

## INVITED PAPER

# Outcomes of oral cancer early detection and prevention statewide model in Maryland

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## Keywords

cancer of mouth; early detection of cancer; early diagnosis; health literacy.

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## Abstract

A high oral cancer mortality rate and a moderately high oral cancer incidence rate prompted Maryland to develop a statewide approach to oral cancer early detection and prevention. This approach can serve as a model for other states. Key lessons learned include the need to: develop a comprehensive plan that focuses on actions to increase awareness, education and training for the public, dental and non-dental providers and policy makers; include oral cancer in the state's comprehensive cancer control plan to keep attention focused on this disease; and maintain high vigilance among stakeholders to keep oral cancer prevention and early detection a high priority within the state. Future efforts will focus on: requiring all dental and dental hygiene students to perform a set number of supervised oral cancer examinations for licensure to ensure a dental workforce that is competent and predisposed to providing routine oral cancer examinations; training health care providers such as doctors, nurse practitioners, and physician assistants to perform oral cancer examinations as part of a comprehensive cancer screening exam to expand the number of individuals that receive oral cancer examinations; and continuing to educate the public about oral cancer risk factors, its symptoms, and ways to prevent it.

## Background

In the early 1990s, Maryland had the seventh highest oral cancer mortality rate and the highest mortality rate for black males among all states. Maryland's oral cancer incidence rate ranked it 27th among all states (1,2). These statistics prompted a small group of stakeholders to develop, implement, and evaluate programs with the long-term goal of reducing morbidity and mortality from oral cancers. The group's primary objectives were to increase the public's awareness and understanding of oral cancer prevention and early detection; increase health care practitioners' awareness and understanding of their role in oral cancer prevention and early detection; increase the number of oral cancer examinations performed by health care providers; and develop activities aimed at improving access to programs for oral cancer prevention, early detection, and treatment (3). The purpose of this paper is to summarize Maryland's approach to developing a model of oral cancer early detection and prevention.

## The Maryland model

The Maryland model of oral cancer early detection and prevention is a statewide public health approach that encompasses the following: targeted health education materials; oral cancer education for the public; oral cancer screening examinations and referral; education and training programs for dental and non-dental health care providers; and program evaluation. Based on a modified PRECEDE-PROCEED Model of Health Program Planning and Evaluation (4), the model consisted of three phases: Phase 1 – Needs Assessment; Phase 2 – Development and Pilot Testing of Educational Interventions; and, Phase 3 – Program Evaluation. A description of each phase follows.

### Phase 1 – needs assessment

The initial group of stakeholders expanded their partnership to include members from the following organizations: Maryland Department of Health and Mental Hygiene (DHMH)

**Table 1** Key Findings from Surveys of and Focus Groups with Maryland Health Care Providers and Adults (1992-2000)

- Most oral cancers were detected at a late stage and were diagnosed by physicians, not dentists (4,5).
- Most dentists and dental hygienists reported providing oral cancer examinations, but the majority of respondents did not perform a critical component of the examination – palpation. And, many did not know where to look or what to look for (4,5).
- Most dentists and dental hygienists did not provide oral cancer examinations for edentulous patients (4,5).
- The majority of health care providers knew that tobacco and alcohol are risk factors for oral cancer, but did not adequately address tobacco and alcohol use with their patients and many felt inadequate in doing so (4,5).
- The adult public was not knowledgeable about oral cancer prevention and early detection. Only 23% of respondents could identify one early sign of oral cancer and only 21% had heard of an examination for oral cancer (3).
- Only 28 percent of surveyed adults reported ever having had an oral cancer examination (3).

Office of Oral Health; the National Institute of Dental and Craniofacial Research (NIDCR); the University of Maryland's schools of dentistry and nursing; health care provider associations such as dentists, dental hygienists, and family practice physicians; local health departments; and the American Cancer Society (3). The partners' key activities in Phase 1 were to assess available funds; review state epidemiological data; conduct surveys and focus groups of health care providers and the public to gather baseline data; and, publish, disseminate, and use the findings.

