"This one is a bit of a taboo subject": A Mixed Methods Investigation into the Impact of Head and Neck Cancer upon Sexuality

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Thesis submitted in part fulfilment of requirements for the degree of

Doctorate in Clinical Psychology to the University of Nottingham

2022

Portfolio Abstract

Background: Previous research demonstrates Head and Neck Cancer (HNC) survivors are vulnerable to a negatively impacted sexuality although it is unclear whether changes are attributable to HNC sequelae or other (e.g. maturation) factors. Sexuality is important to wellbeing and unmet sexuality needs following cancer can increase psychological distress. Gaps in knowledge surround the impact of HNC on sexuality: there is considerably less research in relation to HNC's impact on sexuality in comparison to other cancers. This is surprising as HNC is the seventh most common cancer and can produce various functional, aesthetic, and psychosocial difficulties. Individual differences in coping/response style account for variability in experiences of living with cancer – there are links between particular coping styles and levels of psychological distress which could be explored in relation to sexuality outcomes. These differences can be targeted through psychological intervention in ways that clinical or demographic characteristics cannot be. Additionally, professionals struggle to discuss sexuality, meaning that the perceived support needs for physical, practical, and psychological support around sexuality are not fully known.

Aims: This study investigated the impact of HNC upon sexuality, whether psychological flexibility and other coping responses were associated with sexuality and quality of life outcomes, and what the perceived support needs were, if any, for support around sexuality.

Method: A mixed method design was used: 60 participants took part in an online survey and 18 participants completed semi-structured interviews. Quantitative data were analysed using descriptive statistics and correlational analyses. Qualitative data were analysed using reflexive thematic analysis with an inductive-deductive design.

Results: Findings support previous literature, showing that for many of the current study's sample, sexuality is negatively impacted by HNC. This study extended upon extant research, showing that: for those classified as clinically impaired in relation to sexuality, impairment represented a post-HNC deterioration that was not attributable to other measured variables (e.g., age). The themes developed illustrated a series of events where sexuality is necessarily deprioritised during treatment, sexuality is not discussed by professionals, there is still an impact of altered sexual behaviour which can be understood as due to either psychological or physical barriers, and participants respond by attempting to rebuild/renavigate their sexuality. Significant relationships were not found between response styles and sexuality outcomes. A clear support need was identified for greater physical, practical, and psychological support around sexuality.

Conclusions and Recommendations: The provision of HNC-specific informational resources would benefit patients and assist professionals with discussions of sexuality: the timings of such discussions must be sensitive to the fact that individuals necessarily deprioritise sexuality during active treatment. Consideration should be given to which professional is most appropriate to raise the topic of sexuality in terms of who is most likely to be involved following physical treatment. Future research could helpfully triangulate the perspectives of the HNC patients with healthcare professionals to deepen the understanding of the barriers to discussing sexuality for staff, particularly within a population where impacted sexuality is so relevant. Furthermore, to enhance the generalisability of the results obtained from the current sample, research into this study area should be conducted with an explicit focus on increasing ethnic representation within sample participants.

Acknowledgements

To every person who took part in this project as well as the experts by experience who consulted and the Head and Neck charities who supported with recruitment and advice: thank you. It was a true privilege to hear your experiences and I hope I have done them justice in this study.

To my incredible ‘dream team’ of supervisors: Anna and Nima, this really would not have happened without you both. Thanks for the compassionate and knowledgeable responses to the multiple emails and occasional tears. It came together in the end, and I consider myself very lucky to have had the chance to work with you both. Sanchia, many thanks for your knowledge, advice, and support with recruitment.

To my cohort. I feel grateful to have trained with such a wonderful group of people. Particular thanks to Amie, Emma, Aliya, and Sophie – I am very proud of us all.

To my friends: thank you for continuing to ask about the thesis even when the going got tough and always being there to support me. Special thanks to my best friend, Amrit: you know what you have done to support me during this doctorate, and I would be lost without you.

To my parents, Sophy, Emily, and Granny Joan: I have felt your love and support throughout this process and your pride in me has motivated me during the trickiest parts.

And finally to my husband, Nathan. I dedicate this thesis to you. You have been there for me at every single moment, and I will never have enough words to convey my love and appreciation. The support with table formatting, endless cups of tea, and constant encouragement you provided, all whilst you have been submitting your own PhD thesis has been amazing and I feel so very lucky.

Statement of Contribution

Systematic Review

The systematic review was designed by me, Linda Mary McCabe-White, with supervision from Dr Nima Moghaddam, Dr Anna Tickle, and Dr Sanchia Biswas. Relevant literature was reviewed by me with supervision from Dr Nima Moghaddam and Dr Anna Tickle. Data analysis was conducted by me with supervision from Dr Nima Moghaddam.

Journal Paper and Extended Paper

I, Linda Mary McCabe-White, declare that this research is the product of my own original work conducted since beginning the Trent Doctorate in Clinical Psychology programme in 2019. The research project was conceptualised, planned, and designed in collaboration with my research supervisors, Dr Anna Tickle and Dr Nima Moghaddam, and my field supervisor, Dr Sanchia Biswas. I was responsible for reviewing the literature, gaining ethical approval, data collection and analysis, all interview transcription, and the final write-up with supervision from Dr Anna Tickle, Dr Nima Moghaddam, and Dr Sanchia Biswas. Dr Sanchia Biswas supported with participant recruitment in her capacity as a clinician.

Small Scale Research Project

The small scale research project was designed by me, Heather Cogger-Ward (trainee clinical psychologist), Dr Nima Moghaddam, Dr David Dawson, and Dr Roshan Das Nair, with supervision from the aforementioned individuals throughout the project. Relevant literature was reviewed by me and Heather, with supervision from Drs Nima Moghaddam, Roshan Das Nair and David Dawson. Data was collected by me, Linda Mary McCabe-White and Heather Cogger-Ward. Quantitative and qualitative data was analysed by me and Heather Cogger-Ward with supervision from Drs Nima Moghaddam, Roshan Das Nair and David Dawson.

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SYSTEMATIC REVIEW

Factors associated with psychological distress for couples facing Head and Neck Cancer: A systematic literature review

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Abstract:

Objectives: Cancer patients in supportive relationships display improved health and survival outcomes. Identifying factors that might respond to intervention for Head and Neck Cancer (HNC) dyads is important as HNC patients and their partners experience heightened distress. This article systematically reviewed and evaluated the research findings and methodological quality of studies which identified factors influencing psychological distress for couples facing HNC.

Methods: PsycINFO, Medline, and CINAHL were searched. Studies were included if they used validated psychological distress measures and quantitative data collection methods. 11 studies satisfied inclusion criteria.

Results: Studies identified factors associated with the psychological distress experienced by couples facing HNC, with substantial effect size variation. These factors included clinical, sociodemographic, relational, and psychological variables. Factors associated with increased psychological distress included disease burden, reduced social contact, perception of reduced relationship quality, and less adaptive/assimilative coping although the effect sizes displayed considerable heterogeneity. Overall, studies possessed good methodological quality but generally could have been improved by minimising the risk of non-response bias and fully reporting relational characteristics.

Conclusions: The implications of these results for clinical practice and future research are discussed. Further research is recommended to report effect sizes more consistently for both dyad members to gain greater insight into couple-level distress and to perform moderator analyses to identify which variables influence the magnitude of psychological distress.

Keywords: Anxiety, cancer, couple, depression, dyad, head and neck cancer, oncology, partner, psychological distress, systematic review

1. Introduction

Head and Neck Cancer (HNC) refers to malignancies that occur in the paranasal sinuses, nasal cavity, oral cavity, larynx, and pharynx. There are 300,000 HNC-related deaths and approximately 880,000 incidences of HNC annually (Bray et al., 2018; Fitzmaurice et al., 2017). HNC and its related treatments such as radiotherapy, chemotherapy and surgery pose significant physical and psychological challenges (Lang et al., 2013) concerning visible disfigurements and impaired eating, speaking, swallowing, and breathing (Ledeboer et al., 2005; Millsopp et al., 2006). Psychological distress occurs frequently in HNC patients and can endure post-treatment (Badr et al., 2019). Psychological distress is a particular concern in HNC (Dunne et al., 2017; Korsten et al., 2019), as HNC survivors have increased suicide risk even compared with other cancer patients (Frampton, 2001). Several factors contribute towards this, such as a significant symptom burden, functional difficulties (breathing, swallowing, eating), heightened recurrence risk, stigma associated with alcohol use/smoking in the development of cancer, and poor prognosis outcomes (Milette et al., 2010).

