoria, 2021). This resource was designed with a view to enhance oral health professionals' ability to identify people at risk, detect oral cancers early and refer them appropriately (Dental Health Services Victoria, 2021a). With a similar aim, New South Wales developed a factsheet for health professionals to raise awareness relating to the emerging oral cancer risk factor–areca (betel) nut (NSW Government, 2021). These strategies are an important move in the right direction, but similar approaches can be adopted for general practitioners.

As a starting point, it might be best to target GPs in areas that have high numbers of Indians who are known to indulge in practices of areca nut and betel quid consumption. As also highlighted in Paper 4, time constraints are an issue in overly busy clinical schedules of GPs, thus there is scope to involve and train other health professionals like practice nurses who are actively involved in screening and health promotion as part of their scope of practice (Australian College of Nurse Practitioners, 2022). These strategies could also go a long way to improving the oral cancer awareness of Indian immigrants, particularly as Papers 3 and 5 have shown that they are receptive to receiving oral cancer check-ups, prevention counselling and referral from GPs.

### 9.4.3 Policy-led initiatives to reduce oral cancer risk

The limited oral cancer awareness among Indian immigrants, easy access to betel nut products and limited focus by GPs in Australia highlights the need to strengthen existing oral cancer prevention policies in this area. Without support at a policy level, the strategies already highlighted at the community and primary health care level may not be enough to reduce oral cancer risk behaviours (Ng et al., 2022). It is well documented that efforts to prevent and control cancer are often hampered by the low priority given to the disease by the government and health services (Petersen, 2009).

Oral cancer prevention and control at policy level can help reduce the disease burden and improve general awareness (Bouvard et al., 2022; Petersen & Yamamoto, 2005). To achieve this, a well-designed national cancer control programme has been advocated as the most effective strategy, which when integrated into existing health systems, ensures systematic implementation of control strategies (Petersen, 2009). On an international level, the WHO Global Oral Health Programme, which was launched in 2003, included plans to

work with each country to build capacity in the prevention of oral cancer, allow inter-country exchange of information and experiences from integrated approaches in health promotion, and the development of global surveillance systems for oral cancer and risk factors (Petersen, 2009). Similarly, the WHO Framework Convention on Tobacco Control and WHO MPOWER measures have been introduced to restrict tobacco consumption (Mehrtash et al., 2017). The International Agency for Research on Cancer (IARC) has classified areca nut and betel quid (without added tobacco) as Group 1 carcinogens, which should be seriously considered in the designing of effective oral cancer control policies, especially in South Asia and the Pacific regions where consumption of these preparations is widespread (Sharma, 2003; Warnakulasuriya & Chen, 2022). However, no global policy or framework exists to reduce the burden of areca nut and betel quid use, despite the proven association of betel quid and areca nut with oral cancer (Mehrtash et al., 2017). There are some countries that have tried to implement targeted policies aiming to restrict areca nut use.

In the Asia Pacific region, Taiwan is the only country to have set up national policies to reduce areca nut use through educational and targeted cessation following the high incidence of oral cancer in the country (Yang et al., 2020). Given the carcinogenic nature of areca nut, the Food and Drug Administration (FDA) in the USA has banned the import of its preparations; and the US Department of Agriculture has reinforced a prohibition against the introduction of areca nut in raw or unprocessed forms (U.S. Department of Agriculture, 2020; Van McCrary S, 1998). Nevertheless, these products continue to be easily available across the USA, largely at Asian/Indian stores (Blank et al., 2008). Likewise, betel quid/ 'pan' and other areca nut preparations are still consumed in Canada, despite the steps taken by Canadian administration to restrict the import of such products in Ontario and British

Columbia (Government of Canada, 2022). By contrast, in the UK, policy makers made areca nut use legal in an attempt to monitor its sale and usage in the country (DrugWise, 2021).

Some developing countries like Papua New Guinea and Myanmar have proposed, and to some extent, imposed a ban on chewing betel quid and areca nut products in public spaces; however, the evaluation on the success of such policies remains limited (Mehrtash et al., 2017). In India, most states have banned the sale of gutka (an areca nut preparation with tobacco) following restrictions on the use of smokeless tobacco (Arora & Madhu, 2012), but manufacturers are bypassing these bans by selling gutka ingredients—pan masala and tobacco—separately (S. Nair et al., 2012; Shetty, 2015). Apart from these countries, the United Arab Emirates has imposed a ban on the importation of betel leaf and related products (UAE, 2021). In addition, Singapore has also banned gutka as part of a bigger effort to control emerging tobacco products (Ministry of Health Singapore, 2015). Nevertheless, in some countries like Papua New Guinea the complete banning of these products has led to negative social and economic impacts in the community (Wenogo, 2018). This total ban on betel nut was not the best way forward for all stakeholders (including users and vendors) and a new approach was suggested based on mutual understanding and consultations with vendors/producers of betel nut (Wenogo, 2018) .

Research has also suggested that combining taxation policies for cigarettes with betel quid and areca nut products could have beneficial effects on cessation since the two behaviours are closely related (Chen et al., 2011; Hecht & Hatsukami, 2022). However, the implementation of taxes on areca nut preparations remains weak in many countries, and assessment of the taxation or impact of price increases across smoked tobacco and areca nut products is needed (Mehrtash et al., 2017). Addressing the fast-growing burden of oral

cancers associated with betel quid and areca nut products is a multidisciplinary challenge which requires a balanced and comprehensive mix of economic interventions (supply and demand reduction strategies), investments in surveillance and clinical services, research, and policy considerations (Mehrtash et al., 2017).

From an Australian perspective, some steps have been taken at a policy level to reduce oral cancer risk. Areca nut has been listed as a Schedule 4 poison and classified under prohibited plants and fungi (Federal Register of Legislation, 2017). Hence, it is illegal to possess or sell areca nut without proper authority (Federal Register of Legislation, 2017). Furthermore, the importation of areca nut into Australia is also prohibited (Alcohol and Drug Foundation, 2021). However, as also highlighted in Paper 3 and Paper 5, and in the media, (SBS Punjabi, 2016) areca nut preparations and betel quid is still readily available across many Asian/Indian stores and restaurants (Faa, 2020; Sukumar et al., 2012). The recent policy update by the Australian Government in this area is very encouraging. Areca (betel nut), being a prohibited plant or fungus, has to be referred to the Imported Food Inspection Scheme (IFIS) for inspection after import and if it presents as a food preparation then it will be considered as a prohibited entry and must be re-exported or destroyed (Department of Agriculture, 2022). This is an important action towards the control of areca nut use and potential prevention of oral cancer.

Another area where policy could help is around providing recommendations and guidelines for primary health care providers. This could go a long way to improving their awareness around emerging oral cancer risk behaviours in Australia. Very limited work has been done at policy level to raise awareness about areca nut as an oral cancer risk factor, particularly for GPs. The New South Wales government took the first step in this area in

2021 by developing a factsheet for health professionals to improve their understanding of the health issues associated with areca (betel) nut use and provided guidance in conducting a brief intervention with patients using the substance (NSW Government, 2021). Since prevention offers the most cost-effective long-term strategy, the Victorian government has also come up with the Oral Cancer Screening and Prevention Program funded by the Victorian Department of Health as an initiative under the current Victorian Cancer Plan (Dental Health Services Victoria, 2021c). Under this program, evidence-based learning resources and training were developed for oral health professionals with the next phase intended on focusing on training other health professionals like GPs (ADA Victoria, 2021).

Although the program is currently in progress, it has potential to prevent oral cancer disease. It makes sense that both NSW and VIC states have tried to implement programmes in this area, as they are heavily populated with Indian immigrants. However, other states need to follow similar strategies, as Indians are migrating to all parts of Australia in large numbers. Professional organisations including the Cancer Council and the Australian Dental Association could also play a key role in influencing policy in this area. Although these organisations have highlighted the negative impacts of betel quid chewing (Australian Dental Association, 2020; Cancer Council, 2021c), they have not provided or endorsed any specific recommendations in this area. Thus, there is an obvious requirement for more efforts at a policy level to support preventative strategies to raise oral cancer awareness among Indian immigrants when considering the limited resources available and the ongoing challenges encountered by other developed countries in this area.

## 9.5 Reflection on the Conceptual Model Used for This Study

As described in Chapter 4 (*Figure* 4.1) and highlighted in Paper 5, the conceptual model for the current study was informed by both the Knowledge, Attitude, and Behaviour (K-A-B) Model and Health Belief Model (HBM). This type of integrated behaviour model has been used in other international studies (Hsieh et al., 2021; Rimpeekool et al., 2016). Adapting both models has allowed for the perspectives and practices of both the Indian immigrants and GPs around oral cancer to be captured within the same research. This is the first time this type of model was used to understand the relationship of Indian immigrants' oral cancer related knowledge, attitudes, and practices with cues to action such as their engagement in health care services. In addition, GPs' perceived capacity to identify oral cancer and provide prevention counselling was also taken into consideration.