To gather baseline data, researchers mailed surveys to Maryland dentists, dental hygienists, adult and family nurse practitioners, and family practice physicians to determine their knowledge, opinions, and practices related to oral cancer early detection and prevention; conducted telephone surveys of adults to assess their knowledge of risk factors for and signs and symptoms of oral cancers and whether they ever had an oral cancer examination, and conducted two focus groups with each of the provider groups and the public to gather more detailed information about oral cancer knowledge and practices (3). The data were evaluated to determine which interventions were appropriate and could be implemented, whether the outcomes of these interventions could be measured, and the best methods for educating providers and the public (3). Key findings from the surveys and focus groups are listed in Table 1 (5-7).

## Phase 2 – development and pilot testing of educational interventions

Findings from Phase 1 studies were used in Phase 2 to develop, test, and produce educational materials; develop and pilot test educational interventions for health care providers

and the public; and implement educational interventions. Based on all of these efforts, oral cancer was included in the Maryland Comprehensive Control Plan for 2004-2008. The activities are shown in Figure 1 (8). These are strategic pathways to achieve optimum prevention and early detection of oral cancer.

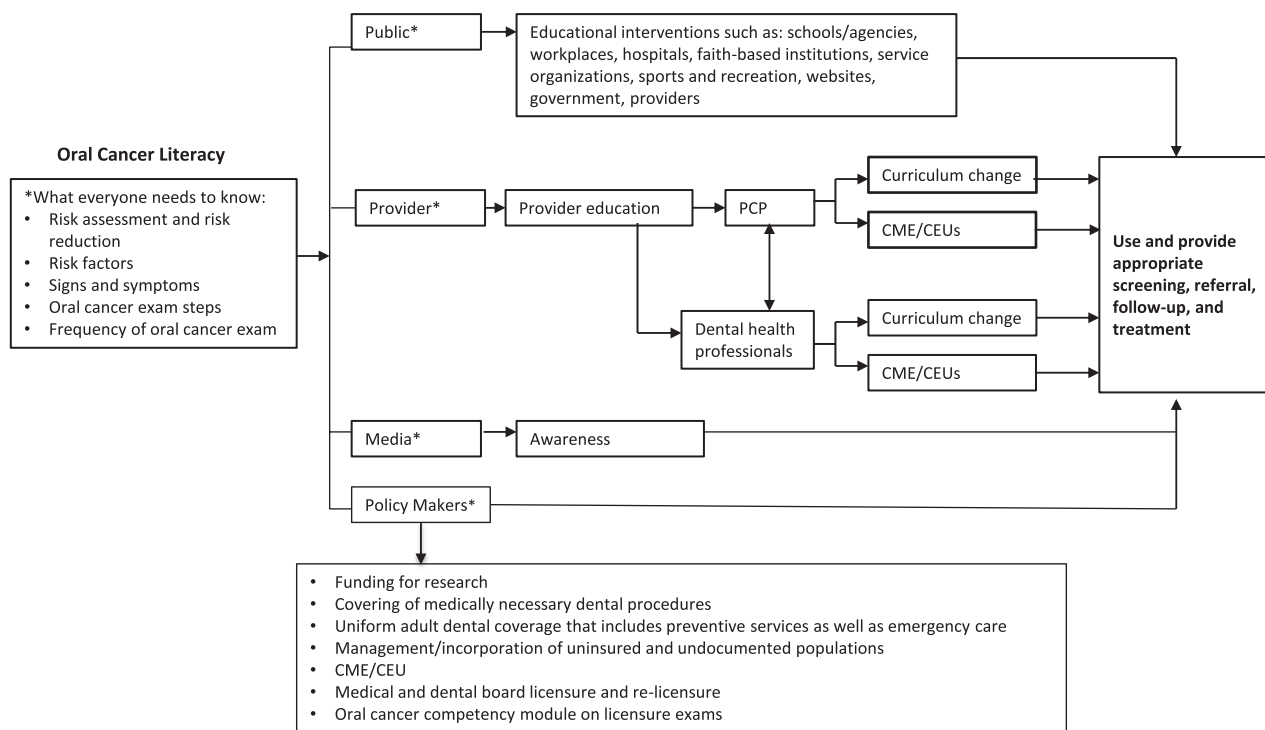
The oral cancer prevention initiative resulted in several key actions. The Maryland General Assembly passed legislation requiring the state's Office of Oral Health to develop a state-wide oral cancer prevention program; funding was provided by NIDCR. This program encompassed development of an oral cancer examination training program for health care providers, an educational and awareness program for providers, and an educational and awareness campaign for the public. A key component of the provider training was responding to what dentists asked for – hands-on training of dentists on how to perform oral cancer screening examinations (6,7). Furthermore, DHMH identified oral cancer as one of seven targeted cancers in the state for which tobacco settlement funds were to be directed, and six Maryland counties targeted oral cancer prevention with these funds (3). In another key action, the governor proclaimed the third week in September 2001 as Maryland Oral Cancer Awareness Week (now held annually in April/May in alignment with the national Oral, Head and Neck Cancer Awareness Week) (3). Free oral cancer examinations were provided at numerous sites throughout the state. Educational materials about oral cancer examinations and risk factors, including one for people with low literacy, were developed, tested, and published for use during the week's activities and after. The awareness initiative continued until Spring 2002 and included additional media and educational events.

