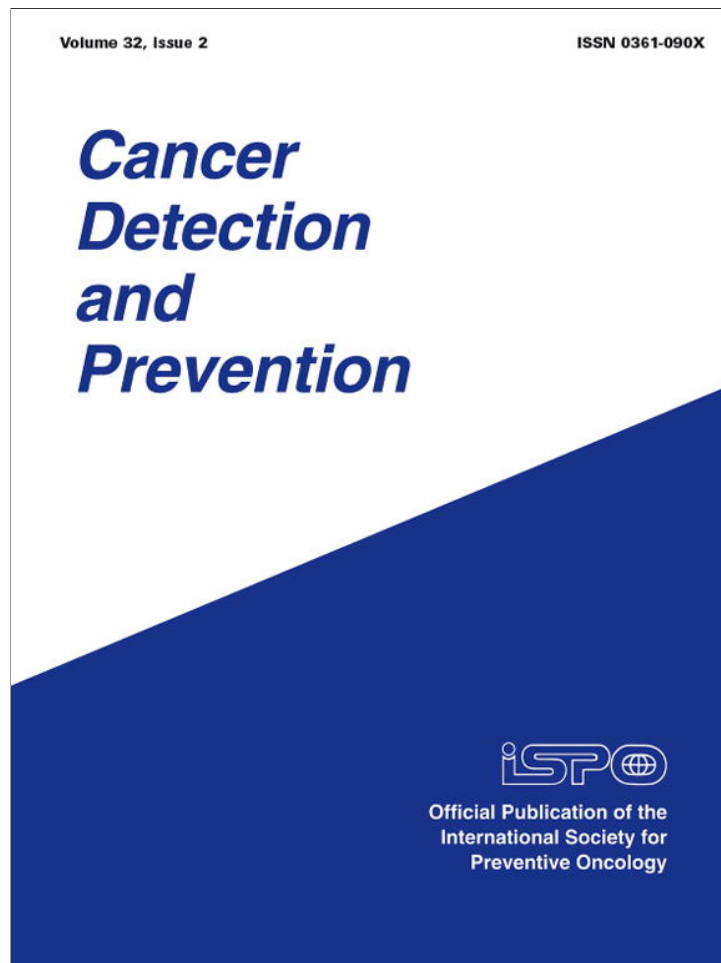


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## Which socio-demographic factors are associated with participation in oral cancer screening in the developing world? Results from a population-based screening project in India

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### Abstract

**Background:** This study examines socio-demographic determinants of participation in a population-based randomized controlled trial that proved that oral visual inspection was effective in reducing oral cancer mortality in high-risk individuals in India. **Methods:** Multivariate logistic regression was used to establish socio-demographic characteristics of participants versus non-participants in the intervention arm. Compliance with referral was analysed according to the socio-demographic characteristics of screen-positives. **Results:** Of 96,517 eligible subjects, 87,655 were screened, 8688 individuals never received the invitation and 174 refused screening. Compared to the non-screened, a higher proportion of screened individuals were women (OR = 4.51; CI: 4.28–4.75), lived in better housing (OR = 1.35; CI: 1.25–1.41), had television/radio (OR = 1.50; CI: 1.43–1.58) and were tobacco and alcohol users (OR = 2.75; CI: 2.57–2.95). Being 65 and older decreased the chances of screening (OR = 0.39; CI: 0.37–0.42), as well as living in high-size households (OR = 0.73; CI: 0.68–0.78). Sixty-three percent of 5143 screen-positives complied with referral. Controlling for all other factors, individuals older than 44, and those with more advanced lesions were more likely to comply with referral ( $p < 0.001$ ). Individuals living in better housing were less likely to comply with referral (OR = 0.79; CI: 0.65–0.95). **Conclusions:** In summary, adequate coverage can be obtained in population-based oral screening in developing countries. The study underscores the important role of patient-provider communication in assuring high compliance with referral.