The study phases addressed various constructs of the KAB model (knowledge, attitude, and practice) and HBM model (perceived benefits, perceived susceptibility, perceived barriers, and cues to action). Most of the GPs and Indians who participated in the study were found to have inadequate knowledge about emerging oral cancer risk factors like areca (betel) nut. Furthermore, the positive attitudes of Indians about preventative oral health practices were evident as they expressed perceived benefits of regular oral cancer check-ups. However, some were involved in oral cancer risk practices like tobacco use and betel quid chewing, despite being aware of the perceived risk. Exploring the engagement of Indian immigrants in health care services identified general practitioners as a potential avenue for cues to action in this area, particularly as dental visits were limited due to financial and time constraints. On the other hand, GPs reported varied beliefs about the

seriousness of oral cancer in Australia and were inconsistent in their clinical practices relating to routine oral cancer check-ups, screening, and dental referrals. In line with Indian immigrants revealing receiving insufficient oral cancer information in primary health care settings, GPs also reported not providing preventative counselling during consultations and perceived various barriers including busy clinical schedules, lack of oral cancer resources and training.

Collectively, our findings reinforced the conceptual model and showed the knowledge and attitudes of Indian immigrants regarding oral cancer risk as interrelated and influenced their practices in this area. Furthermore, interacting with health services– in particular general practitioners, could be an important cue to action for Indian migrants to minimise oral cancer risk behaviours. However, the limited knowledge and varying attitudes with inconsistent practices of GPs towards oral cancer could have a negative impact on this cue to action during their interaction with Indian immigrants. The final aspect of the model (outcomes) provided valuable insight into the overall oral cancer risk behaviours of Indian immigrants in Australia and the scope of potential preventative strategies. The model also helped show that both GPs and Indian migrants in the study were receptive to raising oral cancer awareness, which is important for developing tailored initiatives. Future studies exploring risk behaviours in other areas and the potential role of health services could adopt a similar integrated model.

## 9.6 Strengths and Limitations of the Study

To our knowledge, this is the first Australian study to have explored the knowledge, attitudes, and practices of both Indian immigrants and GPs regarding oral cancer, which has

enabled us to put forward preventative strategies in the Australian context.

This study has resulted in five published papers in high-quality journals (Q1 and Q2) with good impact factors (IF 2.3 – 4.4) and has already received citations in a short period of time (19 citations). In addition, the hypothesis from this study has shed more light on this under-researched area. The findings have identified emerging areas that need continued research and have laid the foundation for the development of evidence-based educational resources, like the factsheet for health professionals endorsed by key stakeholders in NSW (NSW Government, 2021). Based on the study findings another resource is currently being developed with key stakeholders to raise awareness about areca nut use among migrant communities in Australia (see Appendix-15).

This study has several limitations. The qualitative studies included participants (Indians and GPs) from the suburbs of Sydney and Melbourne only, which limits the transferability and representativeness of the findings. Another potential limitation could be researchers' influence on the participants' responses during the interviews. The reported results are subject to information bias, due to the self-reported data as well as social desirability bias since the Indian participants may have under-reported their oral cancer risk behaviours and practices. Other methodological approaches for observational data such as examining oral cancer risk behaviours at large scale community events (festivals, weddings etc.) could help minimise bias. The use of a semi-structured interview guide and directed content analysis approach may have limited the in-depth exploration of participants' (Indians and GPs) responses. Given that some of the GP interviewees were trained overseas, their responses regarding oral cancer awareness may have been influenced by their previous experiences, thus the results reported are subject to information bias. Another limitation

could be ‘volunteer error,’ as some of the GP participants may have participated because they were motivated to learn more about the oral cancer issue and to support their patients.

The quantitative study consisted of a small sample owing to recruitment challenges during the COVID-19 pandemic and more complex analysis was not possible. The study findings may also not be reflective of the whole Indian community living in Australia due to convenience sampling, and therefore cannot be generalised. Furthermore, most of the participants had been residing in Australia for a long period of time, so the findings may not reflect the current knowledge and practices of new immigrants. The majority of the participants were also in their middle age and more research with younger or older generations could give further insight into this research area.

Despite these limitations, this study has provided valuable insights into this under-researched area in Australia and identified potential strategies to raise oral cancer awareness. The next and final chapter of this thesis will detail the conclusions and recommendations.

# Chapter 10: Conclusion and Recommendations

## 10.1 Conclusion

Oral cancer is highly prevalent in the Indian subcontinent owing to the widespread use of smokeless tobacco and areca (betel) nut along with other risk practices. The continued risk behaviours of Indian immigrants' and the potential link to the rise in oral cancer cases has been researched in developed countries including the UK, the USA and Canada to better understand the issues and promote awareness among these population groups. With Indians now being the third largest migrant group in Australia, a potential rise in oral cancer cases could be expected if they continue engaging in oral cancer risk behaviours. However, prior to our study there had been limited evidence in the Australian context describing oral cancer risk behaviours of Indian immigrants and related preventative strategies for oral cancer awareness.

The findings from this thesis suggest that Indian immigrants in Australia have varying levels of knowledge about oral cancer, especially around the harmful effects of areca nut use and oral cancer-related signs/symptoms. Some may also be involved in oral cancer risk practices, though the true extent of this is remains unclear. The study has also drawn attention to the lack of adequate information regarding oral cancer being provided in primary health care settings as well as the uncertainty and inconsistency among GPs around their scope of practice in this area. Factors contributing to this uncertainty and lack of knowledge include the limited information among GPs regarding the emerging risk factors like areca nut and betel quid chewing, and their varied attitudes about the seriousness of oral cancer in Australia. Having said this, GPs were very receptive towards playing a greater role in raising oral cancer awareness, which is very encouraging, as Indian immigrants were

equally responsive to this idea and had a positive attitude towards preventative oral health practices. With the growth in migration of Indians to Australia, more strategies are needed to raise awareness in this community about oral cancer risk practices, particularly around smokeless tobacco, and areca nut use. With adequate training and resources GPs could play a key role in this area, as they are integral to the primary health care setting. Further research through larger studies and more representative samples are needed to explore this area further in Australia and confirm the ALARRM study findings. Gathering more evidence will inform the development of culturally sensitive and tailored preventative strategies for Indian immigrants.

## 10.2 Recommendations

The study findings have highlighted important recommendations across practice, policy, and research in Australia.

### 10.2.1 Practice

*Recommendation 1: Tailored oral cancer preventative strategies should be developed to raise awareness among the Indian communities in Australia.*

Community engagement is essential for improving awareness about health issues. Integration of community engagement with implementation science has been considered promising for improving health research and achieving health equity (Bodison et al., 2015). Involving and consulting communities is important as shared ownership increases credibility and ensures the relevance of resources (Petersen & Kwan, 2004). Despite limited evidence about clinical and cost-effectiveness, this integrated approach for health promotion

interventions to involve minority populations has shown increased salience, acceptability and uptake in the past (Liu et al., 2012). For example, *The Sikh American Families Oral Health Promotion Program* used a community-based participatory approach successfully for development, implementation, evaluation, and dissemination of a culturally tailored oral health/healthy living curriculum for the Sikh-South Asian community in the USA (Northridge et al., 2017). Therefore, adapting evidence-based interventions and resources for ethnic minority populations with the active engagement of affected communities can be more effective (Northridge et al., 2017). Community engagement has also been advocated by Carnegie et al in order to enable dialogue with diverse communities, where priorities can be set by policymakers with the delivery guided by the needs of specific communities (Carnegie et al., 2017). Such an approach was employed in a past study addressing cancer disparities through community engagement to improve breast health among Haitian women community in Tampa (USA), where local community partners were the primary source of information and guided efforts to create a series of health-promoting activities (Meade et al., 2009). This has been suggested as applicable across the spectrum of cancer care, for e.g., oral cancer prevention and education.

Oral cancer awareness strategies in Australia can be identified through a multifaceted needs assessment process with Indian communities (through roundtable discussion, focus groups and interviews) and tailored accordingly to maximise reach and effect. This process is important to address any language, health literacy and cultural barriers. In Australia, NSW Health is currently developing an oral cancer awareness brochure highlighting the health hazards of areca nut use (see Appendix-15). The development process has been undertaken in consultation with policy makers (NSW Health, Cancer Institute), professional

organisations (Australian Dental Association) and consumers (Indian migrants) to ensure the resource is evidence-based, culturally appropriate and geared to an appropriate health literacy level. Other states in Australia could follow the lead of NSW and develop similar educational resources. It is also important that these resources are translated into multiple languages, as we know from the study findings (Paper 3) and international research that oral cancer risk practices may be more prevalent in specific subgroups and religions within the Indian community. Once these resources are developed, a targeted dissemination strategy needs to be formulated to promote them widely using various mediums. These could include visual aids like posters that could be displayed in Indian grocery stores and restaurants as well as in temples and Indian cultural events like Holi, which have become very popular in Australia (Fed Square, 2022). However, materials like posters and leaflets tend to result in increased awareness only in the short-term (Macpherson, 2018). Nevertheless, posters are relatively inexpensive to produce and can provide the audience with concise information of any topic which can be viewed by a number of individuals at their own pace (Ilic & Rowe, 2013). This medium elicits extreme effectiveness in knowledge transfer when integrated with other educational modalities (Ilic & Rowe, 2013). The use of posters and leaflets in a previous oral cancer campaign in the UK was shown to be successful in promoting oral cancer awareness among members of the East London Bangladeshi community (Croucher et al., 2011). In context of current study, oral cancer risk practices appear to be prevalent across different age groups and genders other mediums like social media, local Indian radio and television channels should also be explored to convey key messaging around oral cancer awareness.