Partners of HNC survivors also experience heightened psychological distress (Nightingale et al., 2014; Posluszny et al., 2015); this is consistent with spouses of other cancer-type survivors but could be pronounced in HNC due to high care-giving responsibilities and the severe physical and psychosocial impact of the diagnosis and related treatment (Kam et al., 2015; Offerman et al., 2010). An HNC survivor's partner may need to provide considerable support with symptom management, rehabilitation tasks, emotional distress, and communication needs (Badr et al., 2019; Offerman et al., 2010). Research suggests that rates of psychological distress in partners of HNC survivors are higher than distress reported in individuals diagnosed with other cancers, including breast and prostate cancer (Vickery et al., 2003; Zabora et al., 2001). A study investigating psychosocial adjustment for HNC caregivers in the post-treatment period (6-24 months) found that 39% of caregivers reported moderate to high distress (Ross et al., 2013): this highlights the far-reaching impact upon HNC caregivers during and beyond treatment.

Furthermore, HNC presents difficulties for couple-level functioning relating to intimacy and sexuality; this includes treatment-related consequences that impact on physical connection such as the presence of a feeding tube, body image concerns, and oral difficulties such as a persistent dry mouth or excessive salivation (Badr, Herbert, et al., 2016b; Badr, Milbury, et al., 2016; Rhoten, 2016). Additionally, the physical sequelae of HNC can impact upon couple-level communication; the structures commonly affected by treatment are important for both verbal and non-verbal communication, such as speaking and achieving facial expressions (Rhoten et al., 2013). These difficulties are reflected in research indicating a decline in marital functioning one year post-treatment (Gritz et al., 1999). Another study reported that 83% of HNC spouses and 100% of patients stated that there was increased marital dispute during treatment (Badr, Herbert, et al., 2016a).

It is important to support couples to maintain relationships while they experience the stressors of diagnosis and treatment, as a supportive partner relationship is implicated in increasing quality of life, improved adaptation to the cancer, and better survival rates (Badr et al., 2019); Research found that being married reduced the chance of death for HNC patients by 33% (Aizer et al., 2013) and substantially improved performance status during treatment in comparison to unmarried patients (Konski et al., 2006). Research recommends that developing couple-based interventions for dyads experiencing HNC could focus on communication and collaboration (Manne & Badr, 2010). Understanding a wide range of influencing factors is important, as the development of couple-based interventions has been predominately aimed at patients and partners experiencing breast or prostate cancer (Badr & Krebs, 2013). However, a broader understanding of the psychological, clinical, relational, social, and demographic factors (Cook et al., 2018) that influence dyadic psychological distress, either as causes or exacerbating/buffering factors, is currently missing from the HNC literature. The development of this understanding would make it easier to both identify malleable factors which could be targeted in such couple-based interventions and screen for/assess couples who may be especially vulnerable to experiencing psychological distress.

Psychological distress is variously defined across literature. This review defines it as an aversive emotional state which is experienced by an individual when they are presented with a stressor or demand that causes either temporary or permanent harm (Ridner, 2004).

Rationale for current review

While other reviews have examined factors associated with depression and quality of life in HNC patients (Dunne et al., 2017; Korsten et al., 2019), no review has systematically investigated the factors influencing distress for both HNC patients and their partners. This review aims to systematically identify and synthesise the key findings of studies that identify these associated factors. Furthermore, the review aims to provide a detailed appraisal of the methodological quality of the identified papers. Due to evidence indicating that couples facing HNC experience heightened levels of distress (Bakhshaie et al., 2020), a clearer understanding of factors influencing this experience could inform clinical practice and add to existing theories such as the relationship intimacy model of couples’ psychosocial adaptation to cancer (Manne & Badr, 2008). This model suggests that couples affected by cancer adopt relationship behaviours which either increase or reduce dyadic closeness: this closeness is hypothesised to influence the couple’s adaptation to cancer (Manne & Badr, 2008). A broader understanding of any influencing relational and psychological factors warrants particular attention, given the potential malleability of couple-level relational interactions and individual-level psychological responses/appraisals in reducing psychological distress, as compared to demographic and clinical factors. However, an awareness of the influencing demographic, social, and clinical factors is also important in supporting clinicians/researchers to screen for/assess couples who are vulnerable to experiencing greater distress.

Objectives

(1) Systematically identify and synthesise key findings of studies that identify factors associated with psychological distress for both HNC patients and their partners.

(2) Offer a detailed appraisal of the methodological quality of the identified research papers.

2. Methodology

The review was pre-registered with the International Prospective Register of Systematic Reviews (PROSPERO: ID = CRD42020213101)

Eligibility Criteria

Studies were considered for inclusion if they satisfied the following criteria:

1. Consisted of a sample of couples where one member had experienced HNC. Adult patients at any stage of HNC were included. In line with medical literature (Heroiu Cataloiu et al., 2013; Shah & Lydiatt, 1995) and previous systematic literature reviews (Morris et al., 2018), thyroid cancer patients were included. However, oesophageal cancer was not included (Berry, 2014).

2. Available in English language for practicality.

3. Published in a peer-reviewed journal to ensure a minimum standard for scientific rigour and quality.

4. Included a validated measure of psychological distress which was reported as an outcome measure (either a primary or secondary outcome).

5. Reported separately extractable data for both members of the couple to gain a holistic picture of couple-level psychological distress and the factors influencing this.

6. Used a quantitative method for data collection and analysis. The current review did not list a mixed-methods design as exclusion criteria but would only extract quantitative data.

7. Reported a measure of association between psychological distress and the relevant influencing factor.

Studies were excluded if:

1. A heterogeneous cancer sample was described with no isolable HNC data.

2. The dyads in the study were not specifically described as partner dyads (i.e. caregiver or family member dyads).

No limits existed regarding quantitative study designs or publication years, other than the limitations imposed due to the time periods covered by the databases. Where two papers reported results relating to the same study and participants, they were included if each paper asked different questions of the data.

Systematic Search

Research articles were systematically searched for using the Ovid host (www.ovid.com); the CINAHL, PsycINFO, and MEDLINE databases were searched from the start of the database to the 20th October 2020. A research librarian was consulted to generate individualised search terms for each database (Appendix A). Search terms consisted of medical subject headings (MeSH) and free-text search terms (Appendix A). The three key review search concepts were ‘partners’, ‘head and neck neoplasms’, and ‘psychological distress’; however, several search terms were produced for each key term to ensure thorough searches. The search terms were exploded where appropriate to access articles using different terminology. Following the identification of relevant search terms, the list of terms for each key concept were linked using the Boolean operators of ‘or/and’ to produce the search results for the three databases. The search results were gathered and any duplicates between databases were removed using the Mendeley reference manager (www.mendeley.com). The reference lists of included articles were hand-searched to identify additional articles.

Data Extraction

Articles were initially screened by title and abstract by a single investigator (LM). All of the results from one database were additionally screened by a second author (NM) to generate an inter-rater reliability score: overall weighted kappa = 1.00 (perfect agreement). When it was not possible to assess eligibility through abstract and title screening, full-text copies of the articles were sourced and reviewed by one author (LM) to determine eligibility. Data were extracted using a pre-designed table. Extracted data included: first author, publication year, country, study aims, design, sample size (% male), mean age (age range/standard deviation), primary location of cancer, relationship status (%), mean length of relationship (standard deviation, relationship length range), psychological distress measure, and non-negligible findings. Primary data were converted where necessary to compute associations (transforming medians and ranges to means and SDs (Luo et al., 2018; Wan et al., 2014) and converting standardised mean-differences to correlation coefficients [*r*](Hedges & Olkin, 1985); ultimately all associations were converted to a single metric [*r*]).