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**Keywords:** Oral cancer; Screening; Participation; Compliance with referral; Visual inspection

### 1. Introduction

Oral cancer accounted for 274,300 new cases and 145,500 deaths worldwide in 2002, two-thirds of which occurred in less-developed countries [1,2]. As most oral cancers are preceded by easily visible precancerous lesions, they are particularly suited to prevention through visual screening [3], a simple and accurate screening test for oral neoplasia [4,5]. In 1996 we undertook a randomized controlled trial in Kerala, India, which demonstrated that population-based visual screening by trained health workers

(HWs) reduces mortality among users of tobacco or alcohol or both [6,7]. Our results have encouraged worldwide discussions about the need of oral cancer screening programmes. In addition, the World Health Organization has recently issued a commitment to action against the neglected burden of oral cancer [8], encouraging countries to develop prevention strategies. Therefore, researchers and health planners need complementary information about key programmatic issues when considering the implementation of oral cancer screening programmes.

One of the essential components of a successful screening program is obtaining maximum participation rates. In our study, 90% of the screening group was screened at least once and two-thirds of screen-positive individuals complied with

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referral. However, assuring adequate levels of participation in cancer prevention programs in developing countries is in general a highly difficult goal to achieve, as demonstrated by cervical cancer prevention experiences [9]. Identifying the socio-demographic profile of participants and non-participants is essential to provide health planners with clues about how to increase participation among the underserved; nevertheless, very little evidence exists about these issues in oral screening in low-resource countries. Existing data refer mainly to screening carried out in dental/general clinics or workplaces [10] or through population-based programs in developed countries using invitation letters as the main method of contacting the target population to be screened [11,12]. These strategies, however, are not feasible in many developing countries where occupations related to manual and agricultural work are still predominant, where most individuals do not visit a dentist regularly, and where postal systems are often inefficient.

In this paper we analyze the socio-demographic profile of participants and non-participants of the above-mentioned randomized clinical trial. We also examine socio-demographic determinants of compliance with referral procedures. This collaborative project was undertaken between 1996 and 2004 by the International Agency for Research on Cancer (IARC) in Lyon, France, and the Regional Cancer Centre (RCC), Trivandrum, India.

## 2. Materials and methods

The methodology of the cluster-randomized trial has been described elsewhere [6,13]. Of the 13 clusters called 'panchayaths' (municipal administrative units) in Trivandrum district (Kerala) chosen for the study, 7 were randomized to receive 3 rounds of oral visual screening by HWs at 3-year intervals and 6 to a control group which received usual health care. Eligible individuals in the control arm received health education on oral cancer prevention; for the purpose of this paper they have been excluded from the analysis. The study protocol was reviewed and approved by the scientific and ethical review committees of the RCC and IARC.

### 2.1. Service delivery strategy

The service delivery strategy included trained project staffing; house visits and personal contact with eligible subjects; providing locally adapted health education; pre and post-screening/treatment counseling; and free screening and subsidized treatment.

### 2.2. Screening organization and clinical protocol

Eligible subjects were healthy persons aged 35 years and above, with no history of oral cancer, living in the study clusters. They were identified by HWs during a first house

visit, in which data on socio-demographic characteristics and personal habits (tobacco chewing and/or smoking, and alcohol) of each household member were collected using a household form. Eligible individuals were screened during subsequent house visits by HWs. If the eligible person was not at home during the first visit, HWs re-visited the house to contact him/her at least two times. The HWs fully explained the study to all subjects, and a written informed consent was obtained. The harmful aspects of tobacco/alcohol use were explained, with particular emphasis on the importance of prevention.

Visual inspection was performed in bright daylight with the help of a flashlight. Findings were recorded as normal, non-referable, or referable lesions (suggestive of precancerous lesions or cancer). Screen positivity was defined as the presence of one or more referable lesions. HWs personally visited individuals with oral precancerous lesions and cancers to explain the diagnostic results and referred them for physician's confirmation, necessary investigations and treatment in the RCC and other tertiary care centers in the region.

