Outcomes from the first mouth cancer awareness and clinical check-up day in the Dublin Dental University Hospital

Introduction
Cancer of the head and neck region presents a challenge since, unlike other areas of the body, the boundaries are not always easy to delineate. Head and neck (H&N) cancer is described as cancer of the lip, mouth, tongue, tonsil, pharynx (unspecified), salivary gland, hypopharynx, larynx and other. Oral cancer refers to cancers of the tongue, gingiva, floor of the mouth, palate, vestibule and retromolar area. Unlike other areas in the body, the oral epithelium is readily accessible for inspection and self-examination, but over 60% of patients present with oral cancer with either regional or distant spread.2 The five-year survival rates
for oral cancer range between 50 and 80% depending on the stage of the disease, varying from 86% for stage I to 12-16% for stage IV. Between 2000 and 2004, the Irish National Cancer Registry reported 400 cases of H&N cancer in Ireland annually, and in the region of 150 deaths annually. H&N cancers are the sixth most common cancer diagnoses in men, as they include laryngeal cancer, which occurs most commonly in middle-aged to elderly men. They are the 16th most common cancer diagnoses in women, with increasing prevalence in young women. H&N cancers account for 2.9% of all cancer diagnoses in Ireland. In the United Kingdom, incidence and mortality have increased recently, and overall survival rates have only shown a slight improvement, standing at 50% for intra-oral lesions and with a poorer prognosis for lower socio-economic groups.

Cancer of the head and neck largely affects an older population, with males more frequently affected than females. Lifestyle factors, in particular tobacco smoking, alcohol consumption and use of betel quid are implicated in the aetiology. Alcohol consumption may be associated with a higher prevalence of cancers involving the floor of mouth, tongue and buccal mucosa, and a synergistic effect between alcohol and tobacco use has been documented. The evidence for the involvement of human papillomavirus in the aetiology of oral cancers suggests that it may be a co-factor, particularly in the development of carcinoma of the oropharynx in younger populations.

Prevention strategies include smoking cessation programmes, reduced use of betel, areca nut and smokeless tobacco, reduction in alcohol consumption and a diet rich in antioxidants. A major factor in poor outcome for oral cancers is late presentation, due in part to lack of awareness about oral cancers in the community. In a recent study of an outpatient hospital population, it was concluded that there was a poor level of knowledge about H&N cancers in a population in the West of Ireland. Some 70% of respondents had never heard of H&N cancer, 73% did not consider alcohol a risk factor and less than 50% would be concerned by persistent hoarseness or a prolonged oral ulcer. A study in rural communities in Sri Lanka found that there was a good level of public awareness about mouth cancer. However, there was low awareness of early lesions and of risk/lifestyle factors, especially in low socio-economic groups. Of the individuals referred to a dental school in Iran, 89% had little or no knowledge about oral cancer. In an Indian study of male prisoner tobacco use and oral cancer knowledge, it was found that knowledge about oral cancer did not impact on decisions regarding tobacco use. Subjects in an oral cancer awareness study in the northwest of England were asked to list cancers that they had heard of, and only 11% mentioned oral cancer in the top three. Some 60% of respondents listed cervical cancer as more common than oral cancer. However, 74% were aware that smoking was a risk factor and 61% and 27%, respectively, would attend the doctor or the dentist with a painful mouth ulcer. An earlier UK study reported an awareness of oral cancer among 56% of respondents, compared with 85% awareness of lung, cervical and skin cancers. Some 75% of the population was aware that smoking was a risk factor, but only 19% linked oral cancer to alcohol. These figures were similar to those reported in a similar study from the United States. Mouth self-examination to improve oral cancer awareness and early detection in a high-risk population was tested in an Indian community. The subjects self-examined, and were subsequently examined by healthcare workers and specialists. Self-examination identified red patches and non-healing ulcers, but the detection rate was low for white patches. As a consequence, awareness of oral cancer improved but compliance to seek treatment was poor. The idea of mouth self-examination was well received by a group of high-risk individuals in London. However, they found it difficult to identify lesions and did not readily accept the importance of lifestyle issues in the development of oral cancers.