Quality Assessment

The first author rated the methodological quality of the articles using a quality appraisal tool. There is no “gold standard” quality appraisal tool (Katrak et al., 2004) so an adapted version of the Mixed Methods Appraisal Tool was used (MMAT)(Hong et al., 2018). This was the preferred choice as it supplied criteria on both quantitative descriptive studies and quantitative non-randomised studies which was appropriate based on the heterogenous study designs represented by the included papers. The criterion of “Have relational sample characteristics been fully reported?” was included to enhance the methodological quality assessment regarding which studies had provided full details on the relational details of their sample. Each study was rated as follows against each criterion; 2=’Yes’, 1=’Can’t tell’, 0=’No’. The individual scores were summed, generating a score out of 18; a higher score reflects a study of higher quality. Hong et al. (2018) (Hong et al., 2018) recommend not making inferences regarding study quality and risk of bias based on the overall score. It is suggested that the ratings of each criterion are supplemented by detailed explanations of how the score was chosen to clarify the quality of the studies (Hong et al., 2018). The modified appraisal tool used can be found in Appendix B; this tool also provides operational definitions for individual quality items. To assess the inter-rater reliability of quality appraisal, a subsample of studies (50%) was randomly selected for double coding by a second reviewer (a co-author), with any differences of opinion resolved through discussion. Prior to discussion, the overall weighted kappa = .965.

Coding of Influencing Factors

A coding system was developed to allow conceptual grouping of factors, producing a common nomenclature for the current review. These factors were coded as follows. The factors were assigned to one of four higher-order (general) categories: Clinical, Sociodemographic, and social network, Relational, and Psychological. Within each higher-order category, lower-order (specific) categories were found to identify the relevant factors more specifically. The higher-order and lower-order categories are displayed in Table 1.

Table 1: The conceptual grouping of influencing factors.

Higher Order Factor	Lower Order Factor
Clinical	Cancer [disease and treatment characteristics] Disease burden
Sociodemographic and social network	Social contact Gender Patient vs. carer role Age Education
Relational (within-couple)	Perception of relationship quality Relationship behaviours Communication Intra-dyad coping styles and satisfaction Dyadic relational factors
Psychological	Illness perceptions/appraisals Coping styles Goal disturbance Self-efficacy

Data Analysis

The decision to not conduct a meta-analytic synthesis was informed by the marked heterogeneity across articles, particularly regarding timings of outcome assessments and measurement of psychological distress. A narrative synthesis of the quantitative data is provided and the effect sizes of the association between the influencing factors and psychological distress are reported in Table 3 and explored. Specifically, when synthesising across studies/estimates, we report effect-size ranges and medians to quantify associations of interest without making assumptions about underlying distributions (Grimshaw et al., 2004). Where a study reports multiple coefficients for a given category of factors or range of (patient and partner distress) outcomes, we take the median estimate for that study; a central estimate *across* studies is then estimated as the median of study medians. These central estimates are reported alongside ranges (smallest to largest reported effect) to convey the full span of associations observed across studies. Estimates (range and central tendency of effects) are reported in this way for all higher-order factors; within each higher-order factor, estimates are also reported for the lower-order factor(s) that were considered most robust (i.e., those that appear to have the *largest overall effect[s]*, based on estimates from *at least two primary studies*). For interpretation of the magnitude of associations (effect-size r) we follow Cohen’s (1988) convention (Cohen, 1988): .10 = small, .30 = moderate, .50 = large.

3. Results[1]

Results of the search/study selection

Figure 1 displays the systematic search process in a PRISMA flowchart (Moher et al., 2009) and provides details regarding exclusion reasons. The systematic searches and hand-searching of reference lists produced 1330 results. Duplicates were removed, producing 1190 results. Abstract and title screening was conducted which led to 38 results. A final full-text screening led to the inclusion of 11 studies.

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[1] The effect sizes (r) of studies are provided in Table 3, where studies have reported them. The effect sizes for studies 4 and 11 have been calculated using other available statistical information as the effect sizes were not explicitly provided by the study.

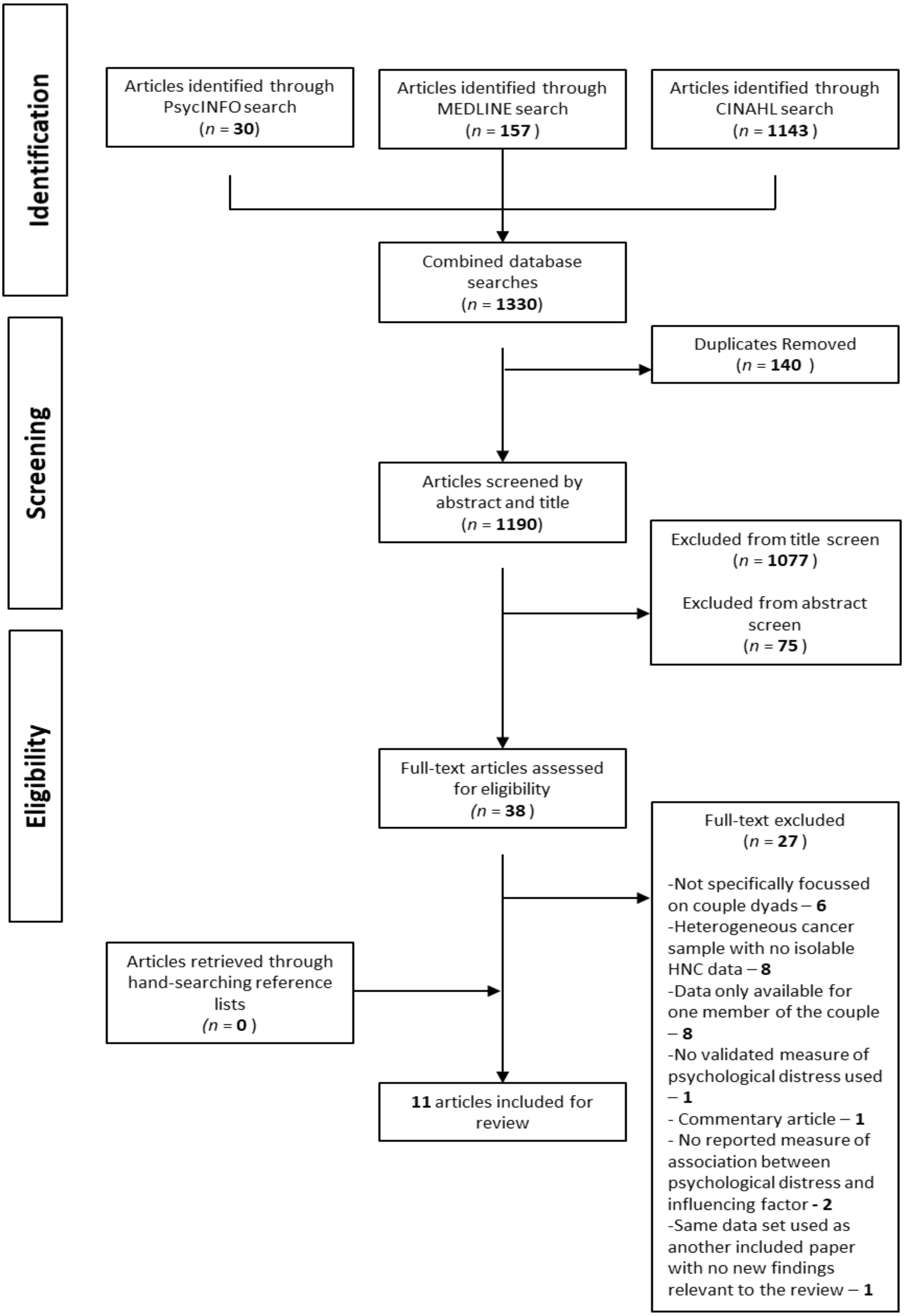

Figure 1: PRISMA flow chart depicts the process of selecting studies. Adapted from Moher et al. (2009)

Study and sample characteristics

11 studies were included (please see study references list). The extracted data is presented in Table 2. Studies were assigned a reference number for identification within the review.

