

Developing information resources
for people with head and neck cancer

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NSWOG Head and Neck

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Developing information resources for people with head and neck cancer

Project description

The project as outlined in the original expression of interest was to develop some comprehensive locally produced (i.e. NSW) information resources for head and neck (H&N) patients and their families. To address this aim, the following tasks were outlined:

- Firstly, a literature review of existing research into the information needs of H & N patients and also to review existing resources from interstate and overseas.
- Secondly, to develop a battery of measures (based on existing literature and the clinical experience of the project team) to survey the self-reported information needs and related mood state of people with H&N cancer and their relatives. The surveys would be administered to patients and their families at two sites (Liverpool Hospital, Calvary Mater Newcastle hospital).
- Thirdly, to synthesise this data and draw upon an expert panel of writers in order to produce a set of information resources with appropriate content and structure to meet the identified needs.

Prior to the commencement of the project however, the third task was superseded by an initiative of The Cancer Council NSW to develop a H&N information resource.

Deliverables as detailed in project contract

1. Completed a review of existing literature about the information needs of H&N patients as well as existing H&N information resources, nationally and internationally.
2. Completed a comprehensive information needs survey that examined address:
 - a. The scope of topics people with H&N cancer and family members wanted on a broad spectrum of information areas.
 - b. Preferred mode of delivery of information content.
 - c. Perceived helpfulness of different sources of information.
 - d. Examine relationship between patient and relative distress and information needs.

3. Developed framework and content of complementary information resources based on survey findings to be developed in collaboration with The Cancer Council NSW.
4. Completed final project report.

Description of activities undertaken

Task 1: Literature and resources review

Step 1: A literature review of studies assessing the information needs of people with cancer of the H&N was conducted.

Process

The literature search was carried out by means of electronic databases including Ovid MEDLINE, CINAHL, EMBASE and PsycINFO and search engines such as 'Google' through the use of the world wide web. The search words used were 'cancer care', 'head and neck neoplasm', 'oral cancer', 'patient information' and 'written information'. The literature search covered the period October 2001 to February 2008 to include research conducted over the past seven years. The recognised limitations of this search are that the literature search was limited to databases with no hand searching and all articles retrieved were in English language only.

Outcome

The search identified 11 articles that had investigated the information needs of H&N cancer patients.

Eleven peer-reviewed journal articles were identified that were relevant to the research area. The types of research approaches described in the articles included questionnaires, information columns, interviews, prospective evaluation studies, randomised controlled trials and literature reviews. The findings demonstrated that cancer patients and their carers have a great need for information (both good i.e. benefits of treatments; and bad i.e. risks, side effects and survivor rate) and they demand it in order to have a better

understanding of their disease, treatment options and help them adapt to living with the uncertainty of a cancer diagnosis. Also highlighted are various secondary benefits that flow from the quality provision of information including increased participation in decision-making, enhanced coping, increased self-esteem and confidence in living with cancer. Clearly there were few studies published addressing this issue. Therefore little is known about the information needs of people with H&N cancers and how these needs vary as a function of disease stage as well as demographic characteristics (e.g. age, sex and education level). Reference list for these articles appears in **Appendix 1**.

Step 2: A second search was undertaken of all web-based information resources available to consumers on cancers of the H&N at local, national and international level.

Process

Another electronic literature search was conducted by the librarian of the Ken Merten Library of Liverpool hospital. The search was requested in February 2008 with the aim of identifying relevant Australian (local) and international information resources available for head and neck cancer patients and their families. The search was web-based.

The findings of this search are consolidated in **Appendix 2 Table 1**. The table is divided into country of origin and by state for the Australian resources. Other information provided includes the source of the publication or author/s, the title and the type of H&N cancer or treatment it explores, a summary of the information provided and a description of the format the resource is available in.

The existing web-based information resources identified in **Table 1** are then evaluated in how they meet the information needs of H&N cancer patients. Refer to **Appendix 2 Table 2**.

Outcome

The number of locally produced information resources is minimal. While the Cancer Institute NSW patient information sheets deal specifically with chemotherapy treatment, the booklet by the Cancer Council Victoria is far more comprehensive.

Task 2: Conducting the information needs survey

Process

Sample

Ethical approval for undertaking the information needs survey was granted by the Sydney South West Area Health Service (Western zone) and the Hunter New England Human Research Ethics Committee. A consecutive series of 79 patients and 52 family members were recruited and completed the questionnaires. The sample was derived from 119 patients with histopathologically confirmed, primary malignancy H&N cancers from the Liverpool Hospital Cancer Therapy Centre and 30 patients from Calvary Mater Newcastle were reviewed for possible inclusion in the study. Out of the 119 H&N patients from Liverpool, 24 were excluded because they were deceased, medically unwell, non-English speaking or unable to be contacted. A total of 95 participants were invited to participate in the study and 69 surveys were completed and returned. Of this group 48 family members and one paid carer also independently completed the same survey. Out of the 30 H&N patients from Newcastle, 20 were excluded because they were deceased, medically unwell, non-English speaking or unable to be contacted. A total of 17 participants were invited to participate in the study and 10 surveys were completed and returned. Seven family members also independently completed the same survey.

Measures

The information needs survey and modes of information provision surveys were purpose-designed measures for the project, styled on measures gathering data on information needs for a range of cancers identified in the literature review (see Task 1). In addition, the following standardised measures of affective distress and Quality of Life were included (Hospital Anxiety and Depression Scale, Distress Thermometer; and H&N Quality of Life measure).

Procedures

Prospective respondents were informed of the study during a hospital visit or alternatively, mailed a letter outlining the purpose of the project and followed up by phone by a research assistant employed by the project team. Respondents who consented to participate either completed the measure by face-to-face interview, phone interview or completed the surveys and mailed them back to the hospital. Respondents were also invited to identify a family member who could also participate in the project. The same procedures were then followed in recruiting and collecting data from the family members. Data were entered into SPSS Version 16.0 and descriptive data generated for the variables from the information needs measures. Descriptive, correlation and chi-square analyses were conducted for the standardised measures.

Outcome

Demographic, illness and clinical characteristics of sample

Data on the sociodemographic profile, illness and clinical characteristics for the 79 patients are displayed in **Table I**. There were small amounts of missing data for some variables.

A total of 56 relatives participated in the study. In four cases, a family member completed surveys but the patient did not. These families were excluded from the subsequent analyses. Demographic data for the remaining 52 family members indicated they were predominantly female (female n=45, 86%; male n=7, 14%), with 11 years education (mean 10.9, SD 3.0), and the spouse or adult child of the patient (spouse n=39, 75%; adult child n=7, 14%; other n=6, 11%).

Table 1 Sociodemographic, illness and clinical characteristics

Variable	Patient (n=79)	Variable	Patient (n=79)
Age (years), Mean (SD)	62.7 (11.9)	Cigarette smoking history, n (%)	
		Used to smoke	42 (53)
		Still smoking	15 (19)
		Never smoked	22 (28)
Sex, n (%)		Duration smoking¹ (yrs), M (SD)	30.0 (15.5)
Male	63 (80)		
Female	16 (20)		
Education (years), Mean (SD)	11.5 (2.9)	Alcohol use history, n (%)	
		Used to drink alcohol	19 (24)
		Still drinking alcohol	48 (62)
		Never drank alcohol	11 (14)
Marital status, n (%)		Quantity drinks (week),² M (SD)	8.3 (10.7)
Married	53 (67)		
Separated/divorced/widowed	15 (19)		
Single	11 (14)		
Current living status, n (%)		Patient	
Own home	54 (68)	Cut down drinking²	
Rent	19 (24)	Yes	7 (13)
Other	6 (8)	No	46 (87)
Tumour type, n (%)		Criticised for drinking², n (%)	
Squamous cell carcinoma	60 (78)	Yes	10 (19)
Other*	17 (22)	No	43 (81)
Tumour location, n (%)		Feel guilty for drinking², n (%)	
Nasopharynx	5 (7)	Yes	2 (4)
Oropharynx (incl base tongue & tonsil)	26 (35)	No	51 (96)
Larynx	12 (16)		
Oral cavity (incl tongue)	11 (15)	Drink in morning², n (%)	
Parotid	2 (3)	Yes	7 (13)
Skin	11 (15)	No	46 (87)
Other	7 (9)		
Stage, n (%)		Patient use non-prescription drugs, n (%)	
I	16 (20)	Yes	9 (12)
II	7 (9)	No	68 (88)
III	11 (14)		
IVa	26 (33)		
IVb	3 (4)		
IVc	-		
Unable to assess	16 (20)		
Surgical intervention, n (%)			
Biopsy (not FNA)	38 (52)		
Resection	12 (16)		
Both	23 (32)		
Radiation Therapy, n (%)			
Definitive (main Rx)	43 (57)		
Post-operative	18 (24)		
Other	15 (19)		
Chemotherapy, n (%)			
Neoadjuvant (before RT)	3 (4)		
Concurrent (with RT)	32 (42)		
None	41 (54)		

¹ For n=55 used to/still smoking.

