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Let's Talk about Mouth Cancer – The Story and the Facts

Abstract: *Let's Talk About Mouth Cancer* is a Scottish charity set up by a group of healthcare professionals with the aim of improving the prognosis of a patient diagnosed with mouth cancer. This article will present the charity's award winning oral health campaigns and the various methods used to empower patients with skills and knowledge to catch mouth cancer early. The social media platforms used in the campaign and the demographic engaged will be discussed, along with the knowledge of mouth cancer signs, symptoms, risk factors and current practice of self-examination in Scotland.

CPD/Clinical Relevance: The incidence of mouth cancer is on the rise in the UK. Dental care professionals in primary and secondary care should be aware of the barriers to early detection, and help to raise awareness of the disease.

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'The number of people being diagnosed with mouth cancer (oral cancer) is increasing, with notable rises in incidence in younger people and in females.'

So started the Joint Statement on Mouth Cancer Diagnosis and Prevention from the British Society for Oral Medicine (BSOM) and Cancer Research UK (CRUK) published in October 2013.^{1,2,3} This document was a rallying call to all dental and healthcare professionals to improve public and professional awareness of mouth cancer and to help institute better

preventive strategies, as well as earlier diagnosis and referral for treatment. Recently published CRUK data⁴ show a 92% rise in the incidence of mouth cancer in the UK since 1970; with incidence and mortality rates being significantly higher in Scotland. They also report that 2386 people died from mouth cancer in 2014, a 21% increase on the last decade. A team of five volunteers took on the challenge of the rallying call and, in 2014, formed the Scottish Incorporated Charitable Organization (SC045100) *Let's Talk About Mouth Cancer* (LTAMC), the main aims of which are outlined in Table 1. The work of the group takes a new innovative approach and, following initial campaigning in Edinburgh, the charity has a national profile in Scotland.

There are two aspects to the work of LTAMC; direct public engagement and professional education. The first public engagement events were held in Edinburgh during 2014:

- During February, centred around the University campus at Bristo Square.
- In June at the popular Edinburgh Canal Festival, a lively community engagement event.
- In August, on The Meadows, a popular recreation area in the centre of the city.

With the help of volunteer dentists, free mouth cancer screening was offered to passing members of the public. Additionally, dental therapy students from the University of Edinburgh and volunteers from the Minority Ethnic Health Inclusion Service helped raise publicity and direct the public to the screening sites. The screening proved popular with 727 people receiving a free mouth check with counselling on risk factors and early detection. The cost of providing such an intervention varied between £1 and £13 per intervention, depending on infrastructure. These campaigns were rewarded when two Trustees received the NHS Lothian Celebrating Success Awards Voluntary Service Award 2014 and, subsequently, a £5000 bursary from the Association of Dental Groups for the 'best voluntary scheme to promote and deliver improvements in oral health 2015'.

As LTAMC took its operations outside of Edinburgh, following advice from indemnity societies and a desire to remove the paternalistic element of screening in favour of patient empowerment, the focus changed from screening to teaching mouth self-examination for mouth cancer. Pop-up style public events held in Dundee (November 2015 and November 2016) in collaboration