### 2.3. Statistical analysis

Data were entered in D-Base and analysed using STATA 8.0 software package. Analysis was based on intention-to-treat, i.e. all eligible subjects were considered irrespective of their participation in the interview or the screening. Socio-demographic variables included in the analysis were: age, sex, household size, type of housing, socio-economic level, presence of television/radio, high-risk habit, and screening findings. Socio-economic level was measured through the household belongings, which were combined to make up an index with three levels: high (included all measured items, i.e., car, washing machine, geyser, gas cooker, refrigerator, phone, scooter, bicycle, TV/radio); middle (included all measured items except car, washing machine and geyser); and low (included all measured items except car, washing machine, geyser, gas cooker, refrigerator, phone and scooter). Type of housing was also used as a measure of socio-economic status, with thatched or tiled hut, tiled pucca and concrete houses corresponding to the low, middle and higher socio-economic status groups, respectively. Education level was included in the analysis of determinants of compliance with referral; however, information was not available for non-screened, and, therefore, we were not able to include that variable in the analysis of determinants of participation in screening.

Participation in screening and compliance with referral were calculated as proportions, from the date of study entry of the individual to 31 December 2004 or death. Univariate and stepwise multivariate logistic regression analysis were used to evaluate the effects of socio-demographic characteristics of eligible individuals on participation in screening and compliance with referral by estimating odds ratios (OR) and their 95% confidence intervals. All variables

included in the univariate analysis were entered in the multivariate model. The model used an entry criterion of  $p = 0.05$  and removal criterion of  $p = 0.051$  to calculate adjusted ORs. Variables that did not fulfill these criteria were removed from the model.

### 3. Results

Table 1 shows socio-demographic characteristics of the 96,517 eligible individuals in the intervention group: 43.0% were men, 81.3% had a low socio-economic level, 42.4% lived in the poorest type of house (thatched or tiled hut), and 40.5% had no television or radio. Mean age was 49 years. Of the overall population, 28.9% were smokers, 28.1% chewed pan tobacco, and 18.8% were alcohol drinkers.

Of the total number eligible, 87,655 (90.8%) were screened with oral visual inspection. Among non-partici-

pants, 8688 (98.0%) were not screened because they were not at home during the visit by HWs; 174 (2.0%) refused screening.

Socio-demographic determinants of participation in screening are given in Table 2. Age, sex, size of household, type of housing, socio-economic level, having television/radio, and risk habits emerged as independent predictors of participation in screening. Women, individuals living in better quality housing, belonging to small households, with television/radio, and those who had risk habits were more likely to be screened. A higher proportion of screened individuals were older than 44, but being 65 and older decreased the chances of screening.

Of the 5143 screen-positive individuals, 3214 (62.5%) complied with referral procedures (Table 3). Age, type of housing, socio-economic level, education level and type of lesion emerged as independent predictors of compliance with referral. Middle-age, older subjects, and those with more advanced lesions, were more likely to comply with referral procedures. Those living in concrete houses (indicator of higher income) had lower probability of compliance. Belonging to the middle socio-economic and education categories increased probability of compliance with referral. Having one risk habit or both did not increase probability of compliance with referral.

### 4. Discussion

This study is the first to examine the socio-demographic determinants of participation and compliance with referral in oral cancer screening in a large, population-based program proven to be effective in reducing mortality from oral cancer in high-risk individuals. We succeeded in achieving a highly satisfactory level of screening uptake (91%), and if we only consider individuals to whom screening was actually offered, the level of acceptance was almost 100%. This finding is very exciting because it demonstrates that high participation rates can be obtained in developing countries in oral cancer screening programs. Barriers to cancer screening include absence of knowledge about the disease, lack of familiarity with the concept of prevention, geographic and economic inaccessibility of health care, poor quality of services, and lack of support from families and communities [14]. The core components of our service delivery strategy were aimed at reducing those barriers: face-to-face invitations, screening during house visits by trained HWs recruited locally, screening provided free of charge and provision of appropriate education and information about the illness and the role of prevention. Our results underscore the importance of using service delivery strategies that are socially and culturally appropriate to assure adequate levels of participation.