All studies were published during or after 2003. Studies were conducted in the USA [S1 - S3, S9], Switzerland [S4 - S6], the UK [S7, S11], and The Netherlands [S8, S10]. The average reported age of HNC patients ranged from 46.5 to 63 and the average reported age of partners ranged from 47.21 to 61. The average reported percentage of male patients ranged from 29% to 100% and the average reported percentage of male spouses ranged from 0% to 71%. Two papers used the same sample but asked different questions of the data [S2 and S3]. The total participant sample from the papers presents as 516 HNC patients and 478 partners but actually reflects 486 patients and 448 partners as Badr et al. (2018, 2019) (Badr et al., 2018, 2019) were based on the same sample of 30 patients and 30 spouses. The studies used either cross-sectional, longitudinal, or randomised-control trial designs. The primary HNC locations included oropharyngeal, oral cavity, nasal cavity, paranasal cavity, laryngeal, hypopharyngeal, thyroid, nasopharynx, salivary gland, and parotid cancer. The relationship length of couples ranged from two weeks to 58 years. However, not all studies provided relational information [S6-S8, S10-S11]. All studies provided a measure of psychological distress, most commonly the Hospital Anxiety and Depression Scale [S6, S8-S11

Table 2: Study characteristics and key findings

Study Characteristics				Sample Characteristics			Psychological Distress Information	
Study Number	First author (year)/country	Study Aims	Design	Sample Size (% male): Mean age (age range/SD)	Primary Location of cancer	Relationship status (%): Mean length of relationship (SD; relationship length range)	Psychological Distress Measure	Non-negligible findings
1	Badr (2016)/USA[15]	To examine whether emotional disclosure and coping focus as conveyed through natural language use is associated with the psychological and marital adjustment of HNC patients and their spouses.	Mixed-Methods Longitudinal	**Patient** 123 (85%): 56.8 (SD = 10.4) **Spouse** 123 (15): 54.3 (10.2)	Oropharyngeal – 60%; Oral Cavity – 15%; Nasal Cavity and Paranasal Cavity – 5% Laryngeal – 2% Other – 18%	Married (94%) Co-habiting (6%): 25.0 (SD=14.7; 2 weeks to 56 years)	NCCN Distress Thermometer BSI-18	**Relational Factors: Communication** - Dyads reported lower distress levels at follow-up when their partners used more 'we-talk', rather than 'I-talk'. **Perception of relationship quality** -Increased marital satisfaction was associated with reduced distress for partners and patients. **Dyadic relational factors** -Patient and partner baseline distress scores were associated.
2	Badr (2018)/USA[37]	To examine: (1) associations between patient and spouse reports of their own positive and negative dyadic coping efforts at baseline and their own and each other's psychological and marital adjustment; (2) effects of an intervention on patient and partner engagement in positive and negative dyadic coping relative to usual medical care; (3) whether changes in positive and negative dyadic coping are associated with changes in psychological and marital adjustment.	Pilot RCT (Longitudinal)	**Patient** 30 (80%): 58.43 (21-78) **Spouse** 30 (23%): 58.07 (10.11)	Oropharyngeal – 63%; Nasopharyngeal – 7%; Hypopharyngeal – 7%; Other – 23%	Married (83%): 28.85 (SD = 12.65; 3–54 years)	6-item PROMIS short-form anxiety measure 6- item PROMIS short-form depression measure	**Relational Factors: Coping Styles** -Increasing patients' Problem-Focussed Stress Communication (PFSC) resulted in significant reductions in spouses' depression. - Improvements in Satisfaction with Dyadic Coping and Problem-Focussed Dyadic Coping (PFDC) were significantly associated with reductions in anxiety for the dyad. -Increases in one's PFDC were consistently associated with improvements in psychological adjustment. -Patients and spouses reported lower depression

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Study Number	First author (year)/country	Study Aims	Design	Sample Size (% male): Mean age (age range/SD)	Primary Location of cancer	Relationship status (%): Mean length of relationship (SD; relationship length range)	Psychological Distress Measure	Non-negligible findings
								levels when they and their partners engaged in PFDC. **Perception of relationship quality** Greater relationship satisfaction was associated with reduced distress, particularly for patients. **Sociodemographic Factors: Age** -Younger age was associated with greater psychological distress for patients and partners.
3	Badr (2019)/USA[40]	(1) To appraise an intervention for HNC patients and their spouses. (2) To examine the treatment effects of this intervention compared with usual medical care in controlling patient physical symptoms and improving patient/spouse psychological and marital functioning.	Pilot RCT	**Patient** 30 (80%): 58.43 (10.49; 21-78) **Spouse** 30 (23%): 58.07 (10.11; 27-79)	Oropharyngeal – 63%; Nasopharyngeal – 7%; Hypopharyngeal – 7%; Other – 23%	Married (83%): 28.85 (SD = 12.65; 3–54)	PROMIS short-form anxiety measure PROMIS short-form depression measure	**Dyadic relational factors** -Partial correlations for patients and spouses for anxiety were significant. **Sociodemographic Factors: Patient vs. carer role** -Spouses reported significantly higher depression and cancer-specific distress than patients. **Clinical Factors: Disease Burden** -In patients, an increased number of physical sequelae and cancer-related interference related to higher levels of distress.
4	Büel-Drabe (2018)	(1) To examine the frequency and quality of perceived relationship	Quantitative Cross-Sectional	**Patient**	Thyroid – 100%	Married (79%)	BAI BDI	**Relational Factors: Relationship behaviours**

Table 2: Study characteristics and key findings

Study Characteristics				Sample Characteristics			Psychological Distress Information	
Study Number	First author (year)/country	Study Aims	Design	Sample Size (% male): Mean age (age range/SD)	Primary Location of cancer	Relationship status (%): Mean length of relationship (SD; relationship length range)	Psychological Distress Measure	Non-negligible findings
	/Switzerland[41]	changes (positive, negative, or mixed) in patients and their partners. (2) To identify associations between these changes and sociodemographic and disease-related variables, as well as outcomes as anxiety, depression, fatigue, and QoL. (3) To detect any changes in the frequency of sexual activity as well as any potential associations with sociodemographic, disease-related, and outcome variables.		38 (29%): 46.5 (11.3; 24-70) **Spouse** 38 (71%): 47.24 (11.7; 26-68)		Long-term relationship (21%): 20.4 (SD = 11.7; 2.25–39.6)		-Increased sexual activity was associated with higher depression scores, as was the perception of decreased sexual activity relative to those reporting no changes. -Patients reporting more sexual activity pre-diagnosis rated their physical QoL significantly lower and their depression significantly higher than patients who reported decreased sexual activity or no change. **Perception of relationship quality** -Perceived negative/mixed relationship changes were associated with increased anxiety and depression and lower-quality relationships in patients, while in partners the perception of negative/ mixed relationship changes was associated with increased depression, lower-quality relationships, and reduced environmental QoL
5	Drabe (2016)/ Switzerland[42]	To examine diagnosis and treatment burden as well as psychological distress (anxiety and depression) and fatigue in thyroid cancer patients and their partners, focusing on the effects of	Quantitative Cross-Sectional	Patient 71 (29.2%): 47.31 (11.6; 24-70) Spouse 40 (70%):	Thyroid – 100%	Co-habiting (82.4%): 20.8 (SD = 13.4; 0.5-50)	BAI BDI	**Sociodemographic Factors: Gender** No gender differences were identified, and there were no role differences (patient versus partner) for depression, fatigue, or QoL.

Table 2: Study characteristics and key findings								
Study Characteristics				**Sample Characteristics**			**Psychological Distress Information**	
Study Number	First author (year)/country	Study Aims	Design	Sample Size (% male): Mean age (age range/SD)	Primary Location of cancer	Relationship status (%): Mean length of relationship (SD; relationship length range)	Psychological Distress Measure	Non-negligible findings
		gender, role, and time since diagnosis.		47.21 (11.7; (26-68))				
6	Jenewein (2008)/ Switzerland[38]	To examine the impact of oral cancer on quality of life (QoL), psychological distress and marital satisfaction.	Quantitative Cross-Sectional	**Patient** 31 (100%): 58.2 (SD = 10.1; 36-77) **Spouse** 31 (0%): 55.4 (SD = 10.8; 33-77)	Oral Cavity – 100%	**Patient[2]** Single (3.2%) Married (80.6%) Divorced (16.1%) **Spouse** Single (6.5%) Married (83.9%) Divorced (9.7%) Relationship length not reported	HADS	**Clinical Factors:** **Disease Burden** -In patients, physical complaints such as pain, swallowing problems and social eating related to higher levels of depression and anxiety. **Cancer [disease characteristics]** -Patients with advanced disease did not report higher degrees of psychological distress than patients with stage I/II disease. **Relational Factors:** **Perception of relationship quality** - Higher perceived marital quality was associated with higher QoL and lower levels of depression in spouses. -Wives in less-balanced couples (i.e. those who reported high discrepancies regarding marital satisfaction) showed considerably more depressive symptoms and

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[2] These figures are as reported in the paper. No explanation could be found to account for either the discrepancy in relationship status between patients and spouses or the number of participants who reported themselves as 'single' within the study.