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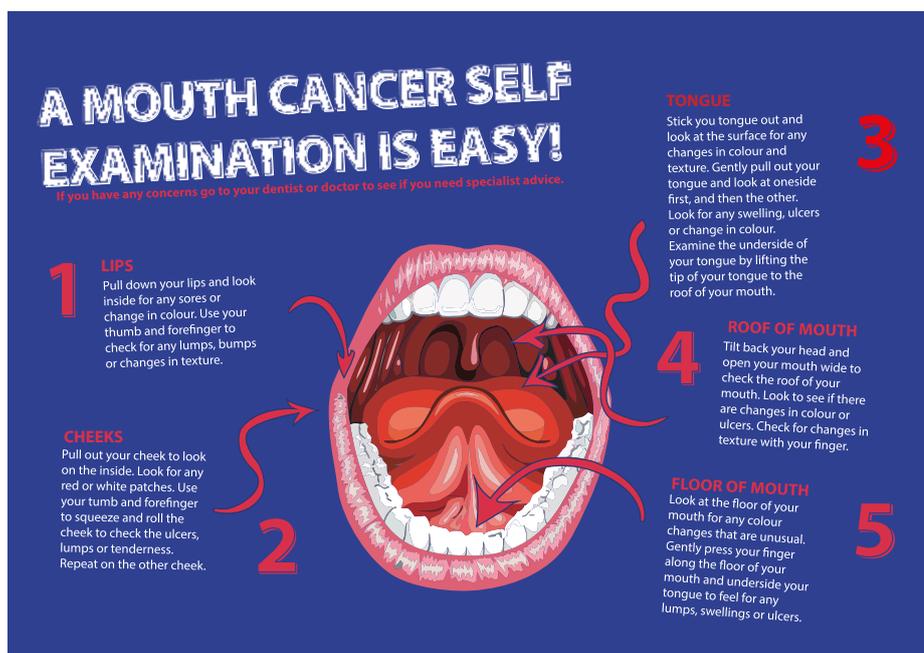


Figure 1. Five simple steps to undertake a mouth self-examination – taken from LTAMC leaflet.

1.	To improve the prognosis of a patient diagnosed with mouth cancer through early detection
2.	To support research into improving diagnostic tools
3.	To raise awareness of mouth cancer amongst the general public
4.	To share knowledge and good practice amongst healthcare professionals

Table 1. The stated aims of Let's Talk about Mouth Cancer.

Stage 1	A survey to assess the participant's knowledge of mouth cancer. This was completed using a tablet-based application called iForm
Stage 2	Educational component – facts, risk factors and signs and symptoms of mouth cancer were communicated with the use of resources, which included models, leaflets and interactive media displayed on tablets.
Stage 3	Mouth self-examination demonstration with the use of a mirror. All the information was reinforced with a campaign leaflet. The advice given was to make a habit of self-examination once a week.

Table 2. LTAMC empowerment journey – the components of an interaction between a volunteer and member of the public engaging with an LTAMC campaign.

with undergraduate dental students from the University of Dundee are now popular in the student curriculum. Additionally, in November 2016, the Dental A&E department at Dundee Dental Hospital collaborated with LTAMC for a

month to provide opportunistic interventions for mouth cancer counselling and instruction on mouth self-examination to all patients who presented. The delivery of interventions is formalized into three phases of what LTAMC

terms the 'empowerment journey' and is detailed in Table 2. The thorough, logical mouth self-examination process followed five simple steps and is demonstrated in Figure 1. The key messages are to check for: red or white patches; lumps in the mouth that grow; ulcers in the mouth that do not heal; and persistent soreness/discomfort. The advice is to attend the dentist or general medical practitioner if any of these signs/symptoms do not resolve in two weeks and to alert the practitioner to a concern about mouth cancer and hopefully remove any taboo about the discussion of mouth cancer..... let's talk about mouth cancer!

All events include local partners from the NHS, universities and community groups (Figure 2). Widespread coverage in national and local press (print, TV, radio and online) is helped in part by the invaluable work of LTAMC charity patron, former Scottish rugby and British Lion, Scott Hastings (Figure 3). LTAMC has its own website and is active with social media (YouTube, Facebook and Twitter).

Along with public engagement events, LTAMC's work involves education for healthcare professionals. The website and social media platforms have sections targeted towards healthcare professionals but the main aspect has been CPD lectures and undergraduate teaching. Feedback from the CPD lectures has always been positive, with attendants stating their increased confidence in counselling patients and examining for mouth cancer. Likewise the direct teaching of final year dental students from Dundee Dental School and dental therapy students in Edinburgh yielded very positive feedback and improved confidence.

In 2016, LTAMC achieved international recognition as one of the intellectual sponsors of the inaugural Global Oral Cancer Forum held in New York. At the forum in March 2016, LTAMC presented research data which has subsequently also been presented to the BSOM.