The vast majority of unscreened individuals were not screened because they were not at home at the time of the house visits by HWs. Thus, predictors of screening uptake

Table 1  
Characteristics of subjects in the intervention arm

Characteristic	Intervention group	%
Overall	96,517	100.0
Age group		
35–44	45,651	47.3
45–54	21,298	22.0
55–64	14,640	15.2
65+	14,928	15.5
Mean (S.D.)	49	(13.1)
Sex		
Male	41,540	43.0
Female	54,977	57.0
Household size		
1–3	20,741	21.5
4–6	60,056	62.2
7+	15,720	16.3
Type of house		
Thatched and tiled hut	40,886	42.4
Tiled pucca	26,517	27.5
Concrete	29,114	30.1
Socio-economic level		
Low	78,434	81.3
Middle	13,489	14.0
High	4594	4.7
TV/radio		
No	39,085	40.5
Yes	57,432	59.5
Chewing habit		
No	69,382	71.9
Yes	27,135	28.1
Smoking habit		
No	68,667	71.1
Yes	27,850	28.9
Alcohol habit		
No	78,338	81.2
Yes	18,179	18.8

Table 2  
Predictors of participation in oral screening: results of univariate and multivariate logistic regression analysis

	Eligible (% participated)	Univariate analysis		Multivariate analysis	
		OR (95% CI)	<i>p</i> -Value	OR (95% CI)	<i>p</i> -Value
Overall	96,517 (90.7)				
Age group					
35–44	45,651 (91.1)	1			
45–54	21,298 (92.6)	1.23 (1.16–1.31)	<0.001	1.18 (1.11–1.25)	<0.001
55–64	14,640 (95.1)	1.89 (1.74–2.05)	<0.001	1.76 (1.62–1.91)	<0.001
65+	14,928 (82.3)	0.46 (0.43–0.48)	<0.001	0.39 (0.37–0.42)	<0.001
Sex					
Male	41,539 (85.6)	1			
Female	54,977 (94.5)	2.88 (2.75–3.01)	<0.001	4.51 (4.28–4.75)	<0.001
Household size					
1–3	20,741 (91.5)	1			
4–6	60,055 (90.9)	0.92 (0.87–0.97)	<0.005	0.88 (0.83–0.93)	<0.001
7+	15,720 (88.7)	0.73 (0.68–0.78)	<0.001	0.73 (0.68–0.78)	<0.001
Type of housing					
Thatched/tiled	40,886 (89.6)	1			
Tiled pucca	26,517 (90.8)	1.14 (1.08–1.20)	<0.001	1.11 (1.05–1.18)	<0.001
Concrete	29,114 (92.1)	1.35 (1.28–1.43)	<0.001	1.35 (1.25–1.41)	<0.001
Socio-economic level					
Low	78,434 (90.2)	1			
Middle	13,489 (92.8)	1.40 (1.30–1.50)	<0.001	1.12 (1.03–1.21)	<0.001
High	4594 (92.6)	1.36 (1.21–1.52)	<0.001	1.06 (0.93–1.20)	0.387
TV/radio					
No	39,085 (88.6)	1			
Yes	57,432 (92.1)	1.50 (1.44–1.57)	<0.001	1.50 (1.43–1.58)	<0.001
Risk habits					
No	50,725 (91.0)	1			
Tobacco only	27,613 (89.8)	0.87 (0.83–0.92)	<0.001	1.58 (1.49–1.67)	<0.001
Alcohol only	1550 (92.8)	1.27 (1.05–1.54)	0.016	3.02 (2.48–3.69)	<0.001
Tobacco and alcohol	16,929 (90.8)	0.98 (0.92–1.04)	0.460	2.75 (2.57–2.95)	<0.001

describe the profile of the population to whom HWs were able to offer screening.

Being a woman was the most important predictor of screening uptake. This is consistent with reported experiences in Sri Lanka, where screening was provided during house visits [15]. This may be explained by the fact that women in these areas are usually in charge of house work, and, therefore, are more likely to be home during the house visit. In order to assure maximum coverage among men, adequacy of screening schedules to the main occupational patterns of the area where screening is to be implemented should be assured. Time schedules might also be an explanatory factor of the lower participation found among individuals with low socio-economic level, who in this area are mainly engaged in fishing or farming activities that keep them away from home until late at night.

