

### Supplementary Information 3: Data Extraction table showing characteristics of the 23 selected papers

First author, year, country	Study Title	Study design	Sample: total, % Oropharyngeal patients MF, age	Treatment	Sampling method and time point of data collection	Method of data collection	Method of data analysis
1. Semple et al (2010) NI, UK	Experience of parents with HNC who are caring for young children	Exploratory descriptive study	12 HNC, unspecified site, 10 M, all <59 yrs.	9 had radiotherapy, 4 + chemotherapy 5 + surgery, 3 had surgery only.	Purposive: diagnosis within 3 yrs. when had children aged 16 or under	Interviews with topic guide & open-ended questions	Cognitive mapping – modelling technique to show ideas, beliefs, values, and attitudes & their relationships to each other. 'How the world is seen'.
2. Andersen and Jarden (2012) Denmark	Coping with RT for HNC: a qualitative exploration	Hermeneutic approach to interpretative study	5 HNC, includes oropharyngeal patient(s), 4 M, 50-65 yrs.	All had radiotherapy	Convenience: within one month of treatment	Semi-structured interviews with topic guide	Thematic analysis with application of Lazarus & Folkman conceptual model of coping
3. Haisfield-Wolfe et al (2012) USA	Perspectives on coping among HNC patients receiving radiotherapy	Longitudinal descriptive study	21 HNC, 16 oropharyngeal patients (76%) 18 M, av. 59.2 yrs.	All had radiotherapy, 15 had concomitant chemotherapy.	Convenience. 4 time points: Radiotherapy week 1, 5, 9 & 12	Interviews with 3 open-ended questions	Content analysis
4. Molassiotis and Rogers (2012) UK	Symptom experience and regaining normality in the first year following a diagnosis of HNC	Longitudinal interpretative explanation	16 HNC, 14 oral and oropharyngeal 14 M, av. 61 yrs. 34-80	12 had radiotherapy, 4 had concomitant chemotherapy, 4 had surgery only. Half palliative	Purposive sampling for variation: 4 time points: diagnosis, 3, 6 (EOT) & 12 months	Interviews: questions used for varied cancer sites & early responses informed questions at later interviews	Content analysis cross-sectionally and longitudinally
5. Moore et al (2014) Australia	'I have quality of life but...' Exploring support needs important to quality of life in HNC	Exploratory descriptive study of experiences throughout treatment trajectory	8 HNC, 3 oropharyngeal = 38%. 7 M, 51-60 yrs. av. 60	All had radiotherapy, 5 also had surgery.	Snowball and convenience sampling from a support group. 1-8yrs after treatment, av.= 4.25yrs.	Semi-structured interviews with open-ended questions	Content analysis – inductive and directed using Lazarus & Folkman model of stress.

6. Schaller et al (2015) Sweden	Experiences of pain: a longitudinal study of HNC patients recently treated with radiotherapy	Longitudinal descriptive study	26 HNC, 9 (35%) oropharyngeal 19 M, av. 64 yrs.	All had radiotherapy, 11 + chemotherapy + varied surgery	Purposive sampling. 1 and 4-6 months after treatment	2 interviews – unstructured	Content analysis
7. McQuestion and Fitch (2016) Canada	Patients' experiences of receiving RT for HNC: before, during & after treatment	Interpretative descriptive study	17 HNC (mixed site not specified), 12 M, 15 <70 yrs.	All had radiotherapy, none had chemotherapy	Purposive sampling - subset of larger study. 3-4 months after radiotherapy	Interviews plus member checking with focus group (4)	Thematic analysis (Giorgi '85)
8. Peeters et al (2018) Netherlands	Support needs of people with HNC regarding the disease and its treatment	Phenomenological study using conceptual framework	13 HNC, 7 (54%) oropharyngeal 10 M, 48-73 years (median = 60)	All had radiotherapy, 9+ chemotherapy	Purposive sampling: 7 for 2 focus groups & 6 interviews. 6 <12months after RT, 7<2yrs	2 Focus groups and 6 interviews	Direct content analysis using Dwarswaard et al '16 conceptual framework of Self-management support needs.
9. Grattan et al (2018) Canada	Experiences of HNC in middle adulthood – consequences and coping	Interpretative descriptive study	10 middle aged HNC: 5 HPV+ve (& 4 untested) 9 M, <65yrs, median = 54	All had radiotherapy, 8 with surgery.	Purposive sampling. 2-19 months after treatment, median = 14	Unstructured interviews	Thematic analysis
10. Dodd et al (2019) UK	Psychosocial impact of HPV HNC diagnosis on patients and their partners: a qualitative interview study	Descriptive study	20 HPV+ oropharyngeal patients (14 M) and 12 partners (2 M) median age = 59, 41-83.	18 had radiotherapy, 5 + chemotherapy 1 had surgery only	Purposive sampling. 1 year after diagnosis, range = 12-53 months, av.= 23	Semi-structured interviews	Thematic analysis – focused on the 12 patients & 5 partners aware of HPV+ve status
11. Calver et al (2019) UK	How patients adjust psychologically to the experience of HNC: a grounded theory	Grounded theory	12 HNC, 4 (33.3%) oropharyngeal inc.1 rec. 8 M, 35-72 yrs. Av 58.75	8 had radiotherapy, 4+ chemotherapy. 1 at diagnosis, 3 surgery only.	Purposive and then theoretical sampling. Only 2 oropharyngeal patients treated within 2 years.	Semi-structured interviews – questions refined through study.	Analysis guided by Corbin & Strauss '15.