Using social media to promote health

The number of people using smartphones globally is now somewhere in the region of two billion. Many of those people are also interacting with social media. LTAMC quickly recognized that social media platforms could be a powerful way to share

Type of post	Average reach
Video	9,656
Photo	435
Status (text only)	160
Link (to external content)	110

Table 3. The success of different post types on Facebook.

Gender	N	%
Male	399	45.34
Female	475	53.98
Unanswered	6	0.68
Age	N	%
under 20	232	26.36
21–30	320	36.36
31–40	73	8.30
41–50	69	7.84
51–60	66	7.50
over 61	111	12.61
Unanswered	9	1.02
SIMD Quintile	N	%
1	81	9.20
2	142	16.14
3	143	16.25
4	137	15.57
5	255	28.98
Unanswered	119	13.52

Table 4. Demographics of sample (N = 880).

ideas and promote health.

The charity created pages on Facebook, Twitter and YouTube to share the work of LTAMC and to engage a wider audience than those interacting with the street campaigns. Each of the social media platforms enabled LTAMC to interact with a wide and varied demographic throughout the world.

Demographic of LTAMC’s social media followers

Using inbuilt analytics on social media platforms it is possible to establish

the demographics of users interacting with campaign pages. The information can be used to tailor and target health promotion messages. Facebook, Twitter and YouTube are social media platforms that allow people to connect and share ideas, thoughts, images, videos and countless other media.

The LTAMC Facebook page has a following of 697 Facebook users with 72% identifying as female and 28% as male. The vast majority of those interacting with online posts are aged 18–34 years old and 86% are in the UK. The remainder are from locations including India, Australia, USA, Egypt and Pakistan. Peak times when LTAMC followers use Facebook are 08:00, 13:00 and 21:00. The LTAMC Twitter account has a smaller following of 208 twitter users with 48% identifying as male and 52% as female.

Of the 19,254 views accumulated on LTAMC’s YouTube channel, 64% identified as male and 36% as female. The region with the highest number of views was in the USA, closely followed by the UK. Again the majority of those interacting were aged between 18–34 years and the majority of users interacted on a mobile device.

Maximizing reach and interaction

It is important to understand how the information on social media is presented and shared. There are a number of ways to do so including videos, photographs, simple text and links to external sites. Facebook ‘reach’ describes the number of people who are presented with a post from a Facebook page.⁵ From the experience of the authors, sharing videos and photos will produce the highest average reach as opposed to text alone (Table 3). A single video shared on Facebook during the November 2016 campaign had a reach of 15,465. During the same campaign we made 6,100 impressions on Twitter. Twitter describes

an impression as when a user is served a tweet on their timeline.⁶ LTAMC’s most popular YouTube videos have been of demonstrations of a professional examination of the neck and mouth. They account for 17,527 of the total views.

Public knowledge of mouth cancer

As part of its campaigns, and now formalized in the empowerment journey, LTAMC undertakes data collection surveys to examine the knowledge of mouth cancer signs, symptoms and risk factors in the Scottish population. Face to face interviews were held with members of the public participating in LTAMC campaigns. Volunteers received calibration training to use iForm, a data collection application on a tablet computer. Participant demographics were captured, along with knowledge of risk factors, signs and symptoms. Closed/recognition style questions were used, with distractor items. Although closed questions have been shown to produce a higher awareness score when compared to open questions, the correlates of the two types of questions are similar.⁷

Socioeconomic characteristics were captured by the use of the Scottish Index of Multiple Deprivation (SIMD). The SIMD is an official tool of the Scottish Government, which incorporates several different aspects of deprivation, combining them into a single index. The index provides a relative ranking for each postcode-based datazone, from 1 (most deprived) to 5 (least deprived).⁸ Data were analysed using SPSS software.