*Recommendation 2: Incorporation of opportunistic oral cancer screening of at-risk*

*populations and prevention counselling.*

The thesis findings indicate that in order to identify oral cancer in the early stages, GPs could apply patient-specific decision-making strategies in their clinical practices through opportunistic screening of at-risk populations like Indian immigrants who are known to be engaged in risk habits (e.g., tobacco and/or alcohol consumption, areca nut/betel quid chewing) (Fatima Dost et al., 2016; Farah et al., 2014). In Australia, opportunistic oral cancer screening of patients involved in the use of tobacco and alcohol products within the dental setting has been suggested as a feasible alternative to mass screening (Farah et al., 2014). A similar approach could be adopted in the primary health care settings since GPs are usually the first point of contact for medical needs. In addition, alongside opportunistic screening, GPs' participation in oral cancer counselling to high-risk populations could be very effective if tailored according to individual cultures.

*Recommendation 3: Development of oral cancer-related training programs and a screening tool to build the capacity of primary health care providers to offer preventive oral cancer counselling and screening to Indian immigrants*

The findings of this thesis (Paper 4) revealed the limited knowledge of GPs about emerging oral cancer risk factors (such as areca nut/betel quid use) and a lack of training relating to oral cancer screening, identification, and referrals. To address these barriers, the design and delivery of accessible oral cancer-related training via short online learning modules and continuing professional development courses could be undertaken. Having these courses endorsed by key organisations like the Royal Australian College of General Practitioners could improve the uptake among GPs. These courses should be focused more on new oral cancer risk factors like areca (betel) nut use to assist GPs while consulting

patients who are known to be engaged in such habits, like Indian immigrants. However, considering the busy schedules of GPs and their time constraints, it is important that the training is self-paced and not too onerous. In the state of Victoria, the public dental services are in the process of developing a tailored oral cancer training program for GPs which looks very promising (Dental Health Services Victoria, 2021c). Other states in Australia should consider following a similar approach to extend the support to all GPs. Furthermore, Primary Healthcare Networks (PHNs), which are independent organisations funded by the Australian Government and set up to improve patient care (Keleher, 2019), can include these educational resources and training modules to assist GPs in understanding the process of oral cancer management in medical settings (Victorian-Tasmanian PHN Alliance, 2019). When promoting the training program, it might be beneficial to first target GPs from similar ethnic backgrounds, as our study findings intimated a preference for this among the Indian immigrants due to communication barriers and cultural sensitivity.

It is equally important to explore other primary health care providers that could support GPs in raising oral cancer awareness and help alleviate their workload. Practice nursing is one of the fastest growing health disciplines in Australia. Numerous general practices are employing nurses to support GPs in key areas like assessment and providing education to promote community wellbeing (Pearce et al., 2010). Training practice nurses to raise awareness about oral cancer would be a very useful and sustainable strategy to support GPs in primary health care settings.

Another important observation was the lack of oral cancer screening tools to assist primary health care providers, since there is no national screening programme for oral cancer in Australia (Cancer Council, 2021b). Hence, the development of an appropriate and

validated oral cancer screening tool could help in early identification and avoid delays in cancer treatment. The tool should be concise for incorporation into medical practice and should focus on identifying patients at risk of oral cancer. Such a screening tool can be time efficient and beneficial for both health care providers and patients. The tool should be included as part of any oral cancer training programme and the inclusion of videos showing how to conduct oral cancer screening could greatly assist GPs.

Lastly, it is important to embed oral cancer training, especially around new and emerging risk factors in undergraduate medical and nursing curricula across Australia. This will help to ensure that new graduates have some knowledge and confidence in this area, which could be further strengthened through CPD courses.

*Recommendation 4: Inclusion of qualified dental specialists accompanying GPs during oral cancer screening and check-ups to facilitate collaborative practice*

The thesis results (Paper 4) recommend integrating dental specialist/dentists in medical settings to facilitate oral cancer screening and checkups. This kind of active involvement of the dental profession in general health care has been advocated by the World Dental Federation's (FDI) Vision 2030 report – *Delivering Optimal Oral Health for All,* which acknowledged the rising burden of oral diseases and the inadequacy of population-level prevention efforts (Glick & Williams, 2021). Dentists can assist GPs in oral cancer screening or checkups through partnerships with either public dental services or private practices, and patients requiring confirmed diagnosis or treatment could be referred to appropriate specialist services. However, it is important to point out that such shared models of care exist in other countries like the UK (NHS, 2015) and its cost-effectiveness in Australia should be considered thoroughly for long-term success. The majority of dentists in

Australia work in private practices and many are independent self-employed practitioners (Sbaraini et al., 2012). In light of this and the low prevalence of oral cancer in Australia, other effective mechanisms for communication could be established between general practitioners and dentists to develop a shared understanding to support a collaborative approach to oral healthcare (Barnett et al., 2015). To facilitate the interaction, regular meetings between local dental practitioners and primary care providers could be arranged which would help build confidence in how oral health problems like oral cancer can be more effectively managed and prevented (Barnett et al., 2015). Alternatively, the inclusion of other oral health professionals (e.g., oral health therapists) with training in oral cancer could be more beneficial and cost effective than dentists in a shared model of care (ADA Victoria, 2021). In the Australian General Practice, a range of incentives for complex fee-for-service activities have been introduced in the past under the Enhanced Primary Care Program which includes care planning for chronic disease management and comprehensive health assessments for vulnerable subpopulations (Davies et al., 2009; Pearce et al., 2011). This could pave the way for arrangement of potential funding to deliver services relevant to oral cancer prevention under a shared model of care (inclusive of GPs and oral health professionals). Moreover, better communications and stronger collaborations between mainstream primary care and oral health services may provide additional momentum to reduce the frequency of oral cancer presentations (Barnett et al., 2015).

## 10.2.2 Policy

*Recommendation 5: National health policies should emphasise the integration of oral health in a medical setting for enhanced access to preventative oral cancer education and counselling.*

The findings from this thesis (Paper 3 and Paper 5) identified limited dental visits of Indian immigrants owing to financial constraints and the lack of availability of oral cancer information in primary medical settings. Currently in Australia, patients who hold a healthcare (Medicare) card, pension card, or other eligibility for publicly funded dental care are placed on long waiting lists that exceed the recommendations for frequency of dental visits (Brennan et al., 2008). On the other hand, for people who do not meet the eligibility criteria for publicly funded treatment (e.g., new migrants) and experience financial disadvantage, professional dental care may be hard to access. This process can also result in a lack of oral cancer awareness and sometimes diagnostic delays due to late identification.

Although inclusion of all patients for public dental health services may not be possible beyond the eligibility criteria, policy initiatives are necessary to enhance the ability for all patients, especially at-risk populations like Indian immigrants, to access oral cancer preventative counselling in medical settings. For this to happen, there is the need to build the capacity of the GP workforce to manage oral cancer and develop national clinical guidelines and standard referral pathways which can assist GPs to refer patients for timely diagnosis/treatment of oral cancer. This can be done through collaborative efforts between the government and professional organisations like Cancer Australia and the Australian Medical Association.

At present, in Australia, the referral pathways for oral cancer disease are either incorporated in head and neck cancer management (Queensland Government, 2021) or broadly explained on a statewide platform (Dental Health Services Victoria, 2021b). An exclusive standard referral system for oral cancer management would be more clear and helpful for GPs. In addition, optimal care pathways could be developed for oral cancer like the existing ones for head and neck cancer (Cancer Council Victoria, 2021).

*Recommendation 6: Effective restrictions and advertising of smokeless tobacco and areca nut/betel quid use*

Australia banned smoking in all federal workplaces in the late 1990s, leaving workplaces to determine their own policies and this has been effective in reducing cigarette smoking (Pierce et al., 2012). The main decrease in smoking prevalence has also been associated with major funds to tobacco control programmes, and higher cigarette prices (Pierce et al., 2012). However, this policy should be reviewed, and this action should be extended further to prevent and reduce the use of any kind of smokeless tobacco products as well. Since oral cancer rates among Indian communities are generally higher owing to typical risk practices like betel quid chewing, regulations on importation, and surveillance at airports, the labelling and sale of areca nut preparations (e.g., betel quid/*pan*, *guthka*) should be enacted and enforced alongside the regulations on smokeless tobacco sale/promotion. Higher taxation can be beneficial as well, as it would lead to increased prices of such products, which may result in decreased use.

### 10.2.3 Research

*Recommendation 7: Larger studies involving GPs and Indian immigrants are needed to confirm the findings*

Since only a qualitative study was undertaken to explore current oral cancer-related knowledge, attitudes and practices of GPs in Australia, larger studies including a national survey of all GPs in Australia in this area would be beneficial to confirm the findings. The recruitment of a larger sample and the use of validated questionnaires/items would be very useful to inform the acceptability and feasibility as well as the barriers and facilitators for GPs to engage in this space. It is equally important to undertake exploratory work with other primary health care providers like practice nurses to explore their perceptions and practices in this area along with their potential role in complementing GPs in raising oral cancer awareness.