Table 2: Study characteristics and key findings

Study Characteristics				Sample Characteristics			Psychological Distress Information	
Study Number	First author (year)/country	Study Aims	Design	Sample Size (% male): Mean age (age range/SD)	Primary Location of cancer	Relationship status (%): Mean length of relationship (SD; relationship length range)	Psychological Distress Measure	Non-negligible findings
								lower levels of QoL than their partners. **Dyadic relational factors** -Increased distress scores for one dyad member was related to increased distress for the other.
7	Moschopoulou (2018)/ UK[43]	(1) To determine the prevalence and correlates of clinical post-traumatic stress disorder (PTSD) and subclinical post-traumatic stress symptoms (PTSS) in HNC patients surviving more than 2 years since treatment and in their partners.	Quantitative Cross-Sectional	The 39 patients and partners were a sub-sample of a wider sample of 93; their demographic details were not separately reported, and demographic data was only reported for the patients. **Patient** 39 (58.1%): 66 (SD = 11; 30-92)	Oral Cavity – 55.9% Oropharynx – 23.7% Nasopharynx – 4.3% Nasal Cavity – 5.4% Salivary gland – 2.2% Hypopharynx – 2.2% Larynx – 2.2% Unknown primary – 4.3%	Not reported	PCL-C	**Sociodemographic:** **Social Support** -Patients' PCL-C score was associated with partners' social support levels.
8	Offerman (2010), The Netherlands[12]	(1) To examine the goals valued by HNC patient and their partners and the extent to which patients and partners experience goal disturbance. (2) To explore associations between goal disturbance, goal re-	Quantitative Cross-Sectional	**Patient** 20 (100%): 60.7 (SD= 10.37) **Spouse** 20 (100%):	Not reported	Not reported	HADS	**Psychological Factors:** **Coping styles** -In patients, more goal disturbance was significantly associated with increased depression and anxiety.

Table 2: Study characteristics and key findings

Study Characteristics				Sample Characteristics			Psychological Distress Information	
Study Number	First author (year)/country	Study Aims	Design	Sample Size (% male): Mean age (age range/SD)	Primary Location of cancer	Relationship status (%): Mean length of relationship (SD; relationship length range)	Psychological Distress Measure	Non-negligible findings
		engagement, (goal)self-efficacy, and psychological distress.		57.6 (SD = 11.37)				- More goal re-engagement was significantly related to lower depression in patients. -More self-efficacy to achieve health outcomes was significantly related to less depression and less anxiety for patients and partners. -More goal self-efficacy was significantly related to less depression.
9	Posluszny (2015)/ USA[10]	(1) To use the PTSD Checklist (PCL to describe and compare the severity of PTSD symptoms and the prevalence of individuals meeting criteria for a clinical diagnosis of PTSD in a sample of newly diagnosed HNC patients and their partners. (2) To examine symptoms of anxiety and depression as likely correlates of posttraumatic stress disorder symptoms. (3) To examine demographic, medical, and psychological factors, including perceived threat and self-blame, as a first critical test of potential risk factors for the development of PTSD in HNC patients and their partners.	Quantitative Cross-Sectional	**Patient** 42 (76%): 55 (SD = 8.7; 35-77) **Spouse** 42 (24%): 53 (SD = 11.3; 27-78)	Larynx – 10% Pharynx – 52% Oral – 31% Salivary – 5% Unknown Primary – 2%	Married (88%) “Marriage-like” relationship (12%): 22 (SD = 13.8; 1-58)	HADS PCL-C	**Sociodemographic Factors:** **Patient vs. carer role** -Levels of PTSD symptoms were significantly higher for partners than for patients. **Age** -Younger age was associated with greater psychological distress for patients and partners **Psychological Factors:** **Illness perceptions/appraisals** -Dyads who believed the disease to be more threatening reported the most traumatic stress. - Attribution of substance-related blame for development of HNC and general blame was related to increased distress.

Table 2: Study characteristics and key findings

Study Characteristics				Sample Characteristics			Psychological Distress Information	
Study Number	First author (year)/country	Study Aims	Design	Sample Size (% male): Mean age (age range/SD)	Primary Location of cancer	Relationship status (%): Mean length of relationship (SD; relationship length range)	Psychological Distress Measure	Non-negligible findings
10	Verdonck-De Leeuw (2007)/ The Netherlands[4] [4]	To gain insight into emotional distress in spouses and patients treated for HNC in relation to age, gender, health status, coping style, cancer and treatment- related factors, functional and social impairment after treatment, and caregiving burden.	Quantitative Cross-Sectional	**Patient** [3] 41 (63%): 61 (27-79) **Spouse** 41 (46%): 58 (31-85)	Parotid – 7% Larynx – 32% Oral/oropharynx – 61%	Not reported	HADS	**Clinical Factors:** **Cancer [disease characteristics]** -Patients and spouses with worse health experience more distress. **Disease Burden** -Speech/swallowing problems and decreased social contacts related to distress. -Spousal distress was related to the presence of a patient feeding tube. -A disrupted daily life schedule due to caring was associated with spousal distress. **Relational Factors:** **Coping Styles** -Passive coping styles were associated with more dyadic distress. **Communication** -Non-expression of emotions was related to more patient distress.
11	Vickery (2003)/ UK[13]	To investigate the effect of HNC on the psychological well-being and QOL of patients and partners accounting for the impact of surgical facial disfigurement in addition to radiotherapy,	Quantitative Cross-Sectional	**Patient** Surgery and radiotherapy /brachytherapy/chemoradiation patients -28	Oral cavity – 39.22% Oropharynx – 9.80% Larynx – 43.14% Hypopharynx – 3.92%	Not reported	HADS	**Clinical Factors:** **Cancer [disease characteristics]** - Undergoing surgery (vs. radiotherapy or brachytherapy alone) was associated with lower anxiety and depression in ***patients.***

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[3] These figures are as reported in the paper.

Table 2: Study characteristics and key findings								
Study Characteristics				**Sample Characteristics**			**Psychological Distress Information**	
Study Number	First author (year)/country	Study Aims	Design	Sample Size (% male): Mean age (age range/SD)	Primary Location of cancer	Relationship status (%): Mean length of relationship (SD; relationship length range)	Psychological Distress Measure	Non-negligible findings
		brachytherapy, and chemoradiation.		(79%): 57 (40-70) Radiotherapy/brachytherapy - 23 (83%): 63 (49-78) **Spouse** Surgery and radiotherapy /brachytherapy/chemoradiation spouses 25 (% not reported): 54 (38-76) Radiotherapy/brachytherapy spouses – 19 (% not reported): 61 (46-75)	Paranasal sinuses – 3.92%			-For ***partners***, patients undergoing surgery (vs. radiotherapy or brachytherapy alone) was associated with greater anxiety and depression.

Measures: BAI -Beck Anxiety Inventory; BDI - Beck Depression Inventory; BSI-18 – Brief Symptom Inventory 18; HADS – Hospital Anxiety and Depression Scale; NCCN Distress Thermometer - National Comprehensive Cancer Network's Distress Thermometer; PCL-C - PTSD CheckList – Civilian Version; PROMIS short-form anxiety measure – Patient Reported Outcomes Measurement Information System® short-form anxiety measure; PROMIS short-form depression measure – Patient Reported Outcomes Measurement Information System® short-form depression measure.

