



Spreading the word about mouth cancer

Topic:

Cancer

Organisation:

West of Scotland Cancer Awareness Project

Location:

West of Scotland

Dates:

2003 to 2004

Budget:

£396,000

Contact:

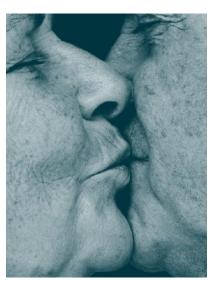
Lisa Cohen

Email:

lisa@xl-communications.co.uk

Telephone:

0141 571 8608



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Overview

The West of Scotland Cancer Awareness Project was a multi-component, early cancer detection campaign aimed at encouraging atrisk populations living in the West of Scotland to present earlier to the NHS if experiencing the signs and symptoms of oral cancer.

The campaign included: mass media communications; training for professionals (doctors, dentists and pharmacists); improved referral pathways for patients so that access to a clinic was guaranteed within two weeks, with high risk cases usually being seen within a week; additional clinics to meet demand at all the main hospital sites; local community-based open access clinics for a free mouth check; and local health promotion publicity events.

Results:

- The campaign raised awareness of mouth cancer, improved knowledge and understanding of symptoms and encouraged people from a 'hard to reach' audience to see their dentist, doctor or pharmacist if concerned about symptoms
- At rapid access clinics, of 34 patients identified with malignant conditions, 9 were detected as a direct result of the campaign; of 53 patients identified with potentially malignant conditions, 18 were detected as a direct result of the campaign



Mouth cancer is defined as cancers of the lip, tongue, oral cavity, oropharynx, hypopharynx and piriform sinus. In the UK, there were 5,300 cases of mouth cancer in 2006, and across the UK the highest incidence (for both males and females) is in Scotland, where over 600 people are affected by mouth cancer each year.

Unfortunately, a high proportion of patients first present with late-stage tumours, making treatment and management complex and significantly increasing morbidity. Although a debilitating disease, it can be treated successfully if it is detected early and survival rates could improve by over 30 per cent. Research has found a clear link between smoking, heavy drinking and deprivation and the onset of mouth cancer. In addition, mouth cancer is more common in men than women, and the risk of developing the cancer increases with age.

Street surveys conducted by Market Research UK in 2001 with 1,000 respondents showed a low (unprompted) awareness (6 per cent) of mouth cancer among the West of Scotland population, and 54 per cent were unable to name a single symptom.

In 2002, the West of Scotland Cancer Awareness Project (WoSCAP) was funded with £1.3 million by the New Opportunities Fund (now The Big Lottery Fund) to run two cancer campaigns, one on mouth cancer and one on bowel cancer. The mouth cancer campaign had a budget of £300,000, which covered production, media, training, support materials and the launch event. An additional £96,000 was spent on formative research, pre-testing, tracking and evaluation.



Delivery team

The project was governed by a steering group, which included representatives from:

- NHS Health Scotland, five participating West of Scotland NHS boards (Argyll and Clyde; Ayrshire and Arran; Forth Valley Greater Glasgow; and Lanarkshire)
- Regional Cancer Advisory Group (West of Scotland Cancer Network)
- Representatives and health professionals providing primary and secondary care services
- Health promotion and public health teams
- Department of General Practice and Primary Care at Glasgow University
- Tak Tent Cancer Support

An oral cancer sub-group of the WoSCAP steering group was set up to guide the implementation and development of the campaign and included representatives from primary and secondary care, public health and members of the project team.

The Institute for Social Marketing (ISM) at the University of Stirling (formerly the Centre for Social Marketing) was also commissioned to conduct formative research to guide the campaign's development, and evaluative research to monitor the campaign's impact.

Local Implementation Teams (LITs) were set up in each NHS Board area to develop and implement local campaign initiatives, training and a communications strategy. The LITs consisted of representatives from primary care, the acute services and other local organisations.



Behavioural goals

Primary goal

To encourage the at-risk population living in the West of Scotland to present earlier to the NHS (namely to doctors, dentists and pharmacists) if they exhibit the signs and symptoms of mouth cancer.