² For n=57 used to/still drinking.

Information needs

Respondents and family members completed the information needs survey independently. The 33 information items were grouped into five domains of disease profile (four items), treatment (eight items), side effects (eight items), psychosocial (nine items) and survivorship (four items). Patient and family respondents rated the importance of accessing information on each of the 33 items on a four point scale (1 = very important to 4 = not important). For the analysis, the frequency of respondents who indicated an item was very important was endorsed. **Figure 1** displays the average frequency of all items within each domain that were endorsed as very important.

Both patients with head and neck cancer and their relatives endorsed information about the disease profile as extremely important. Family members rated issues relating to survivorship as of most concern. In contrast patients rated information about treatment and survivorship as equally important. Both patients and family members rated information about psychosocial care as least the important area. Generally, family members rated the availability of information as more important than the patients across four of the five domains.

An item by item analysis was then conducted to identify

if there were specific areas where patients versus family members rated the availability of information as significantly more important. The frequencies and results of the chi-square analyses (very important vs other responses) are displayed in **Table 2**.

There were no items of information for which a greater number of patients identified as significantly more important than family members (see **Table 2**). In contrast, significantly more family members felt it was very important to have information on a number of items in the treatment, side effects, psychosocial and survivorship domains. There was little difference between the two groups in the importance they attached to learning about the disease.

In order to identify the key areas of information concerns for patients and their family members, their concerns were then ranked from highest to lowest. **Table 3** lists the top 10 information items rated as very important for patients and family members. There was a strong correspondence between patients and families as to their top 10 concerns for information, with both groups sharing seven items in common albeit in different ranking order. The three items unique to patients alone and to family members are highlighted in bold.

Figure 1 Information needs results

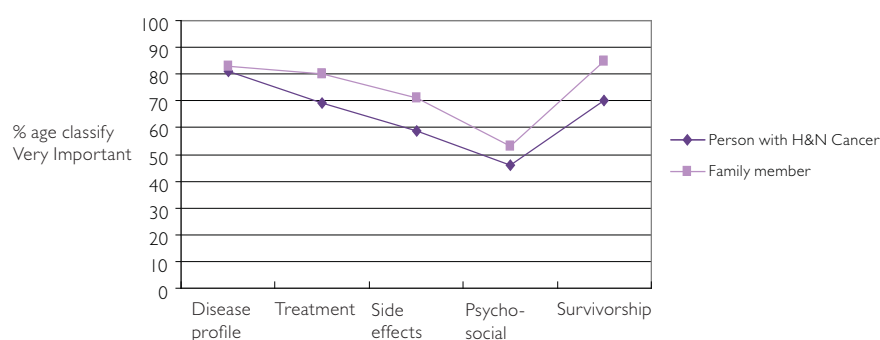


Table 2 Percentages of patients/family members rating information needs as Very Important

Domain	Items	Pat	Fam	Domain	Items	Pat	Fam
Disease Profile	1. Information about Head and Neck cancers that describe the disease	81%	78%	Psycho-social	18. Being able to care for myself at home	52%	67%
	2. The cause of the disease and how it could have been prevented	66%	69%		19. Managing fatigue (feeling tired)	46%	58%
	3. The stage of the disease and how it is expected to progress	85%	84%		20. How the treatment may affect normal daily activities	49%	56%
	4. How far advanced the disease is and how far it has spread	87%	90%				
Treatment					21. Being able to work or concerns about finances	46%	52%
	5. The goals of treatment	79%	90%		22. Cost of treatments	51%	50%
	6. Tests and investigations that may be needed	66%	79%		23. How family and social life will be affected	51%	50%
	7. How to prepare for tests	60%	77%		24. How talking about fears, worries and getting emotional support helps	51%	64%
	8. The different types of treatment available, their advantages and disadvantages	80%	80%		25. Stress management	41%	64%
	9. The chances of being cured of the disease	87%	90%		26. Support groups or other services available for myself and my carer	32%	48%
	10. The evidence behind treatment recommendations	62%	67%		27. How the treatment may affect my feelings about my body, physical appearance and sexual attractiveness	37%	44%
	11. How the treatments are performed	62%	73%		28. How family and close friends will be affected by the disease	48%	50%
			29. Whether my children or other family members are at risk of getting cancer	71%	65%		
Side effects				Survivorship	30. Staying well after treatment is finished	63%	75%
	13. Possible side effects of treatment	77%	78%		31. Getting on with life after cancer treatment	66%	75%
	14. Management of unpleasant treatment side effects	77%	86%		32. Signs of a recurrence or how to tell if the disease has come back	83%	94%
	15. Dental check-ups and care	54%	71%		33. When cancer cannot be cured and needing palliative care	66%	85%
	16. Ways of managing eating and drinking to maintain nutritional intake	62%	80%				
	17. Ways of managing swallowing and communication	63%	79%				

Note. Items significant at p<0.05 in **bold text**.

Table 3 Top ten concerns for patients and families

Patient	%	Family Members	%
4. How far advanced the disease is and how far it has spread	87%	32. Signs of a recurrence or how to tell if the disease has come back	94%
9. The chances of being cured of the disease	87%	4. How far advanced the disease is and how far it has spread	90%
3. The stage of the disease and how it is expected to progress	85%	5. The goals of treatment	90%
32. Signs of a recurrence or how to tell if the disease has come back	83%	9. The chances of being cured of the disease	90%
1. Information about head and neck cancers that describe the disease	81%	14. Management of unpleasant treatment side effects	86%
8. The different types of treatment available, their advantages and disadvantages	80%	33. When cancer cannot be cured and needing palliative care	85%
5. The goals of treatment	79%	3. The stage of the disease and how it is expected to progress	84%
13. Possible side effects of treatment	77%	8. The different types of treatment available, their advantages and disadvantages	80%
14. Management of unpleasant treatment side effects	77%	12. How the treatments work against the disease	80%
29. Whether my children or other family members are at risk of getting cancer	71%	16. Ways of managing eating and drinking to maintain nutritional intake	80%

Not surprisingly, patients with cancer were concerned about the risk of other family members having an increased risk of cancer. Family members had particularly concerns about management issues including the need for palliative care and ways to manage the changed nutritional needs of their relative with cancer.

Overall the findings suggest that particular attention in information resources needs to be directed to areas of the disease and survivorship. In addition, family members in some areas have greater concerns than the patients and this needs to be addressed in the development of information resources.

Open-ended questions were also included where patients and their family members could express their own views on specific information needs, the most important issues for cancer patients, the resources believed to be needed in the local area and any other comments or suggestions about information needs.

The most common responses included:

- Information is needed on what to expect and what will happen.
- It is important to have contact details of support groups, the care coordinator and other survivors.
- Needing information about the cancer such as the cause, types, stages of disease, rare types and prevention.
- All about treatment.
- Effects on eating and drinking.
- Recovery and recurrence.
- What facilities and resources are available.
- Financial support available.
- Transport concerns.
- Home care and community services.

Mode of delivery

Patients were surveyed to determine their preferred mode of delivery in receiving information about their cancer, its treatment and the longer term outcomes. To gather the data, respondents were first asked to nominate from the survey which health staff they had seen in the treatment of their H&N cancer. For the staff that they had seen, respondents were then asked to rate (i) how frequently they used that person as a source of information and (ii) how helpful the information was on a four point scale (0=poor, 1=fair, 2=good, 3=excellent). In addition to rating health staff, patients were also asked to rate the frequency and helpfulness of a number of other common sources of information about H&N cancer.

Patients rated the information they received directly from hospital-based health professionals as the most helpful. This included information from medical staff, nursing staff (both hospital-based and care coordinators) and the dieticians. Of note was the relatively low rating provided to general

practitioners (GPs). GPs received similar ratings levels to The Cancer Council NSW and this may reflect experience that the post-hospital primary health care network is not as salient in the provision of information as their treating health professionals. However, it may also suggest that GPs need further education to increase the level of aftercare provided to patients who have been treated for H&N cancer.

From non-health staff sources, written information, other cancer patients, the internet, family/friends and The Cancer Council were rated as the most frequent sources of information. From these sources, the internet and family/friends were rated as the most helpful. This underscores the importance of guiding people to good quality web-based information and also educating family and friends about the cancer. The score for The Cancer Council may be an underestimate because some of the written information and the web-based information may be products of The Cancer Council NSW.