A total of 880 responses were recorded from four awareness events held between March 2014 and November 2016. The sample demographics are listed in Table 4. A total of 81% (N = 716) had previously heard of mouth cancer. Twenty-one percent (N = 185) of the sample were smokers. There was good recognition of some signs of mouth cancer: ulcer 83% (N = 727), red patch 83% (N = 734) and persistent pain 86% (N = 744)(Table 5). There was high awareness of smoking, 87% (N = 765) and alcohol 77% (N = 678) as risk factors (Table 6), however, only 17% (N = 150) of participants had previously checked their mouth for signs of cancer.

There was no statistically significant difference in SIMD of those who had heard of mouth cancer compared to those who had not (p = 0.85 Mann Whitney



Figure 2. LTAMC campaign in action.



Figure 3. Final year dental students from the University of Dundee together with charity patron Scott Hastings during the campaign held in Dundee in November 2016. Image: The Courier/DC Thomson.

U test). The SIMD in those who consumed alcohol was higher than those who did not ($p = 0.002$ Mann Whitney U test) and there was a higher awareness of mouth cancer in

those who consumed alcohol (Chi squared $p = 0.0205$). There was a lower SIMD in smokers compared to non-smokers ($p = 0.03$ Mann Whitney U test).

The LTAMC data collection project showed that a large proportion of the Scottish population surveyed are aware of mouth cancer on some level. The sample shows a

Question: The following are sign/symptoms of mouth cancer:	Response Yes	Response No	Response Don't Know	Unanswered
A red patch in the mouth that lasts more than 3 weeks	83.41% N = 734	5.91% N = 52	4.32% N = 38	6.36% N = 56
Ulcer that lasts for more than 3 weeks	82.61% N = 727	7.27% N = 64	3.98% N = 35	6.14% N = 54
Pain or discomfort in the mouth for more than 3 weeks	85.55% N = 744	6.25% N = 55	2.84% N = 25	6.36% N = 56

Table 5. Knowledge of signs and symptoms (N = 880).

Question: People are more likely to get mouth cancer if they:	Response Yes	Response No	Response Don't Know	Unanswered
Are >50 years of age	56.36% N = 496	25.45% N = 224	10.91% N = 96	7.27% N = 64
Smoke tobacco (cigarettes, cigars or pipe)	86.93% N = 765	4.66% N = 41	1.25% N = 11	7.16% N = 63
Drink alcohol heavily	77.05% N = 678	10.11% N = 89	5.45% N = 48	7.39% N = 65

Table 6. Knowledge of risk factors (N = 880).

higher proportion of participants who have heard of mouth cancer than in a survey undertaken in 1995 which showed 56% of adults had knowledge of the existence of mouth cancer, with a regional awareness in Scotland of 62%.⁹ However, the Scotland specific sample showed a lower knowledge of mouth cancer than a Great Britain (England, Scotland and Wales) wide survey undertaken in 2005 which showed 95.6% had heard of mouth cancer.¹⁰ The rise in the awareness of mouth cancer may be due to initiatives such as *Mouth Cancer Awareness month*, however, Scotland continues to be a hotspot for the disease.

There was a higher number of smokers in the sample (22%) than the UK average (19%).¹¹ The sample showed a higher awareness of alcohol as a risk factor, 77%, than previous surveys in 1995 and

2005 where 19% and 19.4% of participants could identify alcohol as a risk factor, respectively.^{9,10} Many campaigns such as *Alcohol Awareness Week*, *Drinkaware* and *Dry January* have raised the public knowledge of alcohol as a risk factor for cancer in general. The sample was of a younger age, and of a higher SIMD when compared with the Scottish population as a whole.¹² It has previously been shown that awareness of cancer in general is higher amongst those in a higher socioeconomic grouping.¹³ As the surveyed cohort was from those interacting with the charity's awareness campaigns, it may reflect a health literate proportion of the Scottish population.

Conclusion

It remains difficult to measure

the success of third sector organizations in healthcare but increasingly their role is expanding. The work of LTAMC has been universally popular with all those who have engaged, but particularly with minority groups and with professional groups who have attended CPD sessions in large numbers.