An Australian study found that television advertisements and pictorial health warnings on cigarette packets may operate in a complementary manner, that is, to positively influence awareness of the health consequences of smoking and motivation to quit. A multifaceted social marketing campaign including radio advertisements, billboards and education sessions was found to effectively target a high-risk African-American population. This could result in a significant number of people availing of screening; however, evaluation of the programme is ongoing regarding uptake and cost.

The following assessment strategies have been considered as means to increase early detection:

- national screening programmes;
- targeted screening of risk groups; and,
- opportunistic screening in a primary care setting.

However, there is no clear evidence for the optimal management of potentially malignant lesions. The issue is whether all lesions deemed to be high risk should be surgically removed or should a watch and wait policy be advised. Therefore, national screening programmes for H&N cancers cannot be advocated at the present time. Targeted screening of risk groups has been found to be effective. In the Kerala study it was found that, in a high-risk population, a visual oral examination may detect pathology and save lives. Opportunistic screening of high-risk groups in a primary care setting may promote early detection and be cost-effective, as shown in a simulation modelling study. Opportunistic screening of the oral soft tissues by the dental team at every dental check-up is recommended. However, consideration must be given to the fact that high-risk individuals are often poor dental attendees.

In May 2009 Lia Mills, a writer and survivor of mouth cancer, started a campaign to increase awareness about mouth cancer in Ireland as she was astounded at the lack of knowledge and information available. A group of H&N cancer survivors, healthcare professionals, the Dental Health Foundation and the Irish Cancer Society came together to form Mouth, Head and Neck Cancer Awareness Ireland (MHNCAI). Discussion regarding the way forward included education of dental, medical and pharmaceutical students about mouth, head and neck cancers, public awareness campaigns, and collaboration.
with national organisations to advance the availability of information for the public. By mid 2010, an information brochure had been developed and the Irish Cancer Society had updated their website information on H&N cancers. In order to increase public awareness, it was decided that the Dublin Dental University Hospital and the Cork University Dental School and Hospital should host an awareness day and free mouth check-up in September 2010. The message on the day would focus on information, self-examination, risk management and the importance of early detection. The role of general dental and medical practitioners in the examination of the mouth would also be stressed.

Materials and method

September 28, 2010, was identified as the first Irish Mouth Cancer Awareness Day, with information about the disease, advice regarding self-examination and free mouth check-up. Ethical approval was obtained from the Faculty of Health Sciences (Trinity College Dublin) Research Ethics Committee. A pathway was developed to best utilise the attendee experience at the Mouth Cancer Awareness and Check-up Day with information, advice and clinical examination. Examination criteria were developed and a questionnaire was prepared for those attending for the check-up. Information about the disease was provided on the day by H&N cancer survivors, the Dental Health Foundation and the Irish Cancer Society. Disease prevention advice in relation to smoking cessation and self-examination was provided by dental and dental hygiene students of the Dublin Dental University Hospital. It was a stated objective to involve general dental (and medical) practitioners in this initiative in the future. Even though H&N cancer includes the larynx, nasopharynx and base of the tongue, the epithelium in these areas is not readily accessible for clinical examination.

The event was publicised widely by the organisations and groups involved. Several mouth, head and neck cancer survivors offered to give interviews on television, radio and in newspapers about their experiences during treatment of their disease. A mouth cancer awareness leaflet (Mouth, head and neck cancer: what you should know) was launched prior to Mouth Cancer Awareness Day. This was developed and funded in collaboration with the Dental Health Foundation and the Irish Cancer Society. The event received large coverage in the national media. Data were collected from attendees on the day by questionnaire (see Appendix 1).

Results

A total of 1,661 individuals (675 male, 986 female) were examined over a day and a half (Table 1). The mean age was 60 years (SD=13). Of these, 1,599 completed questionnaires. Almost 70% of those attending were over 55 years of age. Women were represented in a ratio of 3:2.