Table 4a Preferred modes of information delivery (n=79)

Source of information	Frequency access information from this source				Helpful M
	Did you see? n (%)	Most of the time n	Moderate N	Little of the time n	
Surgeon	61 (77)	32	13	16	2.54
Radiation oncologist	67 (85)	51	12	4	2.79
Medical oncologist	46 (58)	29	9	8	2.70
General practitioner	53 (67)	21	12	20	2.08
Radiation therapist	50 (63)	32	6	12	2.46
Radiation nurse	52 (66)	32	11	9	2.65
Chemotherapy nurse	33 (42)	20	3	9	2.52
Ward nurse	36 (46)	15	8	13	2.24
Care coordinator	43 (54)	20	10	13	2.56
Social worker	26 (33)	11	4	11	2.27
Dietician	66 (84)	41	14	11	2.59
Speech pathologist	47 (60)	22	17	8	2.43
Physiotherapist	12 (15)	4	4	4	2.33
Occupational therapist	4 (5)	2	2	-	2.75
Community nurse	18 (23)	6	6	6	2.41

Table 4b Preferred modes of information delivery

Other modes	Most time n	Moderate N	Little time N	None time n	Helpful M
Written information	19	15	20	25	1.98
Cancer Council NSW	8	5	8	58	2.05
Internet	8	4	10	57	2.24
Television/radio	-	2	10	67	1.54
Magazines	1	4	2	72	1.75
Books	2	3	7	67	1.67
Support group	2	-	1	76	2.00
Other cancer patients	6	12	10	51	2.03
Family / friends	15	12	5	47	2.28

The relationship between distress and information needs

The relationship between distress, quality of life and information needs was also investigated. Patients completed three measures of distress (distress thermometer, hospital anxiety and distress scale) and the University of Liverpool quality of life measure for H&N cancer.

Patient mean score on the distress thermometer was 2.97 (SD 3.1). A total of 24.7 per cent of the sample scored at 5 or higher, the agreed cut-off score indicating clinically significant distress. Patients endorsed an average of seven symptoms (median seven, range 0–19).

The five most common symptoms endorsed were: worry (56%), fatigue (48%), sleep (47%), eating (39%) and pain (38%).

The mean anxiety (4.8; SD 3.8) and depression (3.9, SD 4.0) scores were within the normal range on the HADS. Only one patient (1.3%) reported clinically significant levels of anxiety (cut off score 15 or greater) and three patients (3.8%) clinically significant levels of depression. However, a greater proportion (anxiety 6.3%, depression 12.7%) displayed moderate to severe symptoms (score greater than 9). Finally, the mean quality of life (QoL) score was 84.0 (range 44–100).

Pearson's product-moment correlations were calculated to test the association between the information needs and information helpful variables and the distress (HADS anxiety,

HADS depression) and QoL variables (see **Table 5**). The information needs variable comprised each respondent's mean rating score across all 33 responses (item response score/ number of items rated) on the information needs survey. Lower scores meant higher levels of importance. The information helpful variable was based on the mean 'helpfulness' score that respondents from the modes of information form. Higher scores represented ratings of higher levels of perceived helpfulness.

Not surprisingly there were strong inter-correlations between the distress and QoL variables. In addition, there was a modest but significant negative correlation between people rating information important and the number of reported symptoms on the distress thermometer and HADS anxiety scores. Similarly, patients who rated information as most helpful were also likely to be those who endorsed higher numbers of symptoms on the distress thermometer and HADS anxiety. Interestingly, there was a clear demarcation between anxiety and depression. Although the two affective states were strongly inter-correlated ($r = 0.67$, $p < 0.0001$), information needs were clearly correlated to HADS anxiety but not to HADS depression. Finally, QoL scores did not correlate with the information variables at all.

As the final step, an analysis was conducted examining the correlation between the distress, symptom and QoL variables and the individual information items (see **Table 6**).

As indicated by the previous analysis, HADS anxiety scores were significantly associated with many items across a range of the five domains. In contrast, the symptom, distress and QoL scores clustered around the disease domain, with a small number of correlations to items across the other

four domains including the goals of treatment (treatment), ways of managing nutrition intake (side effects) and signs of recurrence (survivorship). Interestingly, the item pertaining to body image and sexuality correlated to QoL.

Table 5 Correlation matrix

	DT score	DT sum Symptoms	Anxiety	Depression	QoL
DT sum symptoms	.58***				
HADS anxiety	.58***	.62***			
HADS depress	.58***	.59***	.67***		
Quality of life	-.49**	-.57***	-.53***	-.80***	
Information importance	ns	-.23*	-.32*	ns	ns
Information helpful	ns	.35*	.29*	ns	ns

Note. * p<.05, ** p<.01, ***p <.001; ns = Not Significant.

Table 6 Correlation between patient distress, symptoms, QoL and Information items (n=79)

Items	DT	DT symptom	QoL	HADS Depress	HADS Anxiety
Disease					
1. Information about head and neck cancers that describe the disease			.31		
2. The cause of the disease and how it could have been prevented	-.34	-.30	.34	-.46	-.30
3. The stage of the disease and how it is expected to progress					-.52
4. How far advanced the disease is and how far it has spread		-.22		-.29	
Treatment					
5. The goals of treatment	-.25	-.26	.32		-.28
6. Tests and investigations that may be needed					-.24
7. How to prepare for tests					
8. Different types of treatment available, advantages & disadvantages					-.23
9. The chances of being cured of the disease					
10. The evidence behind treatment recommendations					
11. How the treatments are performed					
12. How the treatments work against the disease					-.25

Items	DT	DT symptom	QoL	HADS Depresss	HADS Anxiety
Side-effects					
13. Possible side effects of treatment					
14. Management of unpleasant treatment side effects					-.30
15. Dental check-ups and care					-.30
16. Ways of managing eating and drinking to maintain nutritional intake	-.25		.25		-.30
17. Ways of managing swallowing and communication					-.28
18. Being able to care for myself at home					-.33
19. Managing fatigue (feeling tired)		-.25			-.33
20. How the treatment may affect normal daily activities		-.26			-.33
Psychosocial					
21. Being able to work or concerns about finances					
22. Cost of treatments					
23. How family and social life will be affected					
24. How talking about fears, worries, getting emotional support helps					-.23
25. Stress management					-.26
26. Support groups or other services available for myself and my carer					
27. How the treatment may affect my feelings about my body, physical appearance and sexual attractiveness			.30		
28. How family and close friends will be affected by the disease		-.39			-.27
29. Whether my children or other family are at risk of getting cancer		-.23			
Survivorship					
30. Staying well after treatment is finished		-.28			
31. Getting on with life after cancer treatment		-.28			
32. Signs of a recurrence or how to tell if the disease has come back			.23	-.24	-.28
33. When cancer cannot be cured and needing palliative care					

Note. DT Distress Thermometer; DT Symptoms = Sum of DT symptoms. All coefficients significant at 0.05 or 0.01.

Project outcomes

Task 3 of the project to develop the framework and content of the information resource based on the survey findings is to be contracted to The Cancer Council NSW. However during the time since the inception of this project, The Cancer Council NSW proceeded to publish its own H&N patient information booklet. The project coordinators listed at item 2, amongst others, were called upon to contribute to the content of this booklet. *Understanding Head and Neck Cancers, A guide for people with cancer, their families and friends* was released in 2008. This was an important step forward.

Testing the feasibility and validity of the distress thermometer in the Australian H&N population.

The initial results are promising, suggesting that the distress thermometer is a useful brief measure of patient distress. The results are in line with the performance of the Thermometer in other cancer populations.

Ongoing benefits of the project

Developing comprehensive, relevant and easily available information about the diagnosis, treatment, prognosis and psychosocial consequences of H&N cancer will assist patients and their family members to understand and cope with their circumstances and helps them navigate their way through rehabilitation and survivorship.

Presentations, abstracts, papers or reports that have been submitted upon the work of this project

Preliminary results of this research project were disseminated to health professionals via:

Published abstract:

Dall'Armi, L., Simpson, G. K., Forstner, D., Simpson, T. and Kwa, B. (2008). *A survey of the information needs of people with head and neck cancer and their relatives resident in the South West of Sydney: preliminary results.* Asia-Pacific Journal of Clinical Oncology, 4,[Suppl 2], A126. [Poster]

Submitted abstract:

Australian and New Zealand Head and Neck Society, 11th Annual Scientific Meeting at the Fremantle Esplanade Hotel Western Australia on 6-8 August 2009. *Patterns of Information Needs and Affective Distress for People with Head & Neck Cancer and their Family members.*

General comments

The Cancer Institute NSW upon receiving the information contained in this report may proceed to pass on the study's findings to The Cancer Council NSW (TCCNSW). An evaluation of TCCNSW's H&N patient information booklet discussed at item 6.(b) may be considered to determine if the booklet's content addresses the information needs of people with H&N cancers and their family members as found in this study.