Interestingly, increasing age was positively related to screening uptake, except for the category corresponding to the older age group (65+). Nagao and Warnakulasuriya, who analysed socio-demographic determinants of oral screening re-attendance in Japan, also noted similar age differences in participation [12].

Having one or both risk behaviours was strongly associated with screening uptake. Information collected through the household survey allowed HWs to be aware of the risk status of each household member, even of those not at home during the first visit. Therefore, an additional effort by HWs to re-contact persons at risk might explain the increased screening of these groups. As the reduction in oral cancer mortality was demonstrated for high-risk groups [6], their higher participation must have contributed to the success of the programme.

Having television or radio was associated with increased participation after controlling for socio-demographic factors. The exact mechanism whereby mass media might have affected participation is not clear, especially because no oral cancer prevention messages were diffused through radio or TV. However, research has shown that, by exposing people to alternative lifestyles and values, mass media can promote behaviours that are consistent with health prevention models, and therefore, they can have an impact even in the absence of specific campaigns [16]. Our finding suggests that reinforcing screening campaigns with information spots in mass media might further increase screening uptake.

Table 3  
Predictors of compliance with referral procedures: results of univariate and multivariate logistic regression analysis

	Eligible (% complied)	Univariate analysis		Multivariate analysis	
		OR (95% CI)	<i>p</i> -Value	OR (95% CI)	<i>p</i> -Value
Overall	5143 (62.5)				
Age group					
35–44	1313 (55.1)	1			
45–54	1559 (63.3)	1.40 (1.21–1.63)	<0.001	1.38 (1.19–1.61)	<0.001
55–64	1428 (67.3)	1.68 (1.44–1.96)	<0.001	1.60 (1.36–1.87)	<0.001
65+	843 (64.8)	1.50 (1.26–1.79)	<0.001	1.37 (1.14–1.66)	<0.001
Sex					
Male	2674 (60.0)	1			
Female	2469 (65.3)	1.26 (1.12–1.41)	<0.001		
Household size					
1–3	1014 (64.5)	1			
4–6	2991 (61.1)	0.87 (0.75–1.00)	0.055		
7+	1138 (64.5)	1.00 (0.84–1.19)	0.999		
Type of housing					
Thatched/tiled	2957 (62.0)	1			
Tiled pucca	1426 (64.5)	1.11 (0.97–1.27)	0.115	1.08 (0.94–1.23)	
Concrete	760 (61.1)	0.96 (0.82–1.13)	0.636	0.79 (0.65–0.95)	0.050
Socio-economic level					
Low	4699 (61.9)	1			
Middle	338 (68.9)	1.37 (1.08–1.73)	0.010	1.49 (1.14–1.95)	0.003
High	106 (69.8)	1.42 (0.94–2.16)	0.099	1.55 (1.00–2.42)	0.052
TV/radio					
No	2203 (60.2)	1			
Yes	2940 (64.3)	1.19 (1.07–1.34)	<0.005		
Education level					
None	2173 (62.0)	1			
Primary	1270 (63.4)	1.06 (0.92–1.22)	0.429	1.11 (0.96–1.29)	
Secondary	835 (65.2)	1.14 (0.97–1.35)	0.113	1.22 (1.07–1.52)	0.006
College and +	865 (60.0)	0.92 (0.78–1.08)	0.299	1.06 (0.88–1.27)	
Risk habits					
No	280 (63.29)	1			
Tobacco only	3043 (65.1)	1.09 (0.84–1.40)	0.527		
Alcohol only	15 (66.7)	1.16 (0.39–3.50)	0.787		
Tobacco and alcohol	1805 (58.1)	0.81 (0.62–1.05)	0.104		
Screening findings					
Homogeneous leuk.	2191 (56.8)	1			
Non-homogeneous leuk.	1890 (65.5)	1.45 (1.27–1.64)	<0.001	1.45 (1.28–1.65)	<0.001
Submucous fibrosis	732 (68.0)	1.62 (1.36–1.93)	<0.001	1.49 (1.24–1.79)	<0.001
Susp ulcer	330 (71.5)	1.91 (1.48–2.46)	<0.001	1.90 (1.46–2.47)	<0.001