Likewise, current data about oral cancer risk behaviours of Indian immigrants in Australia is from a small convenience sample, and thus larger studies involving a more representative sample are needed to provide a clear reflection of the oral cancer-related knowledge, attitudes, and practices in this community. Through a larger random sample, we will be able to better determine if the oral cancer risk behaviours of Indian immigrants are different between first- and second-generation immigrants as well as across gender, age, religion, and places of origin in India. One way of capturing this information at a population level would be to include a few items around smokeless tobacco use in the Australian national census survey which occurs every five years.

*Recommendation 8: More data on oral cancer prevalence rates among Indian immigrants in Australia*

Lastly, it is important for further research to be undertaken to assess the oral cancer prevalence among Indian immigrants in Australia and whether there has been a change in trends associated with migration patterns. In order to collect this data, it is important to first assess whether current monitoring systems in Australia capture this data and then explore potential data linkage options to get the most accurate picture.

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# Appendices

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## Appendix 1: Recruitment Flyer for Indian immigrants-Interviews

# Be a part of our study!

## We are looking for Indians to participate in our study

We wish to explore oral cancer risk behaviours of Indian immigrants (who themselves or their parents were born in India) in Australia. What you share may make a difference to improve oral cancer awareness among Indians in Australia in the future.

This study involves interviews to explore your knowledge, attitudes and practices in relation to oral cancer risk. The information you provide will assist us in gaining insight into perspective of Indian immigrants regarding oral cancer risk. Interviews will take about 30 minutes to 45 minutes. Participation is voluntary and the information you provide will be strictly confidential.

If you would like to participate in interview, please contact
**Nidhi Saraswat** (Chief Investigator and PhD student),
**Tel: +61 2 8738 9058, or email: 19278243@student.westernsydney.edu.au**

This study has been approved by Western Sydney University Human Research Ethics Committee

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# Appendix 2: Participant Information Sheet – Indian immigrants (Interviews)

**Project Title:** Exploring oral cancer risk behaviours of Indian immigrants in Australia

**Project Summary:** This study seeks to explore oral cancer risk behaviours of Indian immigrants (who themselves or their parents were born in India) in Australia. In addition, this study is also aimed to gain insight into current knowledge and practices of general practitioners regarding oral cancer risk in Australia.

You are invited to participate in a research study being conducted by Nidhi Saraswat, PhD student, School of Nursing and Midwifery, Western Sydney University under the supervision of A/Prof Ajesh George, A/Prof Bronwyn Everett and Rona Pillay. The research will help to gain a clear understanding of oral cancer risk-related perception and practices of Indian immigrants and general practitioners in Australia.

**How is the study being paid for?**

This study will be funded by student funds provided by Western Sydney University to support research.

**What will I be asked to do?**

If you agree to be involved in this project, you will be asked to participate in an interview to help us understand Indian immigrants' knowledge, attitudes and practices regarding oral cancer risk in Australia. This study also involves a survey, which seek to explore Indian immigrants' perceptions and practices regarding oral cancer risk in more detail. You may also choose to participate in pilot testing the survey to check its effectiveness before the larger survey.

If you choose to participate in the interview it will be conducted by the chief investigator and any individually identifying information will be removed prior to sharing the transcript with the supervisory team. In the case, you also agree to participate in pilot test survey, we will provide you further details about the survey.

**How much of my time will I need to give?**

If you agree to participate in an interview, this is expected to take 30 - 45 minutes.

**What benefits will I, and/or the broader community, receive for participating?**

Whilst participation in the study may not directly benefit you, findings from this study will inform the development of culturally-appropriate health promotion materials which can increase awareness of the risks of oral cancer in Indian immigrants in Australia.

**Will the study involve any risk or discomfort for me? If so, what will be done to rectify it?**

The study will not involve any risk for you. However, if you feel any kind of distress during the interview, you will be provided appropriate help and counselling. You can also withdraw from the interview anytime in case of discomfort.

**How do you intend to publish or disseminate the results?**

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that the

participant cannot be identified. Transcripts from the audio-taped interviews will be de- identified prior to the data being analysed.

Findings from the study will be used as part of the Chief Investigator's thesis and may be submitted for publication, however individuals will not be identifiable. If you wish to receive information about the findings of the research study, you may provide your contact details and the Chief Investigator will provide you with a report following project completion.

**Will the data and information that I have provided be disposed of?**

No. Your data will be used as per Western Sydney University's Open Access Policy. This means that data collected from this study can be made available online and world-wide in perpetuity.

**Can I withdraw from the study?**

Participation is entirely voluntary, and you are not obliged to be involved. If you do participate you can withdraw at any time without giving reason. If you participate in an interview and choose to withdraw after transcripts have been de-identified, data collected from you prior to withdrawal may not be able to be deleted and may be used for the purpose of this project.

**Can I tell other people about the study?**

Yes, you can tell other people about the study by providing them with the Chief Investigator's contact details. They can contact the Chief Investigator to discuss their participation in the research project and obtain an information sheet.

**What if I require further information?**

Please contact Nidhi Saraswat should you wish to discuss the research further before deciding whether or not to participate.

Nidhi Saraswat (Chief investigator)
Phone: +61 2 8738 9058
Email: 19278243@student.westernsyndey.edu.au

A/Prof Ajesh George
Phone: +61 2 8738 9356
Email: A.George@westernsydney.edu.au

A/Prof Bronwyn Everett
Phone: +61 2 9685 9034
Email: b.everett@westernsydney.edu.au

Rona Pillay
Phone: 96859504
Email: rona.pillay@westernsydney.edu.au

**What if I have a complaint?**

If you have any complaints or reservations about the ethical conduct of this research, you may contact the Ethics Committee through Research Engagement, Development and Innovation (REDI) on Tel +61 2 4736 0229 or email humanethics@westernsydney.edu.au

Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

If you agree to participate in this study, you may be asked to sign the Participant Consent Form. The information sheet is for you to keep and the consent form is retained by the researcher/s.

This study has been approved by the Western Sydney University Human Research Ethics Committee. The Approval number is [enter approval number once the project has been approved].

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## Appendix- 3: Consent Form – Indian immigrants (Interviews)

**Project Title:** Exploring the oral cancer risk behaviours of Indian immigrants in Australia.

**I hereby consent to participate in the above named research project.**

**I acknowledge that:**

- I have read the participant information sheet (or where appropriate, have had it read to me) and have been given the opportunity to discuss the information and my involvement in the project with the researcher/s

- The procedures required for the project and the time involved have been explained to me, and any questions I have about the project have been answered to my satisfaction.

**I consent to:**

☐ *Participating in an interview*

☐ *Having my information audio recorded*

☐ *Participating in a pilot test Survey*

**Data publication, reuse and storage**

This project seeks consent for the data provided to be used in any other projects in the future.

To make reuse of the data possible it will be stored under Western Sydney University's Open Access Policy.

I understand that in relation to publication of the data:

my involvement is confidential and the information gained during the study may be published but no information about me will be used in any way that reveals my identity.

☐ the researchers intend to make the non-identified data from this project available for other research projects

☐ I can withdraw from the study at any time without affecting my relationship with the researcher/s, and any organisations involved, now or in the future.

**Signed:**

**Name:**

**Date:**

**Email/address (optional):**

*[For participants who wish to receive results of the research]*

**Return Address***:*

Nidhi Saraswat (Chief Investigator)
Level 3, Ingham Institute, Locked Bag 7103, Liverpool BC NSW 1871
Email: 19278243@student.westernsydney.edu.au

**This study has been approved by the Human Research Ethics Committee at Western Sydney University. The ethics reference number is: H13203**

If you have any complaints or reservations about the ethical conduct of this research, you may contact the Ethics Committee through Research Engagement, Development and Innovation (REDI) on Tel +61 2 4736 0229 or email humanethics@westernsydney.edu.au.

Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

## Appendix 4: Interview topic guide -Indian immigrants

*Project: Exploring oral cancer risk behaviours of Indian immigrants in Australia*

Interview protocol:

- Talk to the participants to break the ice.
- Confirm that participants have read the participant information sheet and is consenting for the focus group to be recorded.
- Ask if they have any other questions.
- Provide a brief summary of the project and state the main purpose of this interview is to get their views and suggestions.

Topic areas (to be explored by interview):

- Background about self and family.
- Perceptions towards oral cancer.
- Knowledge of oral cancer risk factors.
- Attitudes of Indian immigrants towards oral cancer risk factors & their practices
- Perceptions of GPs' knowledge, attitudes and practices in this area.
- Other comments/questions

## Appendix 5: Sample email invitation for General Practitioners (Interview)

Dear Practice manager/staff,

Greetings.

My name is Nidhi Saraswat and I am a PhD student at Western Sydney University. We are conducting a research study which is 'To explore oral cancer risk behaviours of Indian immigrants in Australia'. We also seek to assess awareness and current practices of GP's regarding oral cancer risk in Australia.

I am emailing to request if you would like to forward this invitation to your GP/GP's. This invitation is regarding participation in interviews going to be organised as a part of our study. What they share may make a difference to improve oral cancer awareness among Indians in Australia in the future.