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Appendix 2

Consolidation of local and international web-based information resources on H&N cancer

Country	Australia
State	New South Wales
Source	Cancer Institute NSW (Patient Information Sheet): http://www.treatment.cancerinstitute.org.au/
Type of H&N Cancer/Treatment	<ol style="list-style-type: none"> 1. Larynx: Cisplatin & Fluorouracil (5FU) 2. Larynx: Cisplatin with Radiotherapy 3. Nasopharyngeal: Cisplatin with Radiotherapy 4. Nasopharyngeal: Cisplatin with Radiotherapy followed by Fluorouracil (5FU) & Cisplatin 5. Nasopharyngeal: Gemcitabine 6. Nasopharyngeal: Cisplatin with Radiotherapy 7. Salivary Gland: Cisplatin, Doxorubicin & Cyclophosphamide 8. SCC: Carboplatin & Fluorouracil (5FU) 9. SCC: Carboplatin & Fluorouracil with Radiotherapy 10. SCC: Carboplatin with Radiotherapy 11. SCC: Cetuximab with Radiotherapy 12. SCC: Cisplatin (3 weekly) with Radiotherapy 13. SCC: Cisplatin with Radiotherapy 14. SCC: Cisplatin & Fluorouracil (5FU), (3 weekly) 15. SCC: Cisplatin & Fluorouracil (5FU), fractionated (3 weekly) 16. SCC: Methotrexate 17. SCC: unresectable Cisplatin, (3 weekly) with Radiotherapy 18. SCC: Cisplatin, (weekly) with Radiotherapy
Type of Information	<ul style="list-style-type: none"> • Introduction <ul style="list-style-type: none"> • Types and course of chemotherapy drug/s and treatment • Temperature monitoring • Possible Side Effects • Special Instructions <ul style="list-style-type: none"> • Interactions with other medication • Use of vaccines • Use of aspirin • Pregnancy and breast feeding • Cancer Council Helpline 131120 • Contact Info
Description of Resource	Patient Information Sheet – ranging from 2 to 4 pages per cancer type

2			
Country	Australia		
State	New South Wales		
Source	The Sydney Head and Neck Cancer Institute: http://www.shnci.org/ Other links provided: <ul style="list-style-type: none"> - The Sydney Cancer Centre - The Cancer Council Support pages - The ASCO Patients living with Cancer website - The American National Cancer Institute website - The Australian and New Zealand Head and Neck Society (ANZHNS) - The International Federation of Head and Neck Oncologic Societies (IFHNOS) 		
Type of Information	<ul style="list-style-type: none"> • What we do • What is head & neck cancer • What can the SHNCI do? • Why does the SHNCI have a multidisciplinary team approach to treatment 		
Description of Resource	Website – 445 words.		
3			
Country	Australia		
State	Victoria		
Source	The Cancer Council, Victoria: http://www.cancervic.org.au/		
Type of Information	<table border="0" style="width: 100%;"> <tr> <td style="vertical-align: top; width: 50%;"> <ul style="list-style-type: none"> • Introduction • What is cancer? <ul style="list-style-type: none"> • How cancer spreads • The mouth, nose and throat <ul style="list-style-type: none"> • The mouth and throat: Looking into the mouth • Cancers of the mouth, nose and throat • Causes of mouth, nose and throat cancers • How common are cancers of the mouth, nose and throat? • Diagnosis <ul style="list-style-type: none"> • Doctors and other health professionals you may see • How these cancers are diagnosed (Biopsy, CT scan, MRI) • 'Staging' the disease • Treatment <ul style="list-style-type: none"> • Surgery (pre-op & post-op) • Radiotherapy (side effects) • Chemotherapy (side effects) • Prognosis • When cancer can't be cured • Cancer Support Groups • Cancer Connect • Living with Cancer Education Program </td> <td style="vertical-align: top; width: 50%;"> <ul style="list-style-type: none"> • Making decisions about treatment <ul style="list-style-type: none"> • Talking with doctors • Talking with others • A second opinion • Taking part in a clinical trial • Research into cancers of the mouth, nose and throat • Recovery and follow-up care <ul style="list-style-type: none"> • Eating and swallowing • Talking again • Changed appearance • Prostheses • Coping with other people's reactions • Follow-up care • Seeking support <ul style="list-style-type: none"> • Practical and financial help • Diet • Exercise • Relaxing • Sexuality and cancer • Cancer Council Helpline • Multilingual Cancer Information Line • Caring for someone with cancer • Questions to ask your doctors • Definitions • Cancer information in other languages (contact details) </td> </tr> </table>	<ul style="list-style-type: none"> • Introduction • What is cancer? <ul style="list-style-type: none"> • How cancer spreads • The mouth, nose and throat <ul style="list-style-type: none"> • The mouth and throat: Looking into the mouth • Cancers of the mouth, nose and throat • Causes of mouth, nose and throat cancers • How common are cancers of the mouth, nose and throat? • Diagnosis <ul style="list-style-type: none"> • Doctors and other health professionals you may see • How these cancers are diagnosed (Biopsy, CT scan, MRI) • 'Staging' the disease • Treatment <ul style="list-style-type: none"> • Surgery (pre-op & post-op) • Radiotherapy (side effects) • Chemotherapy (side effects) • Prognosis • When cancer can't be cured • Cancer Support Groups • Cancer Connect • Living with Cancer Education Program 	<ul style="list-style-type: none"> • Making decisions about treatment <ul style="list-style-type: none"> • Talking with doctors • Talking with others • A second opinion • Taking part in a clinical trial • Research into cancers of the mouth, nose and throat • Recovery and follow-up care <ul style="list-style-type: none"> • Eating and swallowing • Talking again • Changed appearance • Prostheses • Coping with other people's reactions • Follow-up care • Seeking support <ul style="list-style-type: none"> • Practical and financial help • Diet • Exercise • Relaxing • Sexuality and cancer • Cancer Council Helpline • Multilingual Cancer Information Line • Caring for someone with cancer • Questions to ask your doctors • Definitions • Cancer information in other languages (contact details)
<ul style="list-style-type: none"> • Introduction • What is cancer? <ul style="list-style-type: none"> • How cancer spreads • The mouth, nose and throat <ul style="list-style-type: none"> • The mouth and throat: Looking into the mouth • Cancers of the mouth, nose and throat • Causes of mouth, nose and throat cancers • How common are cancers of the mouth, nose and throat? • Diagnosis <ul style="list-style-type: none"> • Doctors and other health professionals you may see • How these cancers are diagnosed (Biopsy, CT scan, MRI) • 'Staging' the disease • Treatment <ul style="list-style-type: none"> • Surgery (pre-op & post-op) • Radiotherapy (side effects) • Chemotherapy (side effects) • Prognosis • When cancer can't be cured • Cancer Support Groups • Cancer Connect • Living with Cancer Education Program 	<ul style="list-style-type: none"> • Making decisions about treatment <ul style="list-style-type: none"> • Talking with doctors • Talking with others • A second opinion • Taking part in a clinical trial • Research into cancers of the mouth, nose and throat • Recovery and follow-up care <ul style="list-style-type: none"> • Eating and swallowing • Talking again • Changed appearance • Prostheses • Coping with other people's reactions • Follow-up care • Seeking support <ul style="list-style-type: none"> • Practical and financial help • Diet • Exercise • Relaxing • Sexuality and cancer • Cancer Council Helpline • Multilingual Cancer Information Line • Caring for someone with cancer • Questions to ask your doctors • Definitions • Cancer information in other languages (contact details) 		
Description of Resource	Booklet – 50 pages; downloadable online.		

4	
Country	Canada
Source	BC Health Guide: http://www.bchealthguide.org/
Type of H&N Cancer/Treatment	<ol style="list-style-type: none"> 1. Hypopharyngeal 2. Oropharyngeal 3. Oral Cavity 4. Laryngeal 5. Nasal Cavity 6. Nasopharyngeal
Type of Information	<ul style="list-style-type: none"> • General information about Cancer <ul style="list-style-type: none"> • Risk factors • Symptoms • Detection and Diagnosis • Prognosis • Treatment options • Stages of Cancer • Recurrent Cancer • Treatment Option Overview <ul style="list-style-type: none"> • Surgery • Radiation therapy • Chemotherapy • Treatment Options by stage • Treatment Option for Recurrent Cancer <ul style="list-style-type: none"> • Surgery • Radiation therapy • Chemotherapy • A clinical trial of chemotherapy • Get more information from NCI <ul style="list-style-type: none"> • Call 1-800-4-CANCER • Chat Online • Write to us • Search the NCI website • Find Publications
Description of Resource	<p>Online Health Professional Information –</p> <ol style="list-style-type: none"> 1. 5160 words 2. 4630 words 3. 5140 words 4. 4230 words 5. 3300 words 6. 2630 words