Table 3: Effect-size of the relationship between influencing factors and psychological distress

			Effect-size (*r*)											
Factor			Dyad				Patient				Partner			
Study	Lower order	Higher order	Gen Distress	Dep	Anx	Other	Gen Distress	Dep	Anx	Other	Gen Distress	Dep	Anx	Other
1	**Baseline distress score**													
	- 'I'-talk[4]	Relational					-.01				.09			
	- 'We'-talk	Relational					-.10				-.11			
	- 'You'-talk	Relational					-.02				-.05			
	-Use of positive emotion words	Relational					-.05				.03			
	-Use of negative emotion words	Relational					.05				.01			
	-Baseline marital satisfaction	Relational					-.05				-.10			
	-4-month follow up marital satisfaction	Relational					.07				-.10			
	-Intra-dyad baseline distress score	Relational	.24[b]											
	4-month follow-up distress													
	- 'I'-talk	Relational					.07				.08			
	- 'We'-talk	Relational					-.13				-.02			
	- 'You'-talk	Relational					.01				-.01			
	-Use of positive emotion words	Relational					-.01				-.05			
	-Use of negative emotion words	Relational					-.04				.07			
	-Baseline marital satisfaction	Relational					-.08				-.12			
	-4-month follow up marital satisfaction	Relational					-.02				-.30[a]			
	-Intra-dyad 4-month follow up distress score	Relational	.12											
2	Problem-Focussed Stress Comm.	Relational		-.32*[a]				-.45[b]	-.23			-.29	.12	

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[4] 'I-talk' and 'You-talk' refer to the use of pronouns to convey separateness from partners [15].

[4] 'We-talk' refers to when participants discussed the relationship or mutual difficulties to convey a collaborative problem-solving approach[15].

Table 3: Effect-size of the relationship between influencing factors and psychological distress

			Effect-size (*r*)											
	Factor		Dyad				Patient				Partner			
Study	Lower order	Higher order	Gen Distress	Dep	Anx	Other	Gen Distress	Dep	Anx	Other	Gen Distress	Dep	Anx	Other
	Satisfaction with Dyadic Coping	Relational			-.28*^{a}			-.40 ^{b}	-.13			.05	-.27	
	Problem-Focussed Dyadic Coping	Relational		-.29*^{b}				-.18	.09			-.01	-.11	
	Emotion-Focussed Dyadic Coping	Relational		-.29*				-.36	.19			.36	.09	
	Negative Dyadic Coping	Relational						.19	.11			.19	.15	
	Emotion-Focussed Stress Comm.	Relational						-.35	.02			-.10	.10	
	Relationship satisfaction	Relational						-.35	.11			-.10	-.08	
	Age	Soc-Dem						-.05	-.68^{a}			-.44^{a}	-.28	
3	-Intra-dyad distress score	Relational		-.13	.49^{a}									
	-Cancer-related symptoms	Clinical						.21	.50^{a}					
	-HNC specific symptoms	Clinical						-.09	.24					
	-Interference of symptoms upon functioning	Clinical						.37^{b}	-.30					
4	-Negative/mixed relationship changes	Relational						.39	.59			.16	.52	
	-Decreased sex frequency	Relational						.36	.19			.12	.12	
5	-Gender	Soc-Dem						X	X			X	X	
	-Role differences (patient vs. partner)	Soc-Dem						X				X		
6	-Intra-dyad distress score	Relational		.19	.29									
	-Pain in the head and/or neck	Clinical						.40^{b}	.57^{a}					
	-Eating difficulties	Clinical						.66^{a}	.34					
	-Swallowing difficulties	Clinical						.57^{a}	.32					
	-Senses (problems with taste and smell)	Clinical						.22	.37^{b}					
	-Speech difficulties	Clinical						.34	.28					

Table 3: Effect-size of the relationship between influencing factors and psychological distress

			Effect-size (*r*)											
Factor			Dyad				Patient				Partner			
Study	Lower order	Higher order	Gen Distress	Dep	Anx	Other	Gen Distress	Dep	Anx	Other	Gen Distress	Dep	Anx	Other
	-Social contact concerns	Soc-Dem						.25	.17					
	-Sexuality (reduced interest and enjoyment in sex)	Relational						.18	.07					
	-Relationship satisfaction	Relational						-.24	.07			-.46[a]	-.21	
7										*PCL-C:*				
	Partner's level of social support	Soc-Dem								-.45				
8	-Goal disturbance	Psychological						.70[c]	.63[a]			X	X	
	-Goal re-engagement	Psychological						-.60[a]	-.29			X	-.33	
	-Self-efficacy to achieve health outcomes	Psychological						-.73[c]	-.60[a]			-.71[c]	-.60[a]	
	-Goal self-efficacy	Psychological						-.46[b]	-.33			-.45[b]	-.33	
										PCL-C:				*PCL-C:*
9	-Perceived threat of disease to the patient	Psychological								.26				.38[b]
	-Attribution of substance-related blame for development of HNC	Psychological								.12				.42[b]
	-Age	Soc-Dem								-.12				-.32[b]
	-General blame	Psychological								-.06				-.24
	-Disease severity	Clinical								-.12				-.05
	-Undergone surgery	Clinical								-.14				.05
	-Disfigurement	Clinical								-.24				.10
	-Currently receiving treatment	Clinical								.02				-.28
	-Days since treatment onset	Clinical								-.16				-.05
	-Gender	Soc-Dem								-.28				.11
	-Education	Soc-Dem								-.14				.07
	-Income	Soc-Dem								-.07				.09
10	-Intra-dyad distress score	Relational	.34[b]											
	-Speech difficulties	Clinical					.42[a]							

Table 3: Effect-size of the relationship between influencing factors and psychological distress

			Effect-size (*r*)											
	Factor		Dyad				Patient				Partner			
Study	Lower order	Higher order	Gen Distress	Dep	Anx	Other	Gen Distress	Dep	Anx	Other	Gen Distress	Dep	Anx	Other
	-Swallowing difficulties	Clinical					.33[b]							
	-Decreased social contacts	Soc-Dem					.64[a]							
	-Passive coping style	Psychological					.66[a]				.62[a]			
	-Non-expression of emotions	Psychological					.36[b]							
	-Spousal disrupted schedule	Clinical									.47[a]			
	-Age	Soc-Dem					X				X			
	-Gender	Soc-Dem					X				X			
	-Co-morbidity of patient	Clinical					X				X			
	-Patient-reported functional and social impairment of patient	Clinical									X			
11	-Undergoing surgery (vs. radiotherapy or brachytherapy)	Clinical						-.16	-.01			-.10	.09	

Note: *r* values indicate effect-sizes where r=0.10 indicates a small effect-size, *r=0*.30 indicates a medium effect-size and *r*=0.50 indicates a large effect-size. U = unknown/not reported; [a] findings are significant at P<0.01 level; [b] findings are significant at P<0.05 level; [c] findings are significant at P<0.001 level; [d] findings are significant at P<0.0001 level; X = no significant relationship was found (as reported by paper). * r estimates are based upon standardized beta (B) coefficients as research proposes that B values can be used as an indicator of effect-size (see Nathans et al., 2012).
Measures: PCL-C - PTSD CheckList – Civilian Version
Abbreviations: Gen Distress – General Distress, Dep – Depression, Anx – Anxiety, Soc-Dem - Sociodemographic

Factors influencing psychological distress for couples

Several factors influenced psychological distress. These factors were grouped into higher-order (general) categories of Clinical, Sociodemographic, and social relational, Relational, and Psychological factors, and then sub-divided into lower-order (specific) categories, as represented in Table 1. The accompanying narrative provides a synthesis of the results of the studies and characterises the range and median of effect sizes for the higher-order factors to allow for clearer cross-comparative statements to be made regarding the relative strength and directionality of classes of variables. Lower-order factors with the strongest associations are highlighted narratively when they are based on estimates from at least two primary studies.

Clinical Variables.

Five studies identified clinical factors associated with psychological distress [S3, S6, S9-S11]. Observed effects varied (absolute *r* values [*r*s] from .01 to .66) but were typically of small magnitude (median of medians = .27). These clinical variables were sub-divided into two lower-order categories: (1) Cancer [disease and treatment characteristics] and (2) Disease Burden. Regarding cancer [disease and treatment characteristics], absolute *r*s (observed across two studies) ranged from .01 to.28 (median of medians = .09, negligible effect) with the strongest relationship indicating that current provision of treatment to patients was associated with lower traumatic stress for partners. Regarding disease burden, absolute *r*s (observed across four studies) ranged from .09 to .66 (median of medians = .31, moderate effect) with the strongest relationship indicating that eating difficulties were associated with greater depression in patients.

Sociodemographic and Social Network Variables.