A total of 36.5% of those people examined required no action, and slightly less (30%) were advised to return to their general dental practitioner if dental problems were noticed, and to their general medical practitioner if the attendee complained of a cough, hoarseness or difficulty swallowing. Some 8% required smoking cessation advice. If a non-suspicious area was noticed in the mouth,
the individual was advised to carry out self-examination (21.3%). Of the remainder, 3.5% were sent for follow-up or biopsy (Table 2). Some 76% of individuals identified smoking as a risk factor for mouth cancer. However, only 11% identified alcohol. This is worrying in a group where 75% of attendees drink alcohol. It should be noted that the numbers of actions required for attendees did not necessarily add up to 100%, as two actions were often recommended (Table 3).

Correlation of question by type of action, following clinical check-up, is presented in Table 4, along with a chi-square test of association. As the sample was entirely self-selected, a formal interpretation of the chi-square test of independence is not appropriate. The p-value presented can be considered as an indication of possibly interesting differences across response levels. A total of 1,599 attendees (96.2%) completed the questionnaire, with 62 declining. Fifty-two attendees required specialist advice following the clinical check-up and 30 of these were sent for further examination. Twenty-seven of this group required biopsy. The results are presented in Table 5.

For further information regarding the questionnaire and clinical check-up forms, see Appendix 2.

Discussion
The data presented here cannot be said to have been drawn from a true random sample, so the results must be viewed in that context, and the possibility of selection bias considered.
carcinomas or carcinoma as needing active intervention for mouth cancer (squamous cell possible biopsy. Five people were identified from these investigations. Of these, 30 individuals were referred for follow-up and medical practitioner, and 52 required specialist advice on the check-treatment, 964 were advised to attend their general dental or general University Hospital. Over one-third required no action and 60% were referred for follow-up and possible biopsy at the Dublin Dental. Of the 1,599 attendees with completed questionnaires, 3.5% were referred for follow-up and possible biopsy, whereas only 3% of non-smokers were referred for biopsy, whereas only 3% of those who said that they did not self-examine were referred. However, these numbers are very small. The purpose of the awareness day was to do just that – raise awareness around mouth cancers. From this questionnaire data, this was evidently an important aim since very few people knew much about mouth cancers, in keeping with the results from other studies, and an even smaller proportion admitted to carrying out self-examination of their mouths. Other studies have identified a willingness among individuals to undertake mouth cancer self-examination. However, the outcome in the latter study was non-acceptance on the part of those examined to modify lifestyle risk factors in spite of the fact that they were a high-risk population. More than half of the sample claimed to visit a dentist at least annually. This is higher than the proportion of people who, in the 2002 Irish National Oral Health Survey of Adults, claimed to be regular attendees. As such, a significant proportion of the people attending the awareness day in September 2010 must represent the ‘worried well’. In part this is reflected in the profile of people attending who were predominantly dentate, claimed to brush their teeth at least twice a day, and with a significant proportion using mouthwash, at least weekly. In relation to risk factors, however, while the majority were non-smokers, the majority consumed alcohol. The frequency and amounts of tobacco and alcohol consumption were not documented. It has been reported in a 10-year follow-up study that it is not feasible to include high-risk groups in opportunistic oral cancer screening by dentists, as they are not regular attendees. However, it was advised that dentists should continue to opportunistically screen all patients, as oral cancers and potentially malignant disorders are also found in regular attendees. More should be done to encourage high-risk groups to visit their dentists. It is salutary that this opportunity to undertake mouth checks on nearly 1,661 people identified suspicious areas in the mouths of 52 (3.5%). Of these, 30 (1.8%) were referred for further investigation. That such an exercise can pick up five people with mouth cancers, who may not otherwise have been identified for further treatment, means that the inevitable additional burden that this imposes on already overstretched diagnostic and treatment services for mouth as well as other H&N cancers is justified. However, it is inappropriate that such an exercise would remain the preserve of the dental teaching hospitals and it is vital that all dentists – those in primary, secondary and tertiary care – take on the responsibility for the regular mouth checks of all of their patients. There is also a need to mount awareness days as described here to