Secondary goals

- To raise awareness of mouth cancer and the importance of early detection
- To ensure that people know what signs and symptoms to look out for and what action to take if they find something

Segmentation

Primary audience

- Individuals aged 45 and above 90 per cent of mouth cancer cases in the West of Scotland are detected in people aged 45 and over
- Particularly men
- Smoke and drink heavily These behaviours are associated with incidences of mouth cancer
- Reside in lower socioeconomic areas
 (deprivation categories 4 to 7) These
 individuals experience the burden of illness
 and are more likely to smoke and consume
 excessive levels of alcohol and have less
 contact with primary care services

Secondary audience

 Health professionals – To ensure they were aware of the campaign prior to the public launch and to ensure any additional demand created by the campaign could be met

Secondary research

A literature review was conducted by the ISM, with three specific objectives:

- To examine public awareness and perceptions of mouth cancer, including attitudes towards presenting for screening with signs and symptoms and the factors associated with presenting
- 2. To review evidence of the paid and unpaid media's role in promoting cancer awareness and early detection, and to identify principles of effective media activity
- To describe and review specific oral cancer campaigns and to identify relevant lessons for the WoSCAP campaign

Primary research

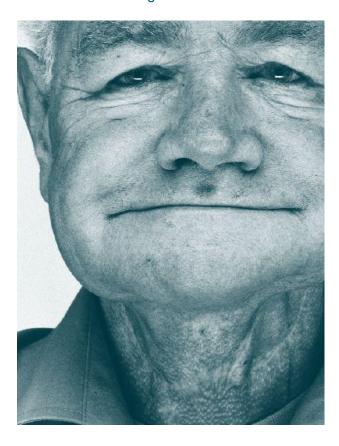
An exploratory study with members of the target audience was carried out to:

- Examine consumer awareness and perceptions of mouth cancer, and assess understanding and response to early signs and symptoms of mouth cancer
- Inform the communications strategy
- Complement the literature review and together inform the advertising brief
- Assist in defining the content and measures for the evaluation tracking study

Eight focus groups were conducted with a total of 57 participants. Participants were selection based on age (40 to 55 years; 56 to 70 years), gender, socioeconomic groups (C1/C2; DE), and location (urban; rural).

To ensure the sample represented those population groups at greater risk due to lifestyle factors, all respondents were smokers, drank over the recommended limit of alcohol and

consumed less than the daily recommended intake of fruit and vegetables.



Insights

- Spontaneous awareness of cancer focuses most commonly on breast, lung, prostate and skin cancers, with bowel, cervix, throat, pancreas and testicular cancer mentioned less frequently
- Amongst the target audience, low awareness is equated with low prevalence – mouth cancer was not on their minds as a potential threat
- Entrenched cultural attitudes lead the target audience (particularly men from more rural communities) to regard frontline health professionals as a last resort, only visited when compelled to, typically as a consequence of pain and discomfort or inability to work
- Considerable reluctance in confronting the issue of cancer – While some individuals endorsed the idea of early cancer detection and expressed intentions to seek help if concerned, others rejected early cancer

detection on the grounds that cancer could not be cured and it was therefore better not to know until the condition was obvious

"They can treat it, if you are quick enough in catching it yourself. It's having the guts to go up to the doctor and say, 'Look, I think this is wrong with me'." (Male focus group participant aged 40 to 55)

"I would rather not know. If it happens it happens." (Female focus group participant aged 56 to 70)

Importantly, some individuals held both views simultaneously. Whilst keen to advise others to go forward with symptoms, many would be much more hesitant to do so themselves:

"I would advise them [friends] to go to the doctor but when it comes to yourself, it's different." (Female focus group participant aged 56 to 70)

A range of attitudinal and practical barriers prevented the target audience from presenting to the NHS with early signs and symptoms of mouth cancer:

- Fear of dentists and doctors
- Fear of cancer diagnosis
- Fatalistic attitudes regarding cancer
- Fear of the unknown
- Complacency or apathy
- Lack of awareness and knowledge of mouth cancer and its signs and symptoms – Most individuals were surprised and in some cases rather anxious that early signs and symptoms of mouth cancer appear to be fairly innocuous 'everyday' conditions, such as a mouth ulcer that does not go away
- Fear of 'wasting' doctor's time
- Cost of dental examinations and process of registering with a dentist – Few participants regularly attended dental checks, particularly those with dentures, and amongst those with low incomes this was largely due to the cost

Competition

People claimed to be too busy to attend clinics for symptoms perceived to be minor and were more likely to discuss symptoms with friends, family or co-workers.