The information they provide will assist us in gaining insight into current perspectives of GPs towards oral cancer risk. Interviews will take about 20 -30 minutes at time and place convenient for them. Apart from face to face interview, there will be an option of interview by telephone or by skype/zoom as well. I have also enclosed study flyer and information sheet with this email for reference.

A $50 gift voucher will be offered at end of interview as a gesture of our appreciation for their time. Participation is entirely voluntary and the information they provide will be strictly confidential.

If you/they have any queries or if they would like to participate in interview, please do not hesitate to contact:
**Nidhi Saraswat** (Chief Investigator and PhD student),
**Tel: +61 2 8738 9058, or email: 19278243@student.westernsydney.edu.au**

Note: This study has been approved by Western Sydney University Human Research Ethics Committee.

Thanks you.

Kind Regards,
NIDHI SARASWAT

## Appendix 6: Recruitment Flyer for General Practitioners

# Be a part of our study!

## We are looking for General Practitioners to participate in our study

We wish to explore oral cancer risk behaviours of Indian immigrants in Australia. We also seek to assess awareness and current practices of GPs regarding oral cancer risk in Australia. What you share may make a difference to improve oral cancer awareness among Indians in Australia in the future.

This study involves interviews to explore your knowledge, attitudes and practices in relation to oral cancer risk. The information you provide will assist us in gaining insight into current perspectives of GPs towards oral cancer risk. Interviews will take about 20 -30 minutes, and a $50 gift voucher will be offered at end of interview as a gesture of appreciation for your time. Participation is voluntary and the information you provide will be strictly confidential.

If you would like to participate in interview, please contact
**Nidhi Saraswat** (Chief Investigator and PhD student),
**Tel: +61 2 8738 9058, or email: 19278243@student.westernsydney.edu.au**

This study has been approved by Western Sydney University Human Research Ethics Committee.

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# Appendix 7: Participant Information Sheet – General Practitioners

**Project Title:** Exploring oral cancer risk behaviours of Indian immigrants in Australia

**Project Summary:** This study seeks to explore oral cancer risk behaviours of Indian immigrants in Australia. In addition, this study is also aimed to gain insight into current knowledge and practices of general practitioners regarding oral cancer risk in Australia.

You are invited to participate in a research study being conducted by Nidhi Saraswat, PhD student, School of Nursing and Midwifery, Western Sydney University under the supervision of A/Prof Ajesh George, A/Prof Bronwyn Everett and Rona Pillay. The research will help to gain a clear understanding of oral cancer risk-related perception and practices of Indian immigrants and general practitioners in Australia.

**How is the study being paid for?**

This study will be funded by student funds provided by Western Sydney University to support research.

**What will I be asked to do?**

If you agree to be involved in this project, you will be asked to participate in an interview to help us understand GPs' perceptions and practices regarding oral cancer risk in Australia. We would also like to collect some information about your background, and your clinical experiences with Indian immigrants in Australia to get an understanding of their knowledge, attitudes and practices in relation to oral cancer risk.

If you choose to participate in the interview it will be conducted by the chief investigator and any individually identifying information will be removed prior to sharing the transcript with the supervisory team.

**How much of my time will I need to give?**

If you agree to participate in an interview, this is expected to take 20 to 30 minutes.

**What benefits will I, and/or the broader community, receive for participating?**

Whilst participation in the study may not directly benefit you, findings from this study may be used to inform the development of educational resources for health professionals, which will support early oral cancer risk assessment in populations at greater risk of developing oral cancer.

**Will the study involve any risk or discomfort for me? If so, what will be done to rectify it?**

The study will not involve any discomfort for you, however, there will be a small time burden.

**How do you intend to publish or disseminate the results?**

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that the participant cannot be identified, except with your permission. Transcripts from the audio-taped interviews will be de- identified prior to the data being analysed.

Findings from the study will be used as part of the Chief Investigator's thesis and may be submitted for publication, however individuals will not be identifiable. If you wish to receive information about the

findings of the research study, you may provide your contact details and the Chief Investigator will provide you with a report following project completion.

**Will the data and information that I have provided be disposed of?**

No. Your data will be used as per Western Sydney University's Open Access Policy. This means that data collected from this study can be made available online and world-wide in perpetuity.

**Can I withdraw from the study?**

Participation is entirely voluntary, and you are not obliged to be involved. If you do participate you can withdraw at any time without giving reason. If you participate in an interview and choose to withdraw after transcripts have been de-identified, data collected from you prior to withdrawal may not be able to be deleted and may be used for the purpose of this project.

**Can I tell other people about the study?**

Yes, you can tell other people about the study by providing them with the Chief Investigator's contact details. They can contact the Chief Investigator to discuss their participation in the research project and obtain an information sheet.

**What if I require further information?**

Please contact Nidhi Saraswat should you wish to discuss the research further before deciding whether or not to participate.

Nidhi Saraswat (Chief investigator)
Phone: +61 2 8738 9058
Email: 19278243@student.westernsyndey.edu.au

A/Prof Ajesh George
Phone: +61 2 8738 9356
Email: A.George@westernsydney.edu.au

A/Prof Bronwyn Everett
Phone: +61 2 9685 9034
Email: b.everett@westernsydney.edu.au

Rona Pillay
Phone: 96859504
Email: rona.pillay@westernsydney.edu.au

**What if I have a complaint?**

If you have any complaints or reservations about the ethical conduct of this research, you may contact the Ethics Committee through Research Engagement, Development and Innovation (REDI) on Tel +61 2 4736 0229 or email humanethics@westernsydney.edu.au

Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

If you agree to participate in this study, you may be asked to sign the Participant Consent Form. The information sheet is for you to keep and the consent form is retained by the researcher/s.

This study has been approved by the Western Sydney University Human Research Ethics Committee. The Approval number is [enter approval number once the project has been approved].

## Appendix 8: Interview topic guide-General Practitioners

*Project: Exploring oral cancer risk behaviours of Indian immigrants in Australia*

Interview protocol:

- Talk to the participants to break the ice.
- Confirm that participants have read the participant information sheet and is consenting for the focus group to be recorded.
- Ask if they have any other questions.
- Provide a brief summary of the project and state the main purpose of this interview is to get their views and suggestions.

Topic areas (to be explored by interview):

- Background about self.
- Knowledge and attitudes of GPs regarding oral cancer risk practices of Indian immigrants in Australia.
- Current practices regarding oral cancer risk assessments.
- Possible Barriers according to GPs in oral cancer awareness among Indian immigrants

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## Appendix 9: Consent Form – General Practitioners

**Project Title:** Exploring the oral cancer risk behaviours of Indian immigrants in Australia.

**I hereby consent to participate in the above named research project.**

**I acknowledge that:**

- I have read the participant information sheet (or where appropriate, have had it read to me) and have been given the opportunity to discuss the information and my involvement in the project with the researcher/s

- The procedures required for the project and the time involved have been explained to me, and any questions I have about the project have been answered to my satisfaction.

**I consent to:**

☐ *Participating in an interview*

☐ *Having my information audio recorded*

**Data publication, reuse and storage**

This project seeks consent for the data provided to be used in any other projects in the future.

To make reuse of the data possible it will be stored under Western Sydney University's Open Access Policy.

I understand that in relation to publication of the data:

my involvement is confidential and the information gained during the study may be published but no information about me will be used in any way that reveals my identity.

☐ the researchers intend to make the non-identified data from this project available for other research projects

☐ I can withdraw from the study at any time without affecting my relationship with the researcher/s, and any organisations involved, now or in the future.

**Signed:**

**Name:**

**Date:**

**Email/address:**

*[For participants who wish to receive results of the research]*

**Return Address***:*

Nidhi Saraswat (Chief investigator)
Level 3, Ingham Institute, Locked Bag 7103, Liverpool BC NSW 1871
Email: 19278243@student.westernsydney.edu.au

**This study has been approved by the Human Research Ethics Committee at Western Sydney University. The ethics reference number is: H13203**

If you have any complaints or reservations about the ethical conduct of this research, you may contact the Ethics Committee through Research Engagement, Development and Innovation (REDI) on Tel +61 2 4736 0229 or email humanethics@westernsydney.edu.au.

Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

# Appendix 10: Reference Codebook

| Code Name | Code Description | Relationship to other sub codes | Examples |
|---|---|---|---|
| Knowledge about Oral Cancer | The awareness, level of information and understanding regarding oral cancer | This is a main code. Sub-codes include:<br><br>- Signs/Symptoms and related risk factors<br><br>- Availability and accessibility of oral cancer risk products<br><br>- Source of oral cancer information | '*I heard about the oral cancer, but I don't know how it happens.*'<br><br>*'They're available if you look for it, you can find them.'*<br><br>*'I saw advertisement in hospital in India, but not here, I think. Yeah, I never seen any, much awareness information available on normal GP or normal medical Centre in Australia'* |
| Attitudes towards Oral cancer | The inclinations, perceptions, and beliefs of the people associated with oral cancer | This is a main code. Sub-codes include:<br><br>- Perceptions of oral cancer in Australia<br><br>- Reasons for engaging in oral cancer risk behaviours | *'Maybe in later years it will be a serious situation. Because I don't think these Australians, they know even about this Indian culture of consuming pan and gutkha.'*<br><br>*'People are using it from ages. I'm pretty sure 90 per cent of the people, they are affected by it. After they get affected, then* |

| Code Name | Code Description | Relationship to other sub codes | Examples |
|---|---|---|---|
| | | | *is the time when they actually know that oh, it was bad for health.'* |
| | | - Views about oral cancer prevention and early risk assessment | '*I think it's important, definitely it's important, yeah it's - definitely prevention is better than cure, so you should check it out, so … I never thought about it. So probably I will go this time for myself.*' |
| Oral cancer risk Practices | Oral cancer risk related habits and the actions regarding initiation, continuation or quitting of these habits. | This is a main code. Sub-codes include:<br><br>- Frequency and types of oral cancer risk product use | '*Every day. Not only every day, I think 10 times a day. It's a very small quantity I am keeping inside between my teeth and chin.*' |
| | | - Initiation and continuation of oral cancer risk practices | *'Yeah, whenever we go for marriage parties, or something, any occasions going on, festivals or something, yeah, we do get a chance to have those because they are being served, so we just have it.'* |
| | | - Preventative healthcare practices | *'I never have to go GP or dentist because I am very healthy person. I don't think in five years, except one, this ulcer, I went to the GP.'* |

## Appendix 11: Recruitment flyer for Indian immigrants (survey)

# Be a part of our study!

## We are looking for Indians to participate in our study

We wish to explore oral cancer risk behaviours of Indian immigrants (who themselves or their parents were born in India) in Australia. What you share may make a difference to improve oral cancer awareness among Indians in Australia in the future.

This study involves completing a questionnaire to explore your knowledge, attitudes and practices in relation to oral cancer risk. The information you provide will assist us in gaining deep understanding of perspective of Indian immigrants regarding oral cancer risk and will further help in informing the development of culturally-appropriate health promotion materials to increase awareness. Completing the questionnaire will take 15-20 minutes. Participation is voluntary and the information you provide will be strictly confidential.

If you would like to complete the questionnaire, please contact
**Nidhi Saraswat** (Chief Investigator and PhD student),
**Tel: +61 2 8738 9058, or email: 19278243@student.westernsydney.edu.au**
OR
**Click on the link to know more (online link for survey)**

This study has been approved by Western Sydney University Human Research Ethics Committee

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## Appendix 12: Participant Information Sheet – Indian immigrants (survey)

**Project Title:** Exploring oral cancer risk behaviours of Indian immigrants in Australia

**Project Summary:** This study seeks to explore oral cancer risk behaviours of Indian immigrants (who themselves or their parents were born in India) in Australia. In addition, this study is also aimed to gain insight into current knowledge and practices of general practitioners regarding oral cancer risk in Australia.

You are invited to participate in a research study being conducted by Nidhi Saraswat, PhD student, School of Nursing and Midwifery, Western Sydney University under the supervision of A/Prof Ajesh George, A/Prof Bronwyn Everett and Rona Pillay. The research will help to gain a clear understanding of oral cancer risk-related perception and practices of Indian immigrants and general practitioners in Australia.

**How is the study being paid for?**

This study will be funded by student funds provided by Western Sydney University to support research.

**What will I be asked to do?**

If you agree to be involved in this project, you will be asked to complete a short, anonymous survey to help us understand Indian immigrants' knowledge, attitudes and practices regarding oral cancer risk in Australia. We would also like to collect some information about your background in the survey to relate all the participants' perceptions about oral cancer risk.

**How much of my time will I need to give?**

If you agree to participate, this survey is expected to take no more than 20 minutes.

**What benefits will I, and/or the broader community, receive for participating?**

Whilst participation in the study may not directly benefit you, findings from this study may be used inform the development of culturally-appropriate health promotion materials which can increase awareness of the risks of oral cancer in Indian immigrants in Australia.

**Will the study involve any risk or discomfort for me? If so, what will be done to rectify it?**

The study will not involve any risk for you. However, if you feel any kind of distress during the survey you will be provided appropriate help and counselling. You can also withdraw from the survey anytime in case of discomfort.

**How do you intend to publish or disseminate the results?**

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that the participant cannot be identified, except with your permission. Survey data is anonymous, and codes will be used to identify participants.

Findings from the study will be used as part of the Chief Investigator's thesis and may be submitted for publication and conferences, however individuals will not be identifiable. If you wish to receive information about the findings of the research study, you may provide your contact details and the Chief Investigator will provide you with a report following project completion.

**Will the data and information that I have provided be disposed of?**

No. Your data will be used as per Western Sydney University's Open Access Policy. This means that data collected from this study can be made available online and world-wide in perpetuity.

**Can I withdraw from the study?**

Participation is entirely voluntary, and you are not obliged to be involved. If you do participate you can withdraw at any time without giving reason. Please note that the researchers will be unable to extract and delete specific information provided by a participant from the survey as this data is anonymous.

Therefore, data collected from you prior to withdrawal may not be able to be deleted and may be used for the purpose of this project.

**Can I tell other people about the study?**

Yes, you can tell other people about the study by providing them with the Chief Investigator's contact details. They can contact the Chief Investigator to discuss their participation in the research project and obtain an information sheet.

**What if I require further information?**

Please contact Nidhi Saraswat should you wish to discuss the research further before deciding whether or not to participate.

Nidhi Saraswat (Chief investigator)
Phone: +61 2 8738 9058
Email: 19278243@student.westernsyndey.edu.au

A/Prof Ajesh George
Phone: +61 2 8738 9356
Email: A.George@westernsydney.edu.au

A/Prof Bronwyn Everett
Phone: +61 2 9685 9034
Email: b.everett@westernsydney.edu.au

Rona Pillay
Phone: 96859504
Email: rona.pillay@westernsydney.edu.au

OR

**Click on the link to know more (online link for survey)**

**What if I have a complaint?**

If you have any complaints or reservations about the ethical conduct of this research, you may contact the Ethics Committee through Research Engagement, Development and Innovation (REDI) on Tel +61 2 4736 0229 or email humanethics@westernsydney.edu.au

Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

If you agree to participate in this study, you may be asked to sign the Participant Consent Form. The information sheet is for you to keep and the consent form is retained by the researcher/s.

This study has been approved by the Western Sydney University Human Research Ethics Committee. The Approval number is [enter approval number once the project has been approved].

Health
South Western Sydney
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WESTERN SYDNEY
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Ingham Institute
Applied Medical Research

## Appendix 13: Study Questionnaire

**Date: _____**

# Oral cancer risk?

*Awareness matters.....*

**This study aims to assess oral cancer risk among Indians in Australia. In this survey we ask you questions to explore your knowledge, attitudes and practices in relation to oral cancer risk. We are interested in understanding your perspective regarding oral cancer. Findings from this study may be used to improve health promotion materials to raise awareness of the risks of oral cancer. Your participation will help us to plan future activities to prevent oral cancer among Indians in Australia. We would appreciate your support, by completing this questionnaire.**

- **The survey will take 10-15 minutes to complete.**
- **Your identity will not be disclosed in any reports arising from this study.**
- **All the information you give will be treated in the strictest confidence.**
- **By completing the questionnaire, you are providing implied consent to participate in this study.**
- **For further information, please contact:**

**Nidhi Saraswat (Chief Investigator and PhD student),**
**email: 19278243@student.westernsydney.edu.au**

## SECTION A: ORAL HEALTH STATUS

1. **How would you rate the condition of your teeth and mouth on a scale of 1-5? (where 1 is "excellent" and 5 is "poor")** *Please Tick √.*

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| Excellent | Very Good | Good | Fair | Poor |

2. **Do you currently have any problems or concerns with your teeth, gums or mouth?**

❒ No ⟶ *Go to section B*

❒ Yes ⟶ If yes, what are your main problems/concerns (*Tick* ☑ all that apply)

| | |
|---|---|
| Swelling or lumps anywhere in your mouth | ❒ |
| Areas of red or white patches in your mouth | ❒ |
| Areas of ulcers (sores) in your mouth | ❒ |
| Pain in any area of your mouth | ❒ |
| Trouble while eating/chewing, swallowing or speaking | ❒ |
| Loose teeth | ❒ |
| Sore throat | ❒ |
| Difficulty in opening the mouth | ❒ |
| Other problems (Please Specify): _____ | ❒ |

_____

3. **Have your mouth problems/concerns affected your health?** (*Tick* ☑ that apply)

❒Yes, always ❒Yes, sometimes ❒ Never ❒ Don't know

If yes, how has it affected your health? Please explain:

_____

_____

**4. Have you received advice from a dentist for this problem/concern?** (*Tick* ☑ all that apply)

❒ Yes ❒ No

If no, why have you not seen a dentist? (tick ☑ all that apply)

I am nervous or scared to go ❒
I didn't think of it ❒
It costs too much ❒
I am too busy ❒
I am self-treating with over the counter products. ❒
Other (Please State): _____ ❒

_____

## SECTION B: KNOWLEDGE ABOUT ORAL CANCER RISK

**1. Have you heard about mouth (oral) cancer?** *(Tick ☑ in box)*

❑ Yes

❑ No ⟶ Go to question 4

❑ Can't remember ⟶ Go to question 3

**2. How have you heard/learnt about mouth (oral) cancer?** (*Tick* ☑ all that apply)

❑ Friends/Family

❑ GP/Specialist

❑ Dentist

❑ Media (Television, radio, newspaper)