12. McQuestion et al (2011) Canada	Changed meaning of food – physical emotional social loss for patients having received HNC radiation treatment	Interpretative descriptive study	17 HNC (mixed site not specified), 12 M, 15 <70 yrs.	All had radiotherapy, none had chemotherapy.	Purposive sampling - subset of larger study. 3-4 months after radiotherapy	Interviews	Thematic analysis (Giorgi '85)
13. Ottosson et al (2013) Sweden	The experience of food, eating and meals after RT for HNC	Descriptive study	13 HNC, 6 (46%) oropharyngeal 11 M, median 60 yrs. 47-70	All had radiotherapy, none had chemotherapy.	Purposive sampling. 8-11 months after RT - with reflection on early post RT	Semi-structured interviews	Content analysis
14a. Nund et al (2014a) Australia	Survivors' experiences of dysphagia-related services following HNC: Implications for clinical practice	Descriptive with phenomenological aspects	24 HNC, 18 (75%) oropharyngeal (14 HPV+ve), 20 M, 18 <65 yrs.	23 had chemo-radiotherapy, 1 had radiotherapy alone.	Purposive sampling: have dysphagia. Av = 18 months after treatment -range 1-60mo, 5< 3mo	Semi-structured interviews	Thematic analysis
14b. Nund et al (2014b) Australia	Lived experience of dysphagia following non-surgical treatment for HNC	As above	As above	As above	As above	As above	As above
15. Charalambous (2014) Cyprus	Hermeneutic phenomenological interpretations of HNC patients experiences living with radiation-induced xerostomia: the price to pay?	Hermeneutic phenomenology	15 HNC, (site not specified) 8 M, 39-66 yrs. (av. 54)	All had radiotherapy	Purposive sampling: including assessment of xerostomia. 3 months after treatment	Unstructured interviews	Thematic analysis and hermeneutic phenomenological structural analysis

16. Brockbank et al (2015) UK	Pre-treatment Information on Dysphagia: Exploring the views of HNC patients	Descriptive study of service experience	24 HNC (site not given) 22 M, median 59 yrs. (44-77)	All had chemo-radiotherapy	Purposive sampling: had dysphagia. Av. 10 months, 2-22 months after treatment	Focus groups (11) and interviews (13)	Thematic analysis
17. Patterson et al (2015) UK	HNC patients' perceptions of swallowing following chemo-radiotherapy	2 stages: Ethnographic observation & descriptive study	12 + 9 HNC, 39% oropharyngeal ( <i>approx. from larger study</i> ). 18 M, age 45-77 median 63.	All had radiotherapy, 17 also had chemotherapy.	Purposive sampling from larger study: presence of dysphagia. 3-18 months after treatment	Observations and interviews	Thematic analysis
18. Ehrsson et al (2015) Sweden	HNC perceptions of QOL and how it is affected by the disease and enteral tube feeding during treatment.	Longitudinal descriptive study	36 HNC, 16 (39%) oropharyngeal 28 M, av. 62.3 yrs.	All had radiotherapy, 13 + chemotherapy, 12 + surgery	Purposive sampling. Pre-radiotherapy and 2 weeks & 3 months after treatment	Structured interviews, using QoL questionnaire.	Content analysis
19. Williams et al (2019) UK	Patients' experience of enteral feeding following chemo-radiotherapy for HNC: a qualitative study	Interpretative descriptive study	10 HNC, 8 (80%) oropharyngeal 8 M, median 54, yrs. 43-65	All had radiotherapy, 9 + chemotherapy	Purposive sampling: presence of feeding tubes. Median 26 days after treatment, range 3-231 days, 9 patients within 12 weeks	Semi structured interviews	Thematic analysis
20. Sandmael et al (2019) Norway	Nutritional experiences in HNC	Descriptive study	10 HNC, 7 (70%) oropharyngeal 5 M, median 59 yrs. 49 – 70	All had radiotherapy	Purposive sampling: from a supportive nutrition rehab intervention pilot study. 2-4 weeks after treatment	Semi structured interviews	Content analysis

21. McGarvey et al (2014) Australia	Lymphoedema following treatment for HNC: impact on patients, and beliefs of HCPs	Interpretative descriptive study of patients and HCP beliefs	10 HNC, 5 oropharyngeal 8 M, av. 60.1 yrs. 32–75 and 10 HCPs.	All had radiotherapy, 5 non-oropharyngeal + neck dissection	Purposive sampling: presence of lymphoedema. Most around 12 months after treatment, all <18 months.	Interviews with open and closed questions	Thematic analysis
22. Jeans et al (2018) Australia	Patient perceptions of living with head and neck lymphoedema and the impacts to swallowing, voice and speech function.	Interpretative descriptive study	12 HNC, 7 (58%) oropharyngeal (6 HPV+ve), 8 M, av. 61.3 yrs. 52–72	All had chemo-radiotherapy, 6 + neck dissection	Purposive sampling: presence of lymphoedema. 3-22 months (av. 8.4) after treatment	Semi structured interviews. Patients had questions beforehand, mixed face to face and phone	Thematic analysis