Pretesting

Formative research also focused on pretesting the most appropriate creative concepts to be used in the campaign. A further six focus groups were conducted, with all participants meeting the pre-determined selection criteria outlined above.

Specific research objectives included to:

- Assess each creative route in terms of popularity and level of fit with the needs of the campaign
- Evaluate communication of key campaign messages
- Assess ability to elicit an appropriate behavioural response
- Evaluate ability to open up critical discussion and debate

Insights from the pretesting included:

Survivor testimonies

Credible and emotive stories of real people who had survived cancer were found to have the most impact, because they provided a compelling way of linking the symptoms with the health consequences. They challenged the fatalism around cancer and gave hope to people with symptoms, while establishing the importance of getting help early.

Careful use of humour

Given the resistance to presenting to an NHS professional, messages that offered reassurance and confidence were likely to be most beneficial. Consequently, fear appeals were likely to be unsuccessful. However, careful use of humour and personal testimonies were thought to ameliorate any underlying fears and help to normalise the desired behaviour by giving the campaign a human face.



Defensiveness about drinking and smoking
Health professionals directing patients to stop
smoking and reduce alcohol consumption
would put off the target audience and was likely
be unsuccessful. Many members of the target
population avoided doctors because they
feared they would be reprimanded and
instructed to stop smoking.

A high level of defensiveness existed about poor health behaviours, especially smoking, and considerable skill was apparent in deflecting any messages intended to challenge the behaviours. This indicated that messages relating to these health risks may lead to key target groups ignoring the campaign altogether. It was therefore crucial that the key messages of the campaign focused on early detection as opposed to prevention.

Dentists not linked to cancer detection

Dentists were not readily associated with
cancer detection, so promoting them as a route
for presenting symptoms might have been
resisted by low income groups. Additionally,
only 41 per cent of people living in lower social
classes were registered with a dentist in
Scotland at that time. GPs (who have less
expertise in mouth cancer) were generally seen
as the first point of contact.

Friends and family

In addition to professional sources of advice, lay advice was an important part of the process of coming forward with potential symptoms. Consulting friends or family helped people decide whether going to a health professional was worthwhile and also generated support in doing so. Men, however, were more inclined to self-treat symptoms and more reluctant to consult professionals or discuss health concerns with family or friends than women.



The project team developed a fully integrated marketing mix, incorporating a high-profile media awareness campaign, training for healthcare professionals, and improved access to services.

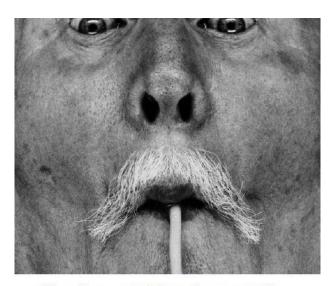
Communications campaign

The media awareness campaign sought to improve the target population's general knowledge of mouth cancer and specifically communicate the importance of early detection. The campaign also aimed to reassure individuals about the treatment success rate of mouth cancers detected early, and encouraged individuals to visit a health professional even if in doubt of the seriousness of symptoms.

Communications activity included:

- A 40-second television and radio campaign that ran in 2 phases over 5 weeks – the first phase ran during October to November 2003, the second from February to March 2004. These adverts shared personal stories from cancer survivors and provided information on signs and symptoms and where to present if worried
- Direct mail shots to selected postcode areas featuring a promotional competition

- A mobile photographic exhibition called 'Celebration of the Mouth' visited selected venues in each area, such as health centres, shopping centres and libraries
- Posters and leaflets distributed via primary care and community venues
- Extensive media coverage on TV, radio, local and national press
- Local promotional events that incorporated free mouth checks by community dental services



We take many things for granted. Don't let mouth cancer take them away.