❑ Social Media (facebook, Instagram, WhatsApp)

❑ Internet (websites)

❑ others, please specify_____

**3. Please indicate whether you think the following causes mouth (oral) cancer?** *(Tick ☑ all that apply)*

| | Yes | No |
|---|---|---|
| Smoking | | |
| Alcohol | | |
| Vitamin Deficiency | | |
| Not brushing the teeth or gums | | |
| Viruses or other germs | | |
| Chewing tobacco | | |
| Chewing Betel nut / 'supari' | | |
| Chewing Betel quid/'Pan' | | |
| Frequent biting of lining of the mouth | | |
| Putting pencils in mouth | | |
| None of above | | |
| Don't know | | |

**4. For each of the following statements, indicate whether you think it is true or false?**
(*Tick* ☑ all that apply)

| **A check up for mouth (oral) cancer:** | **True** | **False** | **Don't know** |
|---|---|---|---|
| a) Is painless | ❑ | ❑ | ❑ |
| b) Is a way of finding mouth (oral) cancer at an early stage | ❑ | ❑ | ❑ |
| c) Helps in treatment of oral cancer if detected early | ❑ | ❑ | ❑ |
| d) Can be done by a GP | ❑ | ❑ | ❑ |
| **The signs/symptoms of mouth (oral) cancer are:** | **True** | **False** | **Don't know** |
| a) A white patch/discoloration in the mouth | ❑ | ❑ | ❑ |
| b) An ulcer (sore) that does not heal | ❑ | ❑ | ❑ |
| c) A painless ulcer (sore) in the mouth | ❑ | ❑ | ❑ |
| d) A red patch in the mouth | ❑ | ❑ | ❑ |
| e) A yellow patch in the mouth | ❑ | ❑ | ❑ |
| f) A lump or swelling in the mouth | ❑ | ❑ | ❑ |
| g) A sore throat | ❑ | ❑ | ❑ |
| h) Discomfort or pain in the mouth | ❑ | ❑ | ❑ |
| i) Bleeding gums | ❑ | ❑ | ❑ |

## SECTION C: ATTITUDES TOWARDS ORAL CANCER RISK

**1.How would you describe the importance of the following activities to prevent mouth (oral) cancer?**
For each statement, please Tick ☑ *one box that comes closest to the way you think.*

| Activity | Very important | Fairly important | Important | Slightly important | Not important |
|---|---|---|---|---|---|
| Doing exercise regularly | ❒ | ❒ | ❒ | ❒ | ❒ |
| Eating a healthy diet (2 fruits & 5 vegetables per day) | ❒ | ❒ | ❒ | ❒ | ❒ |
| Brushing teeth twice a day | ❒ | ❒ | ❒ | ❒ | ❒ |
| Visit a dentist at least once a year | ❒ | ❒ | ❒ | ❒ | ❒ |
| Visit a doctor (G.P.) regularly | ❒ | ❒ | ❒ | ❒ | ❒ |

**2. For each of the following statements, indicate whether you think it is true or false?** (*Tick* ☑ all that apply)

| You are more likely to get oral cancer if you: | True | False |
|---|---|---|
| a) Smoke tobacco, cigars or pipe | ❑ | ❑ |
| b) Smoke hukkah (sheesha) | ❑ | ❑ |
| c) Chew tobacco | ❑ | ❑ |
| d) Drink alcohol heavily | ❑ | ❑ |
| e) Chew gutkha | ❑ | ❑ |
| f) Chew betel quid/'pan' | ❑ | ❑ |
| g) Chew betel nut/'supari' | ❑ | ❑ |
| h) If your family got it | ❑ | ❑ |

**3. Do you think people of Indian background are more at risk of mouth (oral) cancer than local Australian people?**
(Tick ☑ *one box)*

❒ Yes ❒ No ❒ Don't know

**4.Why do you think people use products like tobacco preparations/betel nut/cigarettes/alcohol?**

❑ Peer pressure (pressure from friends)

❑ Social status

❑ To connect with people

❑ Leisure/lifestyle/enjoy it/relaxation

❑ Addiction

❑ Family member use it

❑ It is a cultural practice for some Indians

❑ others, please specify_____

**5. For a white/coloured patch in the mouth (that has lasted more than 3 weeks), please indicate which (if any) healthcare professional you would visit about that symptom.** (*Tick* ☑ that apply)

❑ Doctor

❑ Dentist

❑ Pharmacist

❑ Other, please specify: _____

❑ Would not visit healthcare professional

**6. For an ulcer/sore in the mouth (that has lasted more than 3 weeks), please indicate which (if any) healthcare professional you would visit about that symptom.** (*Tick* ☑ that apply)

❑ Doctor

❑ Dentist

❑ Pharmacist

❑ Other, please specify: _____

❑ Would not visit healthcare professional

**6. Are you seeing health professionals (Doctor/GP) from your cultural background for your regular health check-ups in Australia?**

❑ Yes, I am seeing health professional from similar background

❑ No, I don't ⟶ Go to section D

If yes, what is the reason behind this? (*Tick* ☑ that apply)
❑ More knowledge

❑ More experience

❑ Easy to communicate

❑ More economic/affordable

❑ Cultural similarity

❑ Other (Please state_____

_____)

❑ No specific reason

## SECTION D: PRACTICES RELATED TO ORAL CANCER RISK

**1. Do you consume drinks that contain alcohol?** (*Tick* ☑ all that apply)
❑ No, I have never tried alcoholic drinks ⟶ Go to question 2

❑ No, but I used to and stopped ⟶ Go to question 1.1

❑ Yes, I drink alcohol

If yes, how often do you consume these drinks? (*Tick* ☑ that apply)
❑ Monthly or less

❑ 2-4 times a month

❑ 2-3 times a week

❑ 4 or more times a week

**2. Do you smoke tobacco? [this includes cigarettes, cigars, pipe, or hukkah (sheesha)]**
**(***Tick* ☑ that apply)

❑ No, I have never smoked

❑ No, but I used to and stopped

❑ Yes, I smoke

If yes, how often do you smoke?
Please give details of smoking habit in the table below by filling a number in box;
(where *0-Never, 1-Past, 2-Occasionally, 3-Daily)*

| Smoking type | Type of user (choose a number 0-3 from instruction above) | Frequency (Numbers per day) |
|---|---|---|
| Cigarettes/Bidi/cigar | | |

**3. Do you chew any product such as tobacco, betel nut/ 'supari', betel quid/ 'pan'?**
(*Tick* ☑ that apply)

❑ No, I have never chewed ⟶ Go to section F

❑ No, but I used to and stopped ⟶ Go to question 3.1

❑ Yes, I chew

If yes, how often do you chew these products?

Please give details in the table below by filling a number in box; where

0 = *Never chewed*
*1 = Past- means having stopped the habit for more than one year*

*2 = Occasional - means uses the habit less than daily.*
*3 = Daily*

| Type of Products | Type of User (choose a number 0-3 from instruction above) | Frequency (numbers per day) |
|---|---|---|
| Tobacco | | |
| Betel quid/Pan | | |
| Betel nut /supari/guthka | | |
| Other- Specify _____ | | |

3.1 Did any of the following factors play a role in you starting the habit of chewing such products? (*Tick* ☑ all that apply)
❑ Friends/Family

❑ Peer pressure

❑ Media (Television, radio, newspaper)

❑ Social Media (facebook, Instagram)

❑ Internet (websites)

❑ Stressful time period

❑ While visiting India on holiday/business

❑ others, please specify_____

3.2 If you used to chew such products, did any of the following play a role in you stopping this habit? (*Tick* ☑ all that apply)
❑ Friends/Family

❑ G.P/Specialist

❑ Dentist

❑ Media (Television, radio, newspaper)

❑ Social Media (facebook, Instagram)

❑ Internet (websites)

❑ others, please specify_____

❑ Not applicable

3.3 How do you get these products? (*Tick* ☑ all that apply)
❑ Asian grocery stores

❑ Friends/ relatives visiting from India

❑ Indian restaurants

❑ Temples/religious places

❑ others, please specify_____

## SECTION E: YOUR ACCESS TO HEALTH CARE

**1. Have you visited a doctor (GP) or community health clinic or practice nurse in last 12 months?** (*Tick* ☑ all that apply)

❒ No ❒ Yes

If no, when was your last visit to a doctor?

| | |
|---|---|
| 1-2 years ago | ❒ |
| 2 - 5 year ago | ❒ |
| More than 5 years ago | ❒ |
| Don't remember | ❒ |

**2. Have you visited a dentist in last 12 months?** (*Tick* ☑ all that apply)

❒ No ❒ Yes

If no, when was your last visit to a dentist?

| | |
|---|---|
| 1-2 years ago | ❒ |
| 2 - 5 year ago | ❒ |

More than 5 years ago ❒

Don't remember ❒

**3. Have you received any information about 'oral cancer' during your visits to the doctor (GP) or practice nurse or dentist?** (*Tick* ☑ all that apply)

❒ No
❒ Don't remember → *Go to question 5*

❒Yes

If yes,

3.1 What information have you received? (*Tick* ☑ all that apply)

❒ Instructions about how to look after your mouth and teeth.
❒ Oral cancer risk information through educational material such as leaflets, pamphlets, samples or other.
❒ Other advice
(please specify): _____

3.2 Where have you received this information from? (*Tick* ☑ all that apply)

❒Dentist ❒Doctor (G.P.) ❒ Practice nurse ❒ Other (Please state:_____)

**4. How satisfied are you with the information you received about 'oral cancer', on a scale of 1 to 5 (where 1 = "very satisfied" and 5 is "very dissatisfied")?**
*Please Tick √.*

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|

Very satisfied Very dissatisfied

Was the information easy to understand?