<table>
<thead>
<tr>
<th>Number of cases</th>
<th>Clinical description at check-up</th>
<th>Biopsy</th>
<th>Histopathological report</th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
<td>Lump, ulcer</td>
<td>Yes</td>
<td>Benign (pyogenic granuloma, squamous papilloma, other)</td>
</tr>
<tr>
<td>1</td>
<td>White patch</td>
<td>Yes</td>
<td>Inflammation and fibrosis</td>
</tr>
<tr>
<td>7</td>
<td>White patch</td>
<td>Yes</td>
<td>Mild dysplasia</td>
</tr>
<tr>
<td>5</td>
<td>White patch, ulcer</td>
<td>Yes</td>
<td>Moderate dysplasia</td>
</tr>
<tr>
<td>1</td>
<td>White patch, ulcer</td>
<td>Yes</td>
<td>Severe dysplasia</td>
</tr>
<tr>
<td>1</td>
<td>Blister</td>
<td>Yes</td>
<td>Linear IgA</td>
</tr>
<tr>
<td>4</td>
<td>White/red mucosa</td>
<td>Yes</td>
<td>Lichen planus</td>
</tr>
<tr>
<td>3</td>
<td>White patch, ulcer verrucous</td>
<td>Yes</td>
<td>Carcinoma in situ</td>
</tr>
<tr>
<td>2</td>
<td>Ulcer</td>
<td>Yes</td>
<td>Squamous cell carcinoma</td>
</tr>
</tbody>
</table>

Of the 1,599 attendees with completed questionnaires, 3.5% were referred for follow-up and possible biopsy at the Dublin Dental University Hospital. Over one-third required no action and 60% were offered advice and/or requested to attend general dental or general medical practitioners. A total of 647 people did not need any further treatment, 964 were advised to attend their general dental or general medical practitioner, and 52 required specialist advice on the check-up day. Of these, 30 individuals were referred for follow-up and possible biopsy. Five people were identified from these investigations as needing active intervention for a mouth cancer (squamous cell carcinomas or carcinoma in situ).

In the questionnaire, when asked about the habits or activities that may cause mouth cancers, participants were asked to suggest two possible causes. Some 60% suggested smoking first and alcohol second, 9% suggested alcohol followed by smoking, 5% suggested smoking and poor oral hygiene/bad teeth, 1% suggested poor oral hygiene/bad teeth followed by smoking and <1% suggested all other combinations. Some 75% of the attendees recognised that smoking might cause cancer, with a further 11% suggesting that alcohol consumption might cause mouth cancers. Some 6% of the 269 smokers were referred for biopsy, whereas only 3% of non-smokers were referred.