Promotional competition

- Competition materials provided contestants with information on mouth cancer and contestants answered five true or false questions for a chance to win prizes
- The campaign partnered with Semi Chem, a health and beauty product supplier, to provide winners with gift vouchers or electric toothbrushes
- Pre-paid postage was provided on competition entry cards

1,923 responses entries to the competition were received



Mouth Cancer... Know the facts



Training for health professionals

Every medical and dental practitioner and pharmacist was invited to 1 of 25 training sessions held across West of Scotland and delivered by 20 oral, plastic and maxillofacial specialists from the West of Scotland. Overall 1,280 health professionals attended the training between September and November 2003. Seminars familiarised healthcare professionals with the campaign and aimed to raise awareness about oral cancer issues, including:

- The epidemiology of mouth cancer
- Risk factors
- Signs and symptoms
- Referral pathways, protocols and how to fast-track patients
- Examinations for diagnosing oral cancer
- Treatment and staging of oral cancer

Sessions involved a range of individuals and organisations, specifically:

- WoSCAP
- NHS Education for Scotland (NES) Medical, Dental and Pharmacy
- Specialists in oral cancer working in a clinical or public health setting
- Local Health Care Co-operatives (LHCCs)
- Health promotion departments

Improved access to health services

Referral pathways were improved by clarifying access points and routes of referral. GPs and dentists were updated on referral processes for patients presenting with varying mouth complaints, including:

- Which specialists to refer patients to (such as Maxillofacial Surgery or Oral Medicine)
- How (by telephone, fax, written or email) and under what circumstances to issue 'rapid', 'soon' or 'routine' referrals in response to presentation symptoms
- Essential details to include in referrals

Additional clinics were set up to accommodate increased demand for appointments. Since in the poorest communities in the West of Scotland only 41 per cent of the population were registered with a dentist, it was important to provide people with alternative options of where to present with symptoms.

Subsequently, in areas where registration with a dentist was particularly low, people were provided with alternative professionals (namely doctors and pharmacists) to present with symptoms. NHS Greater Glasgow also offered financial incentives for dentists to provide a free mouth check for patients who were not registered with the practice when the campaign was live. Individuals could self-refer themselves for a free mouth check.



The campaign was launched on 23 October 2003 at a ministerial event held in Glasgow. It received wide media coverage in local, regional and national press, and was covered by the BBC, Scottish Television and national radio stations.



You've checked your lippy.
Have you checked for mouth cancer?



The television and radio adverts were highly successful and were seen to be vital in encouraging people to get checked if they had a persistent 'everyday' ailment, such as a mouth ulcer. One person who took action as a result of the adverts was Jim Baillie, who saw

the TV adverts several times in November 2003:

"I'd had a mouth ulcer for three or four weeks that wasn't clearing up. I wasn't really in any pain or discomfort and just thought it was my tooth rubbing against my tongue, but when I saw the advert, I thought I'd better see someone about it sharpish!"

Shortly afterwards, Jim was diagnosed with mouth cancer, but thanks to catching the cancer early, he did not need to have radiography and is now getting on with life as normal:

"If I hadn't seen that advert, I might have left it for a couple of months. By then it might have been too late. The chaps that made that advert, I mean, I owe them everything. Without a doubt, this campaign and the excellent treatment I received at the Southern General Hospital is responsible for saving my life".

Through the LITs, efforts were made to link the broader campaign to on-the-ground activities and existing local programmes, for example by engaging local media and community dentists and tapping into local road shows and events. In particular the mobile photographic exhibition, 'A Celebration of the Mouth', was beneficial for creating a focus for local events. However, the work of LITs was sometimes limited, as there were some difficulties mobilising community work in certain areas, such as in Glasgow where no localised work was conducted.



The campaign was evaluated via three main studies:

- 1. The ISM conducted pre- and post-campaign research. The research took place in the campaign area (583 interviews in West Scotland) and in a control area (351 interviews in East Scotland) and took the form of semi-structured in-home interviews. The sample reflected the age and social class of the key target group for the campaign. A baseline was taken in July to August 2003 before the campaign launch, with the follow-up in March to April 2004
- A postal survey of responses to the campaign by General Dental Practitioners (GDPs), generating 674 responses (69 per cent response rate)
- 3. A survey of patients attending rapid access clinics (with 538 responses over a 6-week period)