5			
Country	Canada		
Source	Canadian Society of Otolaryngology: http://www.entcanada.org/		
Type of Information	<ul style="list-style-type: none"> Find it early and be cured Here's what you should watch for <ul style="list-style-type: none"> Symptoms Identifying high risk of head and neck cancer What should I do? 		
Description of Resource	Website – 850 words.		
6			
Country	United Kingdom		
Source	Cancer Research UK: http://www.cancerhelp.org.uk/		
Type of H&N Cancer/Treatment	<ol style="list-style-type: none"> Eye Cancer Nasal and Paranasal Sinus Cancer Nasopharyngeal Cancer Mouth and Oropharyngeal Cancer Larynx or Laryngeal Cancer Oesophageal Cancer 		
Type of Information	<table border="0"> <tr> <td style="vertical-align: top;"> <ul style="list-style-type: none"> Overview About the cancer Treatment What's new in head and neck cancer Living with cancer Head and neck cancer questions <ul style="list-style-type: none"> Teeth whiteners and mouth cancers Could red patches in my mouth be cancer Tongue cancer Changes to your face after surgery Salivary gland cancer Information on throat cancer </td> <td style="vertical-align: top;"> <ul style="list-style-type: none"> Tonsil cancer What is the main treatment for nasopharyngeal cancer? What are the symptoms of mouth cancer? Mouth cancer – how to reduce your risk What is adenocarcinoma of the nasal cavity? What is oral cancer? What could a lump on the gum be? What is acinic cell adenocarcinoma of the parotid gland? Can an airway stent be used in the upper airway? </td> </tr> </table>	<ul style="list-style-type: none"> Overview About the cancer Treatment What's new in head and neck cancer Living with cancer Head and neck cancer questions <ul style="list-style-type: none"> Teeth whiteners and mouth cancers Could red patches in my mouth be cancer Tongue cancer Changes to your face after surgery Salivary gland cancer Information on throat cancer 	<ul style="list-style-type: none"> Tonsil cancer What is the main treatment for nasopharyngeal cancer? What are the symptoms of mouth cancer? Mouth cancer – how to reduce your risk What is adenocarcinoma of the nasal cavity? What is oral cancer? What could a lump on the gum be? What is acinic cell adenocarcinoma of the parotid gland? Can an airway stent be used in the upper airway?
<ul style="list-style-type: none"> Overview About the cancer Treatment What's new in head and neck cancer Living with cancer Head and neck cancer questions <ul style="list-style-type: none"> Teeth whiteners and mouth cancers Could red patches in my mouth be cancer Tongue cancer Changes to your face after surgery Salivary gland cancer Information on throat cancer 	<ul style="list-style-type: none"> Tonsil cancer What is the main treatment for nasopharyngeal cancer? What are the symptoms of mouth cancer? Mouth cancer – how to reduce your risk What is adenocarcinoma of the nasal cavity? What is oral cancer? What could a lump on the gum be? What is acinic cell adenocarcinoma of the parotid gland? Can an airway stent be used in the upper airway? 		
Description of Resource	<p>Website –</p> <ol style="list-style-type: none"> 3020 words 33300 words 23400 words 34450 words 27280 words 25130 words 		

Country	United Kingdom	
Source	Cancer of the head and neck information centre – Cancerbackup: http://www.cancerbackup.org.uk/	
Type of H&N Cancer/Treatment	<ol style="list-style-type: none"> 1. Oral Cavity 2. Oropharyngeal Cancer 3. Cancer of the Nose 4. Cancer of the Ear 5. Cancer of the Eye 	
Type of Information	<ul style="list-style-type: none"> • General <ul style="list-style-type: none"> - Cancers of the head & neck - Types of head & neck cancer - What is cancer? - References • Causes & diagnosis <ul style="list-style-type: none"> - Causes - Symptoms - Diagnosis - Further tests - Staging • Treatment <ul style="list-style-type: none"> - Types of treatment - Planning - Consent - Benefits & disadvantages - Before it starts - Surgery - Radiotherapy <ul style="list-style-type: none"> - External radiotherapy - Internal radiotherapy - Chemotherapy - PDT - Biological therapies 	<ul style="list-style-type: none"> • Effects of treatment <ul style="list-style-type: none"> - Quality of life - How you will look - Changes to eating - Changes to speech - Changes to hearing • After treatment <ul style="list-style-type: none"> - Follow-up - If your cancer comes back • Clinical trials <ul style="list-style-type: none"> - Research – clinical trials • Types of head and neck cancers <ul style="list-style-type: none"> - Cancer of the nasopharynx - Paranasal sinus cancer - Salivary gland cancer • Organisations <ul style="list-style-type: none"> - Local Organisations - National Organisations • Resources & support <ul style="list-style-type: none"> - Cancerbackup resources - Patient Information Guide - Useful links
Description of Resource	Website – 18,690 words.	

8	
Country	United Kingdom
Source	Merseyside Regional Head and Neck Cancer Centre: http://www.headandneckcancer.co.uk/
Type of Information	<ul style="list-style-type: none"> • Information Leaflets • Incidence • Risk Factors • Signs & Symptoms • Investigations • Surgery • Radiotherapy • Rehabilitation • Survival
Description of Resource	Downloadable information Leaflets – 42 pages Website – 2530 words
9	
Country	United Kingdom
Source	Mouth Cancer Foundation: http://mouthcancerfoundation.org/
Type of H&N Cancer/Treatment	Oral and Pharyngeal Cancer
Type of Information	<ul style="list-style-type: none"> • Statistics <ul style="list-style-type: none"> • UK and Internationally • Symptoms • Reduce your chances
Description of Resource	Website – 800 words
10	
Country	United Kingdom
Source	NHS Direct: http://www.nhsdirect.nhs.uk/
Type of H&N Cancer/Treatment	<ol style="list-style-type: none"> 1. Oral Cancer 2. Larynx Cancer
Type of Information	<ul style="list-style-type: none"> • Introduction • Symptoms • Diagnosis • Treatment • Medicine guides • Prevention • Related articles
Description of Resource	Online health encyclopaedia – <ol style="list-style-type: none"> 1. 3900 words 2. 830 words

11	
Country	India
Source	Rosemund, S., Murali, S., & Leng, M. (2006). Home care nursing advice for patients with head and neck cancer in India. <i>Indian J Palliative Care</i> , 12(2), 77-80.
Type of Information	<ul style="list-style-type: none"> • Mouth Care <ul style="list-style-type: none"> • What is mouth care and why is it needed? • Main problems • Assessment • Things to look for • Things to ask about • Management • Troubleshooting • Naso-gastric Tubes <ul style="list-style-type: none"> • What is a naso-gastric tube • How to use and care for a naso-gastric tube (Articles needed, preparation of liquid food, procedure, troubleshooting) • Tracheostomy Care <ul style="list-style-type: none"> • What is Tracheostomy care and why is it needed? • How? (Articles needed, procedure, Troubleshooting)
Description of Resource	Journal article – 4 pages
12	
Country	USA
Source	American Dental Association: http://ada.org/public/topics/cancer_oral.asp
Type of H&N Cancer/Treatment	Oral Cancer
Type of Information	<ul style="list-style-type: none"> • Canker Sores • Cold Sores • Candidiasis • Leukoplakia
Description of Resource	Journal article – 1 page