Looking forward, LTAMC hopes to continue its work, spreading the word about mouth cancer and empowering the public through mouth self-examination. The charity is also involved in advocacy work, with both the Scottish and UK governments promoting gender neutral vaccination for HPV. This is seen as a genuine health inequality of particular importance in relation to cancer of the mouth and LTAMC are signatories to the work of the charity *HPV Action*.

The work of LTAMC has made extensive use of social media; a medium that appears to be accepted by many as a useful tool with which to promote health. It is important to use a number of different platforms as each has users with a varying demographic. The vast majority of users interacting with the pages of LTAMC are under 35. YouTube is the favoured platform for sharing videos to reach professionals and Facebook and Twitter for reaching the general public. Timing the release of social media posts to coincide with peaks in user activity helps to maximize reach.

It is not yet possible to draw meaningful conclusions from the data collection exercise but it is pleasing to note anecdotally high levels of public awareness of mouth cancer. It is planned to continue this work and to begin a study to examine the habits and effectiveness of mouth self-examination. Unpublished data from large mouth self-examination studies in India suggest self-examination may be more cost-effective than screening. Such a comparison will be difficult to prove but it is hoped that self-examination is empowering and will lead to better engagement with health promotion as a form of primary prevention in mouth cancer.

Affiliations

Let's Talk About Mouth Cancer is a Scottish Charitable Incorporated Organization SC045100. The five authors are trustees of the charity.

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References

1. British Society of Oral Medicine (BSOM)/ Cancer Research UK (CRUK) (2013) *Statement on Mouth Cancer Diagnosis and Prevention*. Available at: https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/bsomcruk-joint-statement_0.pdf (Accessed 30 December 2016).
2. Scully C, Kirby J. Statement on mouth cancer diagnosis and prevention. *Br Dent J* 2014; **216**: 37–38. Published online: 10 January 2014 | doi:10.1038/sj.bdj.2013.1235 (Accessed 22 March 2017).
3. Kirby J, Scully C. Mouth cancer statement launch. *Prim Dent J* 2014; **3**: 24–25. doi: 10.1308/205016814812135788. PMID:25198325.
4. Cancer Research UK (2016). *Oral Cancer Statistics*. Available at <http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/oral-cancer#heading-One> (Accessed 30 December 2016).
5. Facebook (2016). What's the difference between impressions and reach? Available at: <https://www.facebook.com/help/274400362581037?helpref=related> (Accessed 30 December 2016).
6. Twitter (2016). *Tweet activity dashboard*. Available at <https://support.twitter.com/articles/20171990> (Accessed 30 December 2016).
7. Waller J, McCaffery K, Wardle J. Measuring cancer knowledge: comparing prompted and unprompted recall. *Br J Psychol* 2004; **95**: 219–234.
8. SIMD The Scottish Index of Multiple Deprivation. 2012. Available at: <http://simd.scotland.gov.uk/publication-2012/introduction-to-simd-2012/overview-of-the-simd/what-is-the-simd/> (Accessed 20 December 2016).
9. Warnakulasuriya KA, Harris CK, Scarrott DM, Watt R, Gelbier S, Peters TJ, Johnson NW. An alarming lack of public awareness towards oral cancer. *Br Dent J* 1999; **187**: 319–322.
10. West R, Alkhatib MN, Mc Neill A, Bedi R. Awareness of mouth cancer in Great Britain. *Br Dent J* 2006; **200**: 167–169.
11. Cancer Research UK (2015). *Tobacco statistics*. Available at: <http://www.cancerresearchuk.org/health-professional/cancer-statistics/risk/tobacco> (Accessed 20 December 2016).
12. National Records of Scotland (2015). *Scotland's Population 2014 – The Registrar General's Annual Review of Demographic Trends*. Available at: <https://www.nrscotland.gov.uk/statistics-and-data/statistics/stats-at-a-glance/registrars-general-annual-review-2014> (Accessed 20 December 2016).
13. Robb K, Stubbings S, Ramirez A, Macleod U, Austoker J *et al*. Public awareness of cancer in Britain: a population-based survey of adults. *Br J Cancer* 2009; **101**(Suppl 2): S18–S23.

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