The effectiveness of a screening programme depends not only on the level of acceptance of the test, but also on adequate compliance with follow-up procedures. However, the level of reported compliance has varied widely in developing countries, ranging from 34% to 72% [3,17–20]. In our study, 63% of the screen-positive subjects complied with referral for confirmatory examination. This result is similar to that reported in Sri Lanka [20], with 62% of the population prescribed with follow-up examinations presenting for confirmatory diagnosis. A previous study, also in Sri Lanka, reported that 54% of those needing follow-up procedures complied with referral [19]. In that study, postal reminders were sent to those of the population who did not show up for follow-up, and subsequent field visits were

arranged to contact those who had not responded to the reminder. Although postal reminders increased the level of compliance by 11%, their utilization in developing settings is not always feasible due to the inadequacy of postal systems. A somewhat similar screening project carried out in a nearby area in Kerala, India, also reported an increase in compliance with referral due to postal reminders (from 67% to 72%) [17]. Our study indicates that adequate levels of compliance with referral can be obtained even in the absence of postal reminders.

Increasing age was associated with higher compliance with referral. A similar pattern was reported by Yabroff et al. [21], in a study of determinants of completion of follow-up after abnormal mammograms. For these authors, differences

in relation to physician communication and recommendation efforts might explain the reduced compliance in younger groups. Following their line of reasoning, HWs might be less inclined to strongly recommend diagnostic follow-up to subjects younger than 45, in whom oral cancer incidence is low. It is difficult to determine to what extent in our project reduced non-compliance with referral in younger age groups is due to inadequate communication by health workers. We have discussed above the role of HWs efforts to assure screening of subjects at risk. The fact that compliance with referral was increased for more severe lesions strengthens this hypothesis of the important role of HW persuasiveness, a finding similar to that one reported by Warnakulasuriya et al. [19].

Persons living in thatched/tile houses, belonging to the low socio-economic group and with low levels of education were less likely to comply with referral, indicating that socio-economic barriers might be limiting their access to follow-up care. Interestingly, our results also showed that individuals living in concrete houses – an indicator of high income – were also less likely to comply with referral. Evidence has shown that higher income groups have higher access to cancer screening due to reduced socio-economic barriers [9]. Our results indicate that high-income groups can also have reduced chances of compliance with follow-up, even if this is probably due to different reasons. The utilization of government health services by high-income groups is quite low in India, as they prefer paid, private health services [22,23]. One major reason for this is the overcrowding of government health services. Thus, the fact that confirmatory diagnosis was carried out in public health institutions may have deterred higher income groups from complying with referral. Sankaranarayanan et al. [24] reported similar differences in their study of determinants of participation in cervical cancer screening in rural India.

Our study has certainly some limitations. First, it was not possible to measure the effect of education on participation as this information was only available for screened individuals. As the level of education has been reported to influence participation in screening [24–26], we might have missed an important explanatory factor. Secondly, we were not able to measure compliance with treatment, and socio-demographic determinants of compliance with treatment can be different from those of compliance with referral.

In conclusion, this study shows that oral cancer screening programmes with adequate coverage can be implemented in low-resource settings using a simple, low-cost visual inspection test that can be provided by HWs. To further increase coverage, strategies should be developed to contact individuals that are absent during house visits. For example, the feasibility of screening schedules that are compatible with the working hours of the target population should be considered. HWs should stress the importance of compliance with referral among

young subjects, among those from the higher economic level group and among those diagnosed with homogeneous leucoplakia. Finally, the fact that adequate coverage was also obtained by cervical cancer screening carried out in rural India using visual inspection by nurses [24] indicates that there is a real public health opportunity to implement effective preventive actions for two of the tumours that account for the majority of cancer deaths in developing countries. The feasibility of a prevention strategy that integrates screening of both tumours should be considered.

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### Conflict of interest

None declared.

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