Country	USA	
Source	Medline Plus: US National Library of Medicine & the National Institutes of Health http://nlm.nih.gov/medlineplus/headandneckcancer.html	
Type of Information	<ul style="list-style-type: none"> • Start Here <ul style="list-style-type: none"> • Head and Neck Cancer: Questions and Answers (National Cancer Institute) • Overviews • Head and Neck Cancer (American Academy of Otolaryngology--Head and Neck Surgery) • Latest News <ul style="list-style-type: none"> • High-Tech Imaging No Better for Diagnosing Head/Neck Cancers (05/13/2008, HealthDay) • Head and Neck Cancer Outcomes a Mixed Bag (03/18/2008, HealthDay) • Researchers Find Cause of Severe Allergic Reaction to Cancer Drug (03/12/2008, National Institute of Allergy and Infectious Diseases) • Study Finds Variations in Doses of Radiation Therapy (02/26/2008, HealthDay) • Diagnosis/Symptoms <ul style="list-style-type: none"> • Can Laryngeal and Hypopharyngeal Cancers Be Found Early?(American Cancer Society) • Can Nasopharyngeal Cancer Be Found Early?(American Cancer Society) • Computed Tomography (CT): Head (American College of Radiology, Radiological Society of North America) • Also available in Spanish <ul style="list-style-type: none"> • What Are the Risk Factors for Nasopharyngeal Cancer?(American Cancer Society) • Rehabilitation/Recovery <ul style="list-style-type: none"> • Laryngeal Cancer (American Speech-Language-Hearing Association) • Disease Management <ul style="list-style-type: none"> • Laryngeal and Hypopharyngeal Cancer: What Happens After Treatment?(American Cancer Society) • Nasopharyngeal Cancer: What Happens After Treatment?(American Cancer Society) • Tracheostomy Care (American Head and Neck Society) • Also available in Spanish <ul style="list-style-type: none"> • What Is Cancer of Unknown Primary?(American Cancer Society) • What You Need to Know about Cancer of the Larynx (National Cancer Institute) 	<ul style="list-style-type: none"> • Specific Conditions <ul style="list-style-type: none"> • Adenoid Cystic Carcinoma (American Society of Clinical Oncology) • Chondrosarcoma- Head and Neck (Children's Hospital Boston) • Nasopharyngeal Cancer (American Academy of Family Physicians) • Also available in Spanish <ul style="list-style-type: none"> • Questions and Answers about Cigar Smoking and Cancer (National Cancer Institute) • Smokeless Tobacco and Cancer: Questions and Answers (National Cancer Institute) • Swallowing Problems After Head and Neck Cancer(American Speech-Language-Hearing Association) • What Should You Ask Your Doctor about Laryngeal or Hypopharyngeal Cancer?(American Cancer Society) • What Should You Ask Your Doctor about Nasopharyngeal Cancer?(American Cancer Society) • Videos <ul style="list-style-type: none"> • Advances in Parotidectomy and Thyroidectomy Surgery (OR-Live) - Requires Flash Player - One hour program - 12/11/2007 • Endoscopic Partial Laryngectomy Using Transoral Laser Microsurgery (OR-Live) - Requires media player - One hour program - 5/10/2007 • Clinical Trials <ul style="list-style-type: none"> • ClinicalTrials.gov: Head and Neck Neoplasms (National Institutes of Health) • ClinicalTrials.gov: Laryngeal Neoplasms (National Institutes of Health) • ClinicalTrials.gov: Pharyngeal Neoplasms (National Institutes of Health) • Also available in Spanish <ul style="list-style-type: none"> • Treatment of Laryngeal and Hypopharyngeal Cancers by Stage (American Cancer Society) • Prevention/Screening <ul style="list-style-type: none"> • What Are the Risk Factors for Laryngeal and Hypopharyngeal Cancer? (American Cancer Society) • Related Issues <ul style="list-style-type: none"> • Cigarette Smoking and Cancer: Questions and Answers (National Cancer Institute)

<p>Type of Information cont'd</p>	<ul style="list-style-type: none"> • Research <ul style="list-style-type: none"> • What's New in Laryngeal and Hypopharyngeal Cancer Research and Treatment?(American Cancer Society) • What's New in Nasopharyngeal Cancer Research and Treatment?(American Cancer Society) • Statistics <ul style="list-style-type: none"> • What Are the Key Statistics about Laryngeal and Hypopharyngeal Cancers?(American Cancer Society) • What Are the Key Statistics about Nasopharyngeal Cancer?(American Cancer Society) • Dictionaries/Glossaries <ul style="list-style-type: none"> • Dictionary of Cancer Terms (National Cancer Institute) • Journal Articles (References and abstracts from MEDLINE/PubMed – National Library of Medicine) <ul style="list-style-type: none"> • Article: Survival differences between patients with scalp or neck melanoma and... • Article: Providing effective support for patients facing disfiguring surgery. • Article: Advances in radiation therapy of head and neck cancer • Head and Neck Cancer -- see more articles • Ear, nose, throat and tracheal cancers -- see more articles • Also available in Spanish <ul style="list-style-type: none"> • Do We Know What Causes Laryngeal and Hypopharyngeal Cancers?(American Cancer Society) • Do We Know What Causes Nasopharyngeal Cancer?(American Cancer Society) • Head and Neck Radiation Treatment and Your Mouth (National Institute of Dental and Craniofacial Research) • Directories <ul style="list-style-type: none"> • Find an Otolaryngologist(American Academy of Otolaryngology--Head and Neck Surgery) • National Cancer Institute Cancer Centers Program (National Cancer Institute) • Also available in Spanish • Organisations <ul style="list-style-type: none"> • American Academy of Otolaryngology--Head and Neck Surgery • American Cancer Society • National Cancer Institute 	<ul style="list-style-type: none"> • Also available in Spanish <ul style="list-style-type: none"> • How Are Laryngeal and Hypopharyngeal Cancers Diagnosed?(American Cancer Society) • How Are Laryngeal and Hypopharyngeal Cancers Staged? (American Cancer Society) • How Is Nasopharyngeal Cancer Diagnosed?(American Cancer Society) • How Is Nasopharyngeal Cancer Staged?(American Cancer Society) • MRI of the Head (American College of Radiology, Radiological Society of North America) • Also available in Spanish • Oral Complications of Chemotherapy and Head/ Neck Radiation (PDQ) (National Cancer Institute) • Also available in Spanish <ul style="list-style-type: none"> • Squamous Cell Carcinoma of the Larynx (College of American Pathologists) - Links to PDF • Treatment <ul style="list-style-type: none"> • Chemotherapy and Radiation Together May Help Save Voice box (National Cancer Institute) • Head and Neck Cancer (American College of Radiology, Radiological Society of North America) • Also available in Spanish <ul style="list-style-type: none"> • Hypopharyngeal Cancer (PDQ): Treatment (National Cancer Institute) • Also available in Spanish <ul style="list-style-type: none"> • Laryngeal and Hypopharyngeal Cancer: Surgery (American Cancer Society) • Laryngeal Cancer (PDQ): Treatment (National Cancer Institute) • Metastatic Squamous Neck Cancer with Occult Primary (PDQ): Treatment (National Cancer Institute) • Also available in Spanish <ul style="list-style-type: none"> • Nasopharyngeal Cancer (PDQ): Treatment (National Cancer Institute) • Also available in Spanish <ul style="list-style-type: none"> • Nasopharyngeal Cancer: Treatment Options by Stage (American Cancer Society) • Oropharyngeal Cancer (PDQ): Treatment (National Cancer Institute)
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Country	USA
Source	National Cancer Institute: http://www.cancer.gov/cancertopics/types/head-and-neck/
Type of Information	<ul style="list-style-type: none"> • Definitions of head and neck cancer • Overview of head and neck cancer <ul style="list-style-type: none"> • Head and Neck Cancer: Questions and Answers. • Online booklet <ul style="list-style-type: none"> • What You Need To Know About™ Cancer of the Larynx . • Treatment • Prevention, Genetics, Causes • Screening and Testing <ul style="list-style-type: none"> • Oral Cancer Screening • [patient] [health professional] <ul style="list-style-type: none"> • Interpreting Laboratory Test Results . • Clinical Trials <ul style="list-style-type: none"> • Head and Neck Cancer Trial Results • How to Find a Cancer Treatment Trial • Clinical Trial Search • Cancer Literature <ul style="list-style-type: none"> • Cancer Topic Searches: Head and Neck Cancers • Cancer Topic Searches: Endocrine Cancers • Cancer Literature in PubMed • Research and Related Information <ul style="list-style-type: none"> • Head and Neck Cancer Research Projects • Cancer Research Portfolio: NCI Funding Opportunities • Head and Neck SPORes • Statistics <ul style="list-style-type: none"> • Snapshot of Head and Neck Cancers • Finding Cancer Statistics • Understanding Cancer Statistics

15

Country	USA
Source	Oncology Channel: http://www.oncologychannel.com/headneck/index.shtml
Type of Information	<ul style="list-style-type: none"> • Overview • Anatomy of the head and neck • Risk Factors • Pathology • Signs and Symptoms, Diagnosis • Staging • Types • Treatment and Clinical Trials • Hypopharynx Tumors • Laryngeal Cancer • Nasal Cavity and Paranasal Sinus Tumors • Oropharynx Tumors • Salivary Gland Cancer • Oral Cavity Cancer • Nasopharyngeal Cancer • Questions to ask your doctor about your cancer • Head and Neck Cancer forum • Share and view stories
Description of Resource	Website – 6700 words

16

Country	USA
Source	Oral Cancer Foundation: http://www.oralcancerfoundation.org/
Type of H&N Cancer/Treatment	Oral Cancer
Type of Information	<ul style="list-style-type: none"> • Survivor/Patient forum • Oral cancer in the news • Oral cancer facts • Diagnosis • Treatment • Restoration/Rehabilitation • Dental Issues • Emotional aspects • Oral cancer events • The Tobacco Connection • The HPV Connection • Other Resources • Research/Clinical Trials
Description of Resource	Website – 11600 words