Oral health advice regarding smoking cessation and self-examination was available for all attendees and was provided by dental and dental hygiene students. Despite the gender predilection for males demonstrated in the epidemiology surrounding mouth cancers, the numbers presenting here show the opposite trend, but are consistent with women’s greater and earlier use of health services generally. This is reflected in the outcomes from the check-up day in that far more men were referred for possible biopsy of suspect areas in their mouths (Table 1). Awareness around the need to undertake regular self-examination of the mouth was low, with only 42 people indicating that they did so. Some 12% of these people were referred for biopsy, whereas only 3% of those who said that they did not self-examine were referred. However, these numbers are very small. The purpose of the awareness day was to do just that – raise awareness around mouth cancers. From this questionnaire data, this was evidently an important aim since very few people knew much about mouth cancers, in keeping with the results from other studies, and an even smaller proportion admitted to carrying out self-examination of their mouths. Other studies have identified a willingness among individuals to undertake mouth cancer self-examination. However, the outcome in the latter study was non-acceptance on the part of those examined to modify lifestyle risk factors in spite of the fact that they were a high-risk population. More than half of the sample claimed to visit a dentist at least annually. This is higher than the proportion of people who, in the 2002 Irish National Oral Health Survey of Adults, claimed to be regular attendees. As such, a significant proportion of the people attending the awareness day in September 2010 must represent the ‘worried well’. In part this is reflected in the profile of people attending who were predominantly dentate, claimed to brush their teeth at least twice a day, and with a significant proportion using mouthwash, at least weekly. In relation to risk factors, however, while the majority were non-smokers, the majority consumed alcohol. The frequency and amounts of tobacco and alcohol consumption were not documented. It has been reported in a 10-year follow-up study that it is not feasible to include high-risk groups in opportunistic oral cancer screening by dentists, as they are not regular attendees. However, it was advised that dentists should continue to opportunistically screen all patients, as oral cancers and potentially malignant disorders are also found in regular attendees. More should be done to encourage high-risk groups to visit their dentists. It is salutary that this opportunity to undertake mouth checks on nearly 1,661 people identified suspicious areas in the mouths of 52 (3.5%). Of these, 30 (1.8%) were referred for further investigation. That such an exercise can pick up five people with mouth cancers, who may not otherwise have been identified for further treatment, means that the inevitable additional burden that this imposes on already overstretched diagnostic and treatment services for mouth as well as other H&N cancers is justified. However, it is inappropriate that such an exercise would remain the preserve of the dental teaching hospitals and it is vital that all dentists – those in primary, secondary and tertiary care – take on the responsibility for the regular mouth checks of all of their patients. There is also a need to mount awareness days as described here to
reach that segment of the population who may not regularly engage
with dental services. Such a venture opens up access for a greater
number of people, many of whom may not attend the dentist unless
in pain.

Notwithstanding the desirability of the campaign, there needs to be
recognition of the additional resources required for the detection and
timely management of such cancers, particularly acknowledging the
way that such exercises inevitably adversely impact on other oral and
dental care services.

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Appendix 1:

**ORAL CANCER AWARENESS DAY QUESTIONNAIRE**

— Please circle correct options below —

1. How did you first hear about mouth, head and neck cancer?
   
   THIS CAMPAIGN      FRIEND     FAMILY     INTERNET     PRESS         DOCTOR      CHEMIST

2. List two habits or activities that you believe could cause mouth cancer.
   
   A_________________________________________________________________
   
   B_________________________________________________________________

3. Have you ever received information about mouth cancer? YES NO

4. Have you ever been shown how to examine yourself for mouth cancer? YES NO

5. Do you have any of your own natural teeth? YES NO

6. How often do you attend your dentist? (Please circle one option.)
   
   NEVER       ONLY WHEN IN PAIN          EVERY FEW YEARS        EVERY YEAR            EVERY 6 MONTHS

7. Do you brush your teeth DAILY WEEKLY NEVER

8. Do you use a mouth rinse DAILY WEEKLY NEVER

9. If yes in Q8, name the mouth rinse ______________________________

10. Do you currently smoke? YES NO

11. If you smoke, how many of the following do you use per day? NA

   Cigarettes _____  Cigars _____  Roll up _____oz  Pipe _____oz

12. Are you a past smoker? YES NO  YEARS QUIT_______

13. Do you currently drink alcohol YES NO

14. If you drink alcohol, which of the drinks below do you drink most?

   NA          BEER             WINE                SPIRITS

15. How many alcohol units per week do you drink? (one unit = glass wine, half pint, one shot) ______

16. If you used to drink alcohol, how long ago did you give up?  YEARS QUIT_______

17. What is your AGE: _______ years

   GENDER:        MALE         FEMALE
Acknowledgements

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Appendix 2:

Consent to oral cancer check-up, September 29, 2010

Patient name ____________________________________________________________

ID number: ____________________ DOB:  __________________________________

I ___________________________________________________consent to being checked for oral cancer today. I fully understand that this check-up is only for oral cancer and that I will not be advised about or offered any treatment for any other oral or dental problem.

SIGNED: ______________________________________________________________________

Oral cancer check-up – clinical

Action (circle)  

Biopsy and follow up in DDSH

Smoking cessation advice

Self-examination advice

Advise to return to GDP/GMP

No action required

Examiner: ___________________________________________________________________