Six studies identified sociodemographic and social network factors associated with psychological distress for couples [2, 5, 6, 7, 9, 10]. Again, observed effects varied (absolute *r*s from .05 to .68) but were typically small (median of medians = .29). Sociodemographic and social network factors were sub-divided into five separate categories: (1) Social contact, (2) Gender, (3) Patient vs. carer role, (4) Age, and (5)

Education. Of these, social contact showed the most robust associations with outcome (across three separate studies): absolute *r*s ranged from .17 to .64 (median of medians = .45, moderate effect) with the strongest relationship (in study [10]) indicating that decreased social contact was associated with increased patient distress. Regarding age, absolute *r*s (reported across two studies) ranged from.05 to .68. The strongest sociodemographic effect, observed in study [2], related to age and indicated that older age was associated with lower anxiety in patients. However, the average effect for age (based on estimates across two studies) was small (median of medians = .22, absolute *r*s ranging from .05 to .68).

Relational Variables

Seven studies [S1-S4, S6-S7, S10] identified relational factors associated with psychological distress for couples experiencing HNC. Observed effects were again wide-ranging (*r*s from .01 to .59) though typically small (median of medians = .12). The relational factors were categorised into five lower-order factors: (1) Perception of relationship quality, (2) Relationship behaviours, (3) Communication, (4) Intra-dyad coping styles, and (5) Dyadic relational factors. Of these, dyadic relational factors (pertaining to the inter-relationship between patient and partner distress levels) showed the most robust associations with outcome: demonstrating the strongest average effect (median of medians = .28) based on estimates from four separate studies (with observed *r*s ranging from .12 to .49). These associations essentially evidence interdependence of patient-partner distress. The strongest relational effect observed in primary studies (.59) pertained to perception of relationship quality [4] – specifically indicating that negative or mixed-valence changes in relationship quality were associated with increased patient anxiety – although the average effect for this factor was small (median of medians = .17, *r*s ranging from .02 to .59) across the four studies reporting relevant estimates.

Psychological Variables

Three studies [S8-S10] identified psychological variables associated with psychological distress for couples facing HNC. Absolute effect sizes ranged from .06 to .73 and were typically large (median of medians = .60), with the strongest relationships indicating that health-related self-efficacy is inversely associated with depression in patients (-.71) and partners (-.73). Psychological variables were subcategorised into four lower-order categories: (1) Illness perceptions/appraisals, (2) Coping styles, (3) Goal disturbance, and (4) Self-efficacy. Of these factors, estimates for coping styles were arguably most robust as they were based on data from two studies (whereas effect estimates for other factors were based on data from a single study). Regarding coping styles, absolute *r*s ranged from .29 to .66 (median of medians = .48, moderate); the strongest observed relationship (.66) was between passive coping and greater patient distress – paralleled by the similarly large association between passive coping and greater partner distress (.62) in the same study [S10]. Findings in study [S10] were mirrored in study [S8], which found a strong negative relationship between active re-engagement coping and patient depression (-.60) alongside smaller negative associations between active coping and patient and partner anxiety (-.29 and -.33 respectively).

Quality Appraisal and Risk of Bias within Studies

Table 4 presents the quality appraisal results. The adapted MMAT (Hong et al., 2018) (Appendix B) was primarily used to ensure that the relevant design characteristics were present and inform critical analysis. However, the chief function of the quality appraisal was to identify areas of weakness in the studies to date and inform recommendations for future work. Level of agreement between reviewers was assessed (across 6 studies, i.e., a sampling frame of 50%) and, prior to resolving any differences, overall weighted kappa = .965 ('almost perfect' agreement).

All 11 studies satisfied the initial screening questions regarding clear research questions and the collected data allowing the research questions to be addressed. If a study failed these initial questions, then further appraisal may have been unfeasible or inappropriate (Hong et al., 2018). All studies reported sampling strategies; non-probability sampling was used by all studies which was appropriate due to the specific study population in question. However, regarding the requirement for sample populations to be representative of the target population, only three of the studies had samples judged to be representative of the population [S1, S6, S9]. Two studies drawing from the same data set [S2-S3] did not have representative samples as the majority of the sample population were comprised of advanced-stage HNC patients which limits the generalisability of findings to early-stage HNC patients. It was not possible to ascertain whether the sample populations for six studies [S4-S5, S7-S8, S10-S11] were representative of the target populations as the reasons for eligible individuals not participating were not supplied. Additionally, in one study [S10], it was difficult to establish how many of the approached dyads had actually agreed to participate. Most of the papers satisfied the requirement to have appropriate measures for their specific research questions. However, one paper [4] employed a self-designed, non-validated questionnaire to measure intimacy changes. Only three studies were considered to satisfy the criterion requiring the risk of non-response bias to be low [S2-S3, S9]. Study 1 displayed a potential non-response bias, as differences were found between respondents and non-respondents: non-respondents were found to have worse performance status in relation to their cancer treatment and were found to have higher levels of spousal distress at the recruitment stage. In seven of the included studies [S4-S8, S10-S11], it was difficult to judge non-response bias, as these studies did not provide enough information to assess whether those who participated were different from those who did not in terms of the variables of interest.

All studies were judged to have used appropriate statistical analyses. Additionally, all studies provided complete outcome data; although there is no widely agreed cut-off value for what is considered an acceptable level of outcome data completion, this review adopted the conservative figure of 95% to categorise a study as providing complete outcome data (Higgins et al., 2016). Seven of the studies satisfied the requirement to have fully reported relational sample characteristics: this was an additional quality criterion due to the relational focus of the current review. Four studies did not meet the requirements for this criterion due to studies either only partially reporting characteristics or providing no information [S6-S8, S11].

Table 4: Methodological Quality of the included studies

Quality Appraisal Criteria	**Study number**										
	1	2	3	4	5	6	7	8	9	10	11
1. Are there clear research questions?	2	2	2	2	2	2	2	2	2	2	2
2. Do the collected data allow to address the research questions?	2	2	2	2	2	2	2	2	2	2	2
3. Is the sampling strategy relevant to address the research question?	2	2	2	2	2	2	2	2	2	2	2
4. Is the sample representative of the target population?	2	1	1	1	1	2	1	1	2	1	1
5. Are the measurements appropriate?	2	2	2	2	2	2	2	2	2	2	2
6. Is the risk of non-response bias low?	0	2	2	1	1	1	1	1	2	1	1
7. Is the statistical analysis appropriate to answer the research question?	2	2	2	2	2	2	2	2	2	2	2
8. Are there complete outcome data?	2	2	2	2	2	2	2	2	2	2	2
9. Have relational sample characteristics been fully reported?	2	2	2	2	2	0	0	0	2	2	0
Quality Appraisal Total Score	16	17	17	16	16	15	14	14	18	16	14

Note: This appraisal tool is an adaptation of the Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2018) which can be found in Appendix B. The scoring refers to whether the criterion is present within the study: 2 - ‘Yes’, 1 - ‘Can’t Tell’, 0 - ‘No’. It was possible to achieve a maximum score of 18.

4. Discussion

Key Findings

The current review identified factors associated with psychological distress for couples facing HNC relating to four variables: clinical, sociodemographic, and social network, relational, and psychological. The findings will be discussed in relation to each variable. Overall, the strongest magnitude of association was found for psychological variables (individual differences in coping, illness perceptions, self-efficacy, and goal disturbance).

Regarding clinical factors, several studies identified that the HNC disease burden predicted increased psychological distress for patients and partners. These findings are consistent with research identifying HNC as an especially traumatic cancer due to both the illness and the aggressive treatment options it necessitates (Badr, Herbert, et al., 2016a; Milette et al., 2010). There was considerable variation in the reported effect sizes which ranged from small to large and the overall median *r* was small. However, two studies did not find an association between these variables for patients [S3, S6]. Notably, some studies only reported an effect size in relation to the experienced disease burden for the patient rather than both dyad members. In terms of cancer [disease characteristics], the median *r* was negligible, indicating that disease characteristics of the cancer did not predict distress for couples as compellingly as disease burden. This aligns with literature from breast cancer populations, which found no effect of either the type of surgery or the type of adjuvant therapy on subsequent distress levels (Cook et al., 2018). However, fewer studies in the review investigated the role of disease characteristics in influencing distress, as opposed to disease burden, so it is possible that with larger sample sizes, a stronger relationship may have been found.