Key results

- 83 per cent of members of the public who were questioned recognised the TV advert and felt that it was easy to understand and provided helpful advice
- Spontaneous awareness of mouth cancer increased from 12 per cent to 16 per cent, and spontaneous awareness of the majority of other cancers diminished in the follow-up study
- Awareness of symptoms of mouth ulcers in the campaign area increased from 34 per cent to 46 per cent, sores from 9 per cent to 14 per cent and persistent symptoms from 5 per cent to 18 per cent, while in the control area knowledge remained the same
- GDPs saw an increase in the number of registered and non-registered patients seeking advice about the campaign (over 66 per cent and 40 per cent respectively)
- Over 92 per cent of GDPs in the West of Scotland were aware of the campaign and 60 per cent of those dentists referred patients to secondary care during the campaign
- Referrals to rapid access clinics increased across the West of Scotland following the

- launch of the campaign (increases in referral activity varied across NHS Boards)
- From a survey of 538 patients attending rapid access clinics across the West of Scotland, 64 per cent said they had recently seen or heard of a mouth cancer campaign and of those people, 68 per cent sought advice sooner due to the publicity
- Patients attending the rapid access clinics highlighted that they initially consulted their doctor rather than a dentist (59 per cent versus 29 per cent respectively)
- The initial (provisional) diagnosis of patients attending the rapid access clinics showed that patients with malignant and potentially malignant conditions were coming forward as a direct result of seeing the campaign
- Of 34 patients identified with malignant conditions, 9 were detected as a direct result of the campaign; of 53 patients with potentially malignant conditions, 18 were detected as a direct result of the campaign

"For the first time patients are asking questions relating to oral cancer before I examine them." (Dentist)



Once the campaign was complete it was formally reviewed by the New Opportunities Fund (Big Lottery Fund). In addition, an event was run with all key stakeholders to share what had been done, what had been achieved and to demonstrate the project's impact.

Unfortunately funding for the campaign has not been continued by the Scottish Government. Nevertheless, learning and results from the campaign have been published and shared widely, including in the British Medical Journal, the British Dental Journal, and in the book

Social marketing: why should the Devil have all the best tunes?.



The campaign has also received a number of awards, including:

- Association of Healthcare Communicators: Best Campaign for Inequalities in Public Health. 2004
- Scottish IPA Effectiveness Awards: Silver, 2005
- UK IPA Effectiveness Awards: Silver, 2005
- UK Best of Health Awards: Oral Cancer Resources – Bronze, 2005
- Royal Society of Medicine: British
 Association of Head and Neck Oncologists
 Conference, prize for oral cancer campaign presentation poster, 2005

Lessons learned

Define the problem you are seeking to address

Start with research to help define the scale of the problem you are seeking to address, and be realistic about what you can expect to achieve from the baseline information, considering the resources and time you have to commit to the intervention.

Create a clear vision for your work

Take time to plan the vision and avoid being forced to 'go public' too soon. For WoSCAP, this meant that the first campaign was launched a full year into the project.

Develop comprehensive objectives and ensure you have relevant indicators to measure impact

Objectives have to be clear and realistic, and reviewed regularly to keep operational delivery of the work focused. Then be sure to evaluate on the behavioural goals that were actually set at the start.

Involve key stakeholders at an early stage

Develop positive relationships with key partners to gain confidence and credibility. Aim to gain a 'win-win' solution when negotiating parameters and to keep them on board, and let key partners have some ownership of your activities. This campaign had a database of 3,500 health professionals who were regularly kept informed about activities and progress.

"It's about getting the right stakeholders at a senior enough level. Get the decision makers involved, you need them to help drive things through." (Lisa Cohen, XL Communications)

Get the right team involved

Ensure the team members have the right range of skills to plan, deliver and evaluate the intervention, and that individual members of the team have a clear role and remit.

Ensure campaigns are research driven, not expert led

Start where the target group are, not where professionals think they should be. If you fail to do this, you risk the audience switching off to your message. Gather insights and understanding about the target group's knowledge, perception and attitudes towards the issue you are seeking to address, and then pretest campaign materials. Audience reactions can often be surprising and quite different from a trained expert's view.

Create clear, consistent messages and deliver them via the most appropriate media Get experts to develop the core message, but then allow communications experts to translate them into a language and style that is jargon free, relevant and appropriate to the audience.

Evaluate and disseminate the results

Progress should be monitored through appropriate levels of investment in evaluation, and results and lessons learned should be disseminated widely.