17	
Country	USA
Source	Radiology Info: http://www.radiologyinfo.org/
Type of Information	<ul style="list-style-type: none"> • Head and neck cancer overview • What are my treatment options? • What happens during radiation therapy? • What are possible side effects of radiation therapy? • What are some of the possible risks or complications? • What kind of treatment follow-up should I expect? • Are there any new developments in treating my disease?
Description of Resource	Online general information for patients – 2050 words
18	
Country	USA
Source	Sloan-Kettering – Head and Neck Cancers: http://www.mskcc.org/
Type of H&N Cancer/Treatment	<ol style="list-style-type: none"> 1. Oral Cancer 2. Laryngeal Cancer 3. Pharyngeal Cancer 4. Nasal Cavity & Paranasal Sinus Cancers 5. Salivary Gland Cancer
Type of Information	<ul style="list-style-type: none"> • Overview • Risk Factors • Prevention & Screening • Symptoms • Diagnosis & Staging • Treatment • Our Clinical Trials • Survivorship & Support • A Patient's Story
Description of Resource	Webpage for Memorial Sloan-Kettering Cancer Center – 3830 words

19	
Country	USA
Source	Support for People with Oral and Head and Neck Cancer (SPOHNC): http://www.spoync.org/
Type of Information	<ul style="list-style-type: none"> • Resources for Head and Neck Cancer • Diet and Nutrition • Disability Insurance • Complementary & Alternative Medicine • Medical Guides • Cancer Centers • Cancer Organisations • Clinical Trials • Support Organisations • Professional Societies • Government Sites
Description of Resource	Online resource with links of different information sources.
20	
Country	USA
Source	UCSF Medical Center: http://www.ucsfhealth.org/
Type of H&N Cancer/Treatment	<ol style="list-style-type: none"> 1. Larynx Cancer 2. Oral Cancer 3. Salivary Gland Cancer 4. Throat Cancer
Type of Information	<ul style="list-style-type: none"> • Signs and Symptoms • Diagnosis <ul style="list-style-type: none"> • Indirect laryngoscopy • Direct laryngoscopy • Treatment <ul style="list-style-type: none"> • Radiation therapy • Surgery • Chemotherapy
Description of Resource	Webpage for UCSF Medical Center – <ol style="list-style-type: none"> 1. 830 words 2. 500 words 3. 345 words 4. 690 words

21	
Country	USA
Source	University of Texas, MD Anderson Cancer Center: http://www.mdanderson.org/
Type of H&N Cancer/Treatment	<ol style="list-style-type: none"> 1. Brain Cancer 2. Eye Cancer 3. Laryngeal Cancer 4. Melanoma 5. Nose and paranasal sinus tumors 6. Oral Cancers (including mouth, tongue and lips) 7. Pharyngeal (throat) cancer 8. Salivary gland tumors 9. Sarcomas 10. Skin cancer of the head and neck
Type of Information	<ul style="list-style-type: none"> • Disease Information • Risk Factors • Symptoms • Diagnosis • Treatment • Side Effects of Therapy • Patient Stories
Description of Resource	<p>Webpage for MD Anderson Cancer Center –</p> <ol style="list-style-type: none"> 1. 1285 words 2. 500 words 3. 560 words 4. 5400 words 6. 520 words 9. 1000 words 10. 1530 words

22	
Country	USA
Source	The Yul Brynner Head and Neck Cancer Foundation: http://www.yulbrynnerfoundation.org/
Type of Information	<ul style="list-style-type: none"> • About the Yul Brynner Foundation • Mission of the Foundation • Head and Neck Discussion Forum • Information on Clinical Trials • More On the Risks of Smoking • More on the risks of Smokeless Tobacco • Events
Description of Resource	Online cancer foundation – 790 words
23	
Country	USA
Source	American Academy of Otolaryngology – Head and Neck Surgery: http://www.entnet.org/
Type of H&N Cancer/Treatment	1. Laryngeal
Type of Information	<ul style="list-style-type: none"> • Early Detection • Causes • Symptoms • Risk Factors • What You Should Do
Description of Resource	Online ENT health information and fact sheet – 1550 words
24	
Country	USA
Source	American Cancer Society: http://www.cancer.org/
Type of H&N Cancer/Treatment	1. Laryngeal 2. Hypopharyngeal
Type of Information	<ul style="list-style-type: none"> • Overview • Detailed Guide <ul style="list-style-type: none"> • What Is It • Causes, Risk Factors and Prevention • Early Detection, Diagnosis, Staging • Treating Laryngeal and Hypopharyngeal Cancer • Talking With Your Doctor • More Information
Description of Resource	Booklet: downloadable – 43 pages

25	
Country	USA
Source	American Dental Association: http://www.ada.org/
Type of H&N Cancer/Treatment	Oral Cancer
Type of Information	<ul style="list-style-type: none"> • The Importance of Early Detection • You Should Know <ul style="list-style-type: none"> • Symptoms • Regular Dental Check-ups Important • Facts About Oral Cancer <ul style="list-style-type: none"> • Incidence and Mortality • Risk Factors • Prevention and Detection
Description of Resource	Online fact sheet – 1045 words
26	
Country	USA
Source	InteliHealth: http://www.intelihealth.com/
Type of H&N Cancer/Treatment	<ol style="list-style-type: none"> 1. Upper Aerodigestive Tract 2. Salivary Glands 3. Nasopharynx 4. Sinuses and Nasal Cavity
Type of Information	<ul style="list-style-type: none"> • What Is It? • Symptoms • Diagnosis • Expected Duration • Treatment • When To Call A Professional • Prognosis
Description of Resource	Online resource by Harvard Medical School – 2000 words

27

Country	USA
Source	Medicine Net: http://www.medicinenet.com/
Type of H&N Cancer/Treatment	<ol style="list-style-type: none"> 1. Oral Cavity 2. Salivary Glands 3. Paranasal Sinuses and Nasal Cavity 4. Pharynx 5. Larynx 6. Lymph Nodes In The Upper Part Of The Neck
Type of Information	<ul style="list-style-type: none"> • What is cancer? • What kinds of cancers are considered cancers of the head and neck? • How common are head and neck cancers? • What causes head and neck cancers? • What are common symptoms of head and neck cancers? • How are head and neck cancers diagnosed? • What health professionals treat patients with head and neck cancers? • How are head and neck cancers treated? • Are clinical trials (research studies) available for patients with head and neck cancers? • What rehabilitation or support options are available for patients with head and neck cancers? • Is follow-up treatment necessary? What does it involve? • What can people who have had head and neck cancer do to reduce the risk of developing a second primary (new) cancer?
Description of Resource	Website – 3380 words

28

Country	USA
Source	American Speech-Language-Hearing Association: http://www.asha.org/public/speech/disorders/LaryngealCancer.htm
Type of H&N Cancer/Treatment	Laryngeal Cancer
Type of Information	<ul style="list-style-type: none"> • What is laryngeal cancer? • What are some signs or symptoms of laryngeal cancer? • How is laryngeal cancer diagnosed? • What treatments are available for individuals with laryngeal cancer? • What is a laryngectomy
Description of Resource	Webpage – 580 words

29

Country	USA	
Source	American Head and Neck Society: http://www.headandneckcancer.org/patienteducation/index.php	
Type of Information	<ul style="list-style-type: none"> • Do I have a tumor of the oropharynx? • Oral Cavity Cancer <ul style="list-style-type: none"> • Anatomy • Incidence, Epidemiology and Pathology • Risk Factors • Symptoms • Evaluation and Diagnosis • Tumour Staging • Treatment • Reconstruction • Rehabilitation • Follow-up • Sinonasal Malignancy / Skull Base Surgery <ul style="list-style-type: none"> • Incidence/Epidemiology/Risk Factors • Anatomy/Pathology • Symptoms • Diagnosis • Treatment Options • Follow up 	
Description of Resource	Webpages – 310 words, 2570 words, 1070 words	
30		
Country	USA	
Source	American Society of Clinical Oncology: http://www.cancer.net/patient/Cancer+Types/Adenoid+Cystic+Carcinoma	
Type of H&N Cancer/Treatment	Adenoid Cystic Carcinoma	
Type of Information	<ul style="list-style-type: none"> • Overview • Risk Factors • Symptoms • Staging • Diagnosis • Treatment <ul style="list-style-type: none"> • Surgery • Radiation therapy • Neutron and proton therapy • Chemotherapy 	<ul style="list-style-type: none"> • Clinical Trials Resources • Side Effects of Cancer and Cancer Treatment • After Treatment • Current Research • Questions to Ask the Doctor • Patient Information Resources
Description of Resource	Webpage – 4470 words	