## Phase 3 – program evaluation

In Phase 3, program evaluation included the number of individuals educated about oral cancer, the number of individuals screened for oral cancer, and the number of people reached through the media and resource materials (Table 2). To assess the reach of our efforts, we collected information from health care professionals and trainers at Continuing Education (CE) courses and seminars, and from the general public at community events, health fairs, and cancer screenings. Findings were used to adjust the educational interventions and to establish needed policies. One resultant policy is the specified actions and follow-up actions to be taken for positive and negative oral cancer examination findings.

## Progress: 1995 to 2009

Maryland has made progress in its efforts to reduce the morbidity and mortality associated with oral cancer. Examples of its progress include an oral cancer mortality rate of 2.6



**Figure 1** Strategic pathways to oral cancer prevention and early detection. Source: developed by the Oral Cancer Committee of the Maryland Comprehensive Cancer Control Plan.

percent (2007) which decreased Maryland’s ranking from seventh (1995) to 21st among the states and the District of Columbia and an oral cancer incidence rate of 9.5 percent (2007) which decreased its ranking from 27th (1995) to 47th (2,9). Furthermore, the percentage of Marylanders ages 40 and over that reported having an oral cancer exam in the past

year increased from 20 percent in 1996 to 40 percent in 2008 (10). However, much work still remains. Specifically, Maryland’s oral cancer mortality rate is still higher than the US average, significant disparities exist in oral cancer mortality rates between blacks and whites, and only 28 percent of all oral cancers are detected at the earliest stage (2,11).

**Table 2** Outcomes of Maryland Statewide Model of Oral Cancer Early Detection and Prevention (1/2000-10/2005)

<ul style="list-style-type: none"> <li>■ 20,325 individuals educated and made aware of oral cancer                             <ul style="list-style-type: none"> <li>• 18,971 members of general public</li> <li>• 711 health care professionals</li> <li>• 643 trainers</li> </ul> </li> <li>■ 5,352 individuals screened for oral cancer                             <ul style="list-style-type: none"> <li>• 81 with findings of cancer or possible cancer                                     <ul style="list-style-type: none"> <li>■ 44 abnormal but work up unknown or incomplete</li> <li>■ 4 cancers detected</li> <li>■ 33 no cancer detected or suspected</li> </ul> </li> </ul> </li> <li>■ 1.6 million people potentially reached through media and resources</li> <li>■ Maryland General Assembly passed legislation requiring the state’s Office of Oral Health to develop a statewide oral cancer prevention program (2000)</li> <li>■ Oral cancer is included in the Maryland Comprehensive Cancer Control Plan</li> <li>■ Annual Oral Cancer Awareness Week (held annually in April/May in alignment with the national Oral, Head and Neck Cancer Awareness Week)</li> </ul>
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In 2009, the University of Maryland School of Public Health received a grant to conduct a follow-up study to assess general practice dentists’ knowledge, opinions, and practices relating to oral cancer prevention and early detection (6,7). We used the same methodology for the current study that was used for the initial study. However, we modified the instrument to include questions about human papillomavirus (HPV) as a risk factor for oral cancer and use of adjunctive procedures to detect and diagnose oral cancers. Preliminary findings indicate that deficiencies in knowledge and practices persist. Dentists’ reported knowledge of oral cancer risk factors and diagnostic procedures remained relatively unchanged between the baseline study (1995) and the 2009 study, with differences of only one or two percentage points. On a positive note, 88 percent of respondents knew that HPV is a risk factor for oral cancer. However, only 50 percent assess their patient’s HPV history, and less than a quarter (21 percent) ask their patients if they have had the HPV vaccine. With regard to oral cancer screening practices, respondents in the 2009 study reported higher levels of compliance with