❒Yes ❒No

**5. For each of the following statements,** (*Tick* ☑ all that apply).

| | | | | |
|---|---|---|---|---|
| *a)* | Do you think doctor (GP) could assist you in identifying oral health problems like oral cancer? | ❒Yes | ❒ No | ❒ Don't know |
| *b)* | Do you think doctors (GP) have sufficient knowledge about oral cancer to advise you? | ❒Yes | ❒ No | ❒ Don't know |

| | | | | |
|---|---|---|---|---|
| *c)* | Would you consider oral health advice given by your doctor (GP)? | ❒Yes | ❒ No | ❒ Don't know |
| *d)* | Would you make an appointment to see a dentist if you were provided a dental referral by a doctor (GP)? | ❒Yes | ❒ No | ❒ Don't know |

## SECTION F: ABOUT YOU

**1. Personal Details:**

| | |
|---|---|
| Gender/sex: | |
| Age at your last birthday: | _____years |
| Were you born in Australia? (*Tick* ☑ that apply) | ❒ Yes ❒ No<br>If yes, were your parents born in India?<br>❒ Yes ❒ No |
| How long did you live in India? (*Tick* ☑ that apply) | ❒ Never lived ❒ lived for: ___years<br>❒ Don't remember |
| Do you visit India? (*Tick* ☑ that apply) | ❒ Yes ❒ No |
| Area of Residence in Australia: | Suburb/Postcode: |
| Years since living in Australia: | |
| Language spoken at home: | |
| Marital status: | ❒ Single ❒ Married/partnered<br>❒ Divorced ❒ Widowed |

**2. What do you consider as your current religion, if any?**

❒ Prefer not to answer

**3. Level of education**

What is the highest level of educational you completed? *Tick* ☑ *one box*

| | |
|---|---|
| Primary school | ❒ |
| High school | ❒ |
| TAFE | ❒ |
| University | ❒ |
| No formal education | ❒ |

**4. Employment Status** (Please describe your work status by Ticking ☑ *one box)*

❒ Full time ❒ Part time ❒ Casual

❒ Not working ❒ Home/Domestic duties ❒ Retired

**5. What is your average annual combined household income?** *Tick* ☑ *one box*

| | |
|---|---|
| Less than $40,000 | ❒ |
| $40,000 to less than $60,000 | ❒ |
| $60,000 to less than $80,000 | ❒ |
| $80,000 to less than $100,000 | ❒ |
| $100,000 to less than $120,000 | ❒ |
| More than $120,000 | ❒ |
| Don't know | ❒ |
| Prefer not to answer | ❒ |

**6. Do you have private health insurance that includes dental cover?** *Tick* ☑ *one box*

❒ Yes ❒ No ❒ Don't know

**7. Do you currently have the following cards?** *Tick* ☑ all that apply**.**

| | | | |
|---|---|---|---|
| Pensioner concession card | ❒ Yes | ❒ No | ❒ Don't know |
| Health care card | ❒ Yes | ❒ No | ❒ Don't know |
| Department of Veterans Affairs card | ❒ Yes | ❒ No | ❒ Don't know |

**8. Do you have a family history of Cancer/mouth (oral) cancer?** *Tick* ☑ *one box*

❒ Yes ❒ No ❒ Don't know ❒ Prefer not to answer

THANK YOU FOR YOUR TIME AND YOUR VALUABLE CONTRIBUTION TO THIS STUDY

If you would like to receive the summary of study results, please provide your contact details:

Phone: _____

OR Email id: _____

(Note: your information will remain anonymous)

Appendix 14: Ethical approval from WSU

WESTERN SYDNEY
UNIVERSITY

# HUMAN RESEARCH ETHICS COMMITTEE

15 May 2019
Associate Professor Ajesh George
School of Nursing and Midwifery

Dear Ajesh,

Project Title: "Exploring the oral cancer risk behaviours of Indian immigrants in Australia"

**HREC Approval Number: H13203**
**Risk Rating: HREC - Moderate**
I am pleased to advise the above research project meets the requirements of the National Statement on Ethical Conduct in Human Research 2007 (Updated 2018).
Ethical approval for this project has been granted by the Western Sydney University Human Research Ethics Committee. This HREC is constituted and operates in accordance with the National Statement on Ethical Conduct in Human Research 2007 (Updated 2018).
Approval of this project is valid from 15 May 2019 until 15 May 2022.
This protocol covers the following researchers:
**Ajesh George, Nidhi Saraswat, Bronwyn Everett, Rona Pillay**

**Summary of Conditions of Approval**

1. A progress report will be due annually on the anniversary of the approval date.

2. A final report will be due at the expiration of the approval period.

3. Any amendments to the project must be approved by the Human Research Ethics Committee prior to being implemented. Amendments must be requested using the HREC Amendment Request Form.

4. Any serious or unexpected adverse events on participants must be reported to the Human Research Ethics Committee via the Human Ethics Officer as a matter of priority.

5. Any unforeseen events that might affect continued ethical acceptability of the project should also be reported to the Committee as a matter of priority.

6. Consent forms are to be retained within the archives of the School or Research Institute and made available to the Committee upon request.

**7. Project specific conditions:**
There are no specific conditions applicable.

Please quote the registration number and title as indicated above in the subject line on all future correspondence related to this project. All correspondence should be sent to humanethics@westernsydney.edu.au as this email address is closely monitored.

Yours sincerely

[redacted]
Professor Elizabeth Deane
Presiding Member,
Western Sydney University Human Research Ethics Committee

Appendix 14: Ethical approval for amendment from WSU

WESTERN SYDNEY UNIVERSITY

Ethics Reference: H13203
Expiry Date: 15 May 2022

# HUMAN RESEARCH ETHICS COMMITTEE

13 August 2020

Associate Professor Ajesh George
School of Nursing and Midwifery

Dear Ajesh,

**RE: Amendment Request to H13203**

I wish to formally advise you that the Human Research Ethics Committee has approved your request to amend your approved research protocol H13203 "Exploring the oral cancer risk behaviours of Indian immigrants in Australia".

The approved amendments are:

Finalised questionnaire

Project specific approval conditions:

Please quote the registration number and title as indicated above in the subject line on all future correspondence related to this project. All correspondence should be sent to humanethics@westernsydney.edu.au as this email address is closely monitored.

Regards

[redacted]

Professor Brett Bowden
Presiding Member,
Western Sydney University Human Research Ethics Committee

Early checks may produce better health outcomes.

## Who can I get help from?

Speak to your dental practitioner or doctor about any teeth and mouth problems. They can:

- Identify early signs of cancer.
- Help you establish an oral hygiene routine to take care of your teeth.
- Provide advice on risk factors and managing symptoms.
- Assist with referrals to specialists.

## Accessing dental care

- Visit your dental practitioner or contact your health fund for further information.
- Find a private dentist at: www.ada.org.au/Find-a-Dentist.
- Free dental care is available in public dental clinics for eligible people.

Please scan the QR code to check your eligibility for free dental care or go to health.nsw.gov.au/oralhealth/Pages/info-patients.aspx

### Cancer information & support
### Free & confidential

Cancer Council
- Call 13 11 20
- Website cancer.org.au/support-and-services

Proudly supported by the NSW Government in association with South Western Sydney Local Health District and Western Sydney Local Health District

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NSW Health

# Betel Nut & Oral Cancer


## What is betel nut?

- Betel nut, also known as areca nut, is the seed of the fruit areca palm.
- Chewing betel nut is a common cultural and social practice in Asia and the Pacific.
- It is a highly addictive substance.
- Betel nut use can cause oral cancer.

## What are betel nut products?

- Betel nut can be used alone or in a mixture of ingredients called ‘betel quid’.
- Betel quid is made up of betel leaf, betel nut, and slaked lime, and it is commonly mixed with tobacco.
- It may be self-prepared with the betel leaf or commercially available in tins or sachets, which are known as *paan/supari, bin lang, puwak,* and *buai/daka*.

**Frequent use of betel nut products over time increases the risk of oral cancer.**

## How do I reduce my risk of oral cancer & improve my oral health?

- Stop the use of betel nut products.
- Do not smoke, vape, or use tobacco products, and limit alcohol intake.
- Brush your teeth twice a day using a soft toothbrush and fluoridated toothpaste, and floss your teeth daily.
- Get regular dental checks every 6 to 12 months.


## Signs & symptoms of oral cancer

- A red, white, or black patch in the mouth.
- A lump in the mouth, neck, or face.
- Any abnormality that bleeds easily when touched.
- Pain or difficulty swallowing, speaking, chewing, or moving the jaw or tongue.
- Soreness in the throat and mouth.
- Numbness in the mouth or face.
- Any of the above symptoms that continue for more than three weeks.