31	
Country	USA
Source	American Academy of Family Physicians: http://familydoctor.org/online/famdocen/home/common/cancer/types/674.html
Type of Information	<ul style="list-style-type: none"> • What is nasopharyngeal cancer? • Who might get nasopharyngeal cancer? • What causes nasopharyngeal cancer? • What are some signs of nasopharyngeal cancer? • How can my doctor tell if I have nasopharyngeal cancer? • How is nasopharyngeal cancer treated?
Description of Resource	Webpage – 550 words
32	
Country	USA
Source	National Institute of Dental and Craniofacial Research: http://www.nidcr.nih.gov/OralHealth/Topics/CancerTreatment/HeadNeckRadiation.htm
Type of Information	<ul style="list-style-type: none"> • Are you being treated with radiation for cancer in your head or neck? • How does head and neck radiation affect the mouth? • What mouth problems does head and neck radiation cause? • Why should I see a dentist? • When should I see a dentist? • What will the dentist and dental hygienist do? • What can I do to keep my mouth healthy?
Description of Resource	Webpage – 970 words

Existing Web-Based Information Resources Meeting Information Needs of Patients

Web-Based Information Resources	Information Needs of Patients															
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
Information about Head and Neck cancers that describe the disease	N	M	Y	Y	Y	Y	M	M	M	M	N	Y	Y	Y	M	Y
The cause of the disease and how it could have been prevented	N	N	Y/N	Y	N	Y	Y/N	Y	M	Y	N	Y	Y	Y/N	M	Y
The stage of the disease and how it is expected to progress	N	N	Y	Y	N	N	M	N	N	N	N	N	Y	M	Y	N
How far advanced the disease is and how far it has spread	N	N	N	Y	N	N	M	N	N	N	N	N	N	N	Y	N
The goals of treatment	N	N	Y	Y	N	M	Y	N	N	Y	N	N	Y	M	N	Y
Tests and investigations that may be needed	N	M	Y	Y	Y	N	Y	M	N	Y	N	M	Y	Y	N	Y
How to prepare for tests	N	N	N	N	N	N	Y	M	N	Y	N	N	N	N	N	N
The different types of treatment available and their advantages and disadvantages	N	N	Y	Y/N	N	Y	Y	M	N	Y	N	N	Y	Y/M	Y/N	Y
The chances of being cured of the disease	N	N	N	Y	N	M	N	Y	M	N	N	N	N	N	N	N
The evidence behind treatment recommendations	N	N	N	Y	N	N	N	N	N	N	N	N	M	N	N	N
How the treatments are performed	M	N	Y	Y	N	Y	Y	M	N	Y	N	N	N	Y	N	Y
How the treatments work against the disease	N	N	M	Y	N	Y	Y	N	N	M	N	N	M	Y	N	Y
Possible side effects of treatment	Y	N	Y	N	N	M	Y	N	N	Y	N	N	N	N	M	Y
Management of unpleasant treatment side effects: Radiation therapy - skin care, mouth care Chemotherapy - nausea and vomiting	Y	N	Y	N	N	N	Y	N	N	N	N	N	N	N	N	Y
Dental check-ups and care	M	N	M	N	N	N	Y	Y	N	N	Y	Y	N	N	N	Y
Ways of managing eating and drinking to maintain nutritional intake	N	N	M	N	N	M	Y	N	N	N	N	N	N	Y	N	Y

Legend:

Y – Yes (Existing web-based information met the information needs of patients)

N – No (Existing web-based information does not meet the information needs of patients)

M – Minimum (Only little information have been provided to meet the information needs of patients)

Web-Based Information Resources	Information Needs of Patients															
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
Ways of managing swallowing and communication	N	N	Y	N	N	Y	Y	N	N	N	N	N	N	N	N	N
Being able to care for myself at home	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N
Managing fatigue (feeling tired)	M	N	N	N	N	N	N	N	N	N	N	N	N	Y	N	Y
How the treatment may affect normal daily activities	N	N	N	N	N	N	Y	M	N	N	N	N	N	N	N	M
Being able to work or concerns about finances	N	N	M	N	N	N	N	M	N	N	N	N	N	N	N	N
Cost of treatments	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N
How family and social life will be affected	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	M
How talking about fears, worries and getting emotional support helps	M	N	Y	N	N	Y	Y	N	N	N	N	N	N	N	N	Y
Stress management	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N
Support groups or other services available for myself and my carer	M	N	Y	Y	N	Y	Y	N	Y	N	N	N	N	Y	N	N
How the treatment may affect my feelings about my body, physical appearance and sexual attractiveness	N	N	Y	N	N	N	Y	Y	N	N	N	N	N	N	N	N
How family and close friends will be affected by the disease	N	N	M	N	N	N	N	N	N	N	N	N	N	N	N	Y
Whether my children or other family members are at risk of getting cancer	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N
Staying well after treatment is finished	N	N	Y	N	N	N	M	M	N	N	N	N	N	N	N	Y
Getting on with life after cancer treatment	N	N	Y	N	N	N	N	M	N	N	N	N	N	N	N	Y
Signs of a recurrence or how to tell if the disease has come back	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N
When cancer cannot be cured and needing palliative care	N	N	Y	N	N	N	N	N	N	N	N	N	N	N	N	N

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Web-Based Information Resources	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32
Information Needs of Patients																
Information about Head and Neck cancers that describe the disease	M	Y	Y	N	M	N	M	Y	M	M	Y	M	Y	Y	M	M
The cause of the disease and how it could have been prevented	N	Y	Y	N	M	M	M	Y	Y	M	Y/N	Y/N	Y/N	M	M/N	Y
The stage of the disease and how it is expected to progress	N	M	Y	N	N	N	N	Y	N	N	N	N	N	Y	N	N
How far advanced the disease is and how far it has spread	N	N	N	N	N	N	N	N	N	N	N	N	Y	N	N	N
The goals of treatment	M	Y	Y	N	M	N	N	Y	N	M	M	N	N	Y	N	N
Tests and investigations that may be needed	N	Y	Y	Y	N	N	N	Y	N	N	Y	Y	N	Y	N	Y
How to prepare for tests	N	N	N	N	N	N	N	N	N	N	N	N	M	N	N	Y
The different types of treatment available and their advantages and disadvantages	Y	Y	Y	Y/N	M	N	N	Y	N	M	Y	Y	Y/N	Y	M/N	N
The chances of being cured of the disease	N	N	N	N	N	N	N	N	N	N	N	N	Y	N	N	N
The evidence behind treatment recommendations	M	N	M	N	N	N	N	M	N	N	N	N	N	N	N	N
How the treatments are performed	M	M	N	N	N	N	N	Y	N	N	M	N	N	Y	N	M
How the treatments work against the disease	M	N	M	N	N	N	N	M	N	N	M	N	N	Y	N	N
Possible side effects of treatment	Y	N	N	N	M	N	N	M	N	N	Y	Y	N	Y	N	Y
Management of unpleasant treatment side effects: Radiation therapy - skin care, mouth care Chemotherapy - nausea and vomiting	M	N	Y	N	N	N	N	M	N	N	Y	N	N	Y	N	Y
Dental check-ups and care	N	N	N	N	N	N	N	N	Y	N	M	N	N	N	N	Y
Ways of managing eating and drinking to maintain nutritional intake	N	N	Y	N	N	N	N	Y	N	N	Y	N	N	Y	N	N

Legend:

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Web-Based Information Resources	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32
Information Needs of Patients																
Ways of managing swallowing and communication	N	N	N	N	N	N	N	Y	N	N	N	N	N	N	N	N
Being able to care for myself at home	N	N	N	N	N	N	N	M	N	N	N	N	N	N	N	Y
Managing fatigue (feeling tired)	N	N	N	Y	N	N	N	Y	N	N	N	N	N	N	N	N
How the treatment may affect normal daily activities	N	N	N	N	N	N	N	Y	N	N	N	N	N	N	N	N
Being able to work or concerns about finances	N	N	N	N	N	N	N	M	N	N	N	N	N	N	N	N
Cost of treatments	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N
How family and social life will be affected	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N
How talking about fears, worries and getting emotional support helps	N	M	N	N	N	N	N	N	N	N	N	N	N	N	N	N
Stress management	N	N	N	N	N	N	N	N	N	N	N	N	N	Y	Y	N
Support groups or other services available for myself and my carer	N	Y	Y	N	Y	N	N	Y	N	N	Y	N	N	Y	N	N
How the treatment may affect my feelings about my body, physical appearance and sexual attractiveness	N	N	N	N	N	N	N	Y	N	N	N	N	N	Y	N	N
How family and close friends will be affected by the disease	N	N	N	N	N	N	N	N	N	N	N	N	N	Y	N	N
Whether my children or other family members are at risk of getting cancer	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N
Staying well after treatment is finished	N	N	N	N	N	N	N	Y	N	N	M	N	N	N	N	N
Getting on with life after cancer treatment	N	N	N	N	N	N	N	Y	N	N	M	N	N	N	N	N
Signs of a recurrence or how to tell if the disease has come back	N	N	N	N	N	N	N	N	N	N	N	N	M	N	N	N
When cancer cannot be cured and needing palliative care	N	N	N	Y	N	N	N	N	N	N	N	N	N	Y	N	N

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