recommended screening exams and a greater percentage reported routinely palpating patients' lymph nodes. Additionally, the percentage of dentists indicating they had taken an oral cancer CE course in the past 12 months doubled from the baseline study (14 percent to 29 percent).

While Maryland's cancer control plan has garnered successes, critical work remains. To address deficiencies in dentists' knowledge of oral cancer early detection and prevention, Maryland should consider requiring oral cancer CE courses that emphasize hands-on training in early detection and prevention for licensure and relicensure. To our knowledge, this is not a requirement in other states, although in 2001, New York mandated that all dentists take 2 hours of coursework and training on a one-time basis on how to recognize, diagnose, and treat the effects of tobacco on oral health (12). To ensure a dental workforce that is competent and predisposed to providing routine oral cancer examinations, all dental and dental hygiene students should be required to perform a set number of supervised oral cancer examinations for graduation. Furthermore, to expand the number of individuals that receive oral cancer examinations, health care providers such as doctors, nurse practitioners, and physician assistants should be trained to perform oral cancer examinations. Training these health care providers to perform oral cancer examinations as part of a comprehensive screening exam would provide many high-risk individuals with an oral cancer examination that they might otherwise not receive (13). Additionally, follow-up studies should be conducted with dental hygienists, physicians, and nurse practitioners to understand their knowledge and practices relating to oral cancer early detection and prevention so that appropriate educational interventions can be developed and implemented. Finally, Maryland must continue its work to increase oral cancer literacy, including oral cancer early detection and prevention, among the public, providers and policy makers. The state's recently released 5-year oral health plan identified increasing oral health literacy, including health literacy of oral cancer, as one of three key focus areas, which should help support these efforts (14).

## Conclusions

By taking a comprehensive approach to oral cancer early detection and prevention, Maryland raised awareness about these cancers among the public, health care providers and policy makers. Maryland's approach can serve as a model for other states, and several key lessons should be considered when developing a state cancer control plan. First, the stakeholder group should be broad-based to best address the state's populations, needs, and laws. Next, the approach should be comprehensive and include actions that increase awareness, education, and training for the public, dental and non-dental providers and policy makers. Furthermore, stake-

holders must be continuously vigilant in their efforts to keep oral cancer early detection and prevention a high priority within the state, which is especially important with the increased number of HPV-related cases of oral cancer. Otherwise, resources will not be available to achieve objectives and past successes will quickly fade, as happened here in our state – Maryland conducted hands-on training of dentists throughout the state a decade ago, but no funds are currently available to continue this program or follow-up studies.

The recommendations in this manuscript reflect the opinions of the authors and not necessarily those of the institutions with whom they are affiliated.

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## Conflict of interest

This study was supported by a gift to the School of Public Health. The authors declare no other conflict of interest.

## References

1. Carpenter RD, Yellowitz JA, Goodman HS. Oral cancer mortality in Maryland. *Md Med J*. 1993;42(11):1105-9.
2. Howlader N, Noone AM, Krapcho M, Neyman N, Aminou R, Waldron W, Altekruse SF, Kosary CL, Ruhl J, Tatalovich Z, Cho H, Mariotto A, Eisner MP, Lewis DR, Chen HS, Feuer EJ, Cronin KA, Edwards BK, editors. SEER cancer statistics review, 1975-2008, National Cancer Institute. Bethesda, MD. Based on November 2010 SEER data submission, posted to the SEER web site, 2011. [cited 2011 September 4]. Available from: [http://seer.cancer.gov/csr/1975\\_2008/browse\\_csr.php?section=20&page=sect\\_20\\_table.06.html](http://seer.cancer.gov/csr/1975_2008/browse_csr.php?section=20&page=sect_20_table.06.html)
3. Alfano MC, Horowitz AM. Professional and community efforts to prevent morbidity and mortality from oral cancer. *J Am Dent Assoc*. 2001;132(S1):24S-9.
4. Green LW, Kreuter MW. *Health program planning: an educational and ecological approach*. 4th ed. New York: McGraw-Hill Higher Education; 2005.
5. Horowitz AM, Moon HS, Goodman HS, Yellowitz JA. Maryland adults' knowledge of oral cancer and having oral cancer examinations. *J Public Health Dent*. 1998;58:281-7.
6. Horowitz AM, Drury TF, Canto MT. Practices of Maryland dentists: oral cancer prevention and early detection. *Oral Dis*. 2000;6:282-8.
7. Canto MT, Drury TF, Horowitz AM. Maryland dentists' knowledge of oral cancer risk factors and diagnostic procedures. *Health Promot Pract*. 2001;2(3):255-62.
8. Maryland Department of Health and Mental Hygiene. The Maryland Comprehensive Cancer Control Plan 2004-2008; Chapter 12: Oral Cancer. 2003.

9. National Cancer Institute. State Cancer Profiles. Incidence rates for Maryland, 2004-2008: oral cavity & pharynx, all races (includes Hispanic), both sexes, all ages (SEER areas). [cited 2011 September 2]. Available from: <http://statecancerprofiles.cancer.gov/map/map.withimage.php?24&001&003&00&0&1&0&1&6&0#map>.
10. Poppell CF, Hopkins A, Zhan M, Steinberger EK, Groves C, Gugel D, Dwyer DM. Maryland cancer survey 2008. Department of Epidemiology and Preventive Medicine, University of Maryland, Baltimore, MD and Center for Cancer Surveillance and Control, Maryland Department of Health and Mental Hygiene, Baltimore, MD; 2009. [cited 2011 September 4]. Available from: [http://fha.maryland.gov/pdf/cancer/2008\\_MCS\\_report.pdf](http://fha.maryland.gov/pdf/cancer/2008_MCS_report.pdf).
11. Altekruse SF, Kosary CL, Krapcho M, Neyman N, Aminou R, Waldron W, Ruhl J, Howlander N, Tatalovich Z, Cho H, Mariotto A, Eisner MP, Lewis DR, Cronin K, Chen HS, Feuer EJ, Stinchcomb DG, Edwards BK, editors. SEER cancer statistics review, 1975-2007, National Cancer Institute. Bethesda, MD. Based on November 2009 SEER data submission, posted to the SEER web site, 2010. [cited 2011 September 4]. Available from: [http://seer.cancer.gov/csr/1975\\_2007](http://seer.cancer.gov/csr/1975_2007).
12. Gajendra S, Cruz GD, Kumar JA. Oral cancer prevention and early detection: knowledge, practices, and opinions of oral health care providers in New York State. *J Cancer Educ.* 2006;**21**(3):157-62.
13. Horowitz AM, Goodman HS, Yellowitz JA, Nourjah PA. The need for health promotion in oral cancer prevention and early detection. *J Public Health Dent.* 1996;**56**(6): 319-30.
14. Maryland Oral Health Plan Committee, Holt K, editor. *Maryland oral health plan: 2011-2015*. Columbia, MD: Maryland Dental Action Coalition; 2011. [cited 2011 September 2]. Available from: <http://www.mdac.us/wp-content/uploads/2011/02/MOHP-Dental-Action-r4.pdf>.