Regarding sociodemographic and social network factors, several factors were identified. Two studies [S7, S10] identified large, significant relationships between supportive social contact and lower levels of psychological distress for couple members. These results are consistent with literature suggesting that social support produces less psychological distress for those experiencing HNC (De Leeuw et al., 2000; Katz et al., 2003). The quality of research on this topic would be further enhanced if future research consistently reported effect sizes for both patients and partners. In relation to gender, a negligible median *r* was found: this aligns with research from another systematic review which found that gender was a significant predictor of distress in only two out of 13 papers (Cook et al., 2018). In terms of age, a small, negative *r* was found, indicating that a younger age was associated with greater distress: this finding reflects research which found that younger age was related to increased anxiety 18 months after an HNC diagnosis (Neilson et al., 2013).

Regarding relational factors, there was a relationship between the perception of relationship quality and psychological distress for both patients and partners as identified by four studies [S1, S2, S4, S6]. The reported effect sizes for this relationship displayed considerable variation, ranging from small to large. These findings are important for clinicians and researchers to consider, as research shows that the quality of partnered relationships is linked to psychological adaptation and cancer-related health outcomes (Burman & Margolin, 1992). These results might inform future research and clinical practice: when considering potential interventions for HNC dyads experiencing distress, there is potentially greater scope for intervening with more malleable relational factors as opposed to more static clinical and sociodemographic factors. In terms of communication and intra-dyad coping styles, small median *r*s were found: this was inconsistent with evidence highlighting the importance of intra-dyad coping styles in improving distress outcomes in couples with HNC (Badr et al., 2018).

Three studies identified psychological factors [S8-S10] which appeared to have the strongest relationships with distress (large median of study medians) – perhaps partially reflecting the interdependence of mood and cognition (individual appraisal and response-style), and common method variance (for factors assessed via subjective self-report measures). Findings from two independent studies [S8, S10] converged in suggesting that greater distress (for both patients and partners) is associated with passive (versus engaged) ways of coping. In terms of illness perceptions/appraisals, a small median *r* was found: previous research has found limited support for the role of appraisal of illness and subsequent distress (Cook et al., 2018). However, the previous evidence was based on a small number of studies and was based on the patient’s perception of the illness: there is a paucity of research investigating the relationship between partner perceptions of the illness and distress outcomes.

Study Limitations

Systematic literature reviews can be associated with limitations such as heterogeneity, issues concerning study selection, and incomplete or inaccurate analyses and outcomes (Gopalakrishnan & Ganeshkumar, 2013). It is therefore crucial to consider the limitations of the papers and current review. A limitation of the studies concerned the heteronormative sample populations; while no studies reported that they had specified heterosexuality as an inclusion criterion, the vast majority of participating couples were heterosexual. However, little published research has explored the impact of cancer upon non-heterosexual individuals, and such patients have reported negative experiences during healthcare treatment (Katz, 2009). This is particularly problematic in this review, as literature suggests that non-heterosexual patients may experience greater psychological distress than heterosexual patients: a study examining women experiencing breast cancer found that lesbian women disclosed greater stress levels during diagnosis and treatment (Matthews et al., 2002). There is also an under-representation of racial and ethnic minorities, and individuals of a lower socioeconomic status in cancer research more generally (Ford et al., 2008): these details were not reported for the included studies so it is difficult to ascertain if this was an issue for the current review but it may have affected the reprentativeness of the studies. Furthermore, almost all included studies used cross-sectional study designs; this is limiting as it means that causality cannot be determined from the provided correlational information (Spector, 2019). This is problematic as examining the bi-directional relationships between influencing factors and the psychological distress experienced by couples was not possible.

Regarding the current review’s limitations, only peer-reviewed papers were included to ensure a minimum standard for scientific quality. However, excluding grey literature could introduce publication bias which increases the likelihood of finding papers with a ‘positive’ result (Gopalakrishnan & Ganeshkumar, 2013). Another potential limitation concerns the inclusion criterion specifying that papers must explicitly identify that the participants were in a relationship: the findings cannot, therefore, be assumed to apply to other caring dyads. The current review excluded papers not available in English which means that eligible papers written in another language may have been excluded, therefore introducing language bias (Tricco et al., 2008). A further consideration is the decision to include thyroid cancer patients within the definition of Head and Neck Cancer. This is contested, with more recent literature not including it (Dunne et al., 2017). However, previous systematic literature reviews on HNC have included thyroid cancer patients (Morris et al., 2018) and in this study, the results from the studies including thyroid cancer patients were relatively consistent with other types of HNC. Finally, the key findings of the current review are based on a relatively small number of papers, reducing their generalisability. However, there is still a paucity of information available on this topic, so the small number of included papers is reflective of the available evidence.

Clinical Implications

The reviewed studies indicate factors that could influence clinical practice, and potentially reduce psychological distress levels for couples experiencing HNC. These areas include:

1. Considering ways to increase the helpful received social support available to couples (directing couples to HNC support groups where they can meet others, signposting couples to supportive organisations/HNC charities).
2. Including partners in psychological work where appropriate/providing individual support for partners (support couples/individuals with marital difficulties which could accompany the significant disease and psychological burden associated with HNC) (Badr, Herbert, et al., 2016b)
3. Providing partners with preparatory information regarding the impact of HNC and how to access support when the patient receives their diagnosis/initial treatment.(D’Souza et al., 2017)
4. Establishing the nature of couple’s disease burden, regarding the physical and functional sequelae of diagnosis and treatment, alongside factors such as disrupted schedules/working patterns – this could identify areas where couples may benefit from further support.
5. Assessing coping styles and providing psychological intervention to promote coping (Badr et al., 2019) for both patients and partners (this could include individual intervention around adaptive self-regulation which could be

achieved through re-engaging in more realistic goals/ identifying and modifying beliefs around locus of control or self-efficacy).

Research Implications

This review identifies that various research projects have a broadly similar interest in investigating the factors influencing psychological distress in couples experiencing HNC; however, most of these studies have measured different factors. Future research would benefit from a more systematic approach which reflected the different layers of factors influencing distress: these range from the psychological and patient-clinical, through to the relational, and then beyond to broader contextual factors including social support and demographics. When studies in this area focus on just one of these categories, crucial data may be missed. Furthermore, future studies might benefit from reporting on the relationship between factors predominately experienced physically by the patient, such as disease burden, and spousal distress to provide a fuller picture of the distress experienced by the dyad as evidence suggests that partners are affected by the patient’s disease-related symptoms. This would help to achieve a broader picture of the distress experienced by couples. Research on this topic suggests that the effectiveness of social support as a buffer against psychological distress could be related to the number of physical health issues a patient experiences; future research could usefully investigate whether the benefit which dyad members derive from social support is moderated by the extent of the patient’s physical sequelae (Katz et al., 2003). This would be beneficial as it would support a more nuanced understanding of how particular factors may interact to influence distress. Regarding the influence of relational factors, future studies in this area could usefully employ moderator analyses to find variables which influence the relationship magnitude between the perception of relationship quality and psychological distress.

Conclusions

This review identifies several factors associated with psychological distress for couples experiencing HNC. Based on available evidence, among the strongest correlates of distress are malleable psychological factors – such as coping responses – and this finding holds promise for developing psychologically-informed interventions that might thereby promote better outcomes for patients and partners.

However, across studies, there is considerable heterogeneity in terms of effect sizes, and methodological limitations in terms of inconsistent reporting of associations for both patients and partners alongside small, under-powered samples. This review highlights the importance of future research addressing the paucity of literature in this area while also using large, representative samples and reporting for both dyad members to improve the quality of the studies. This review has also offered clinical and research recommendations to better understand and support couples experiencing HNC.

Disclaimer Statements

Funding

No specific funding was received for this work which was conducted as part of the first author’s doctoral training.

Conflicts of Interest

No conflicts of interest to report.

Ethical Approval

Not required for this review.

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Appendices

Appendix A: Tabulated search strategies

PsycINFO

	Searches	Results
1	(head and neck cancer).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh]	558
2	(“head and neck” adj2 (neoplasm* or tumor* or tumour* or carcinoma*)).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh]	40
3	HNC.mp. and exp neoplasms/ [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh]	128
4	exp Spouses/	15768
5	exp Marriage/	11809
6	(couple* or spouse* or “significant other*” or partner* or dyad* or wife or wives or husband* or married).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh]	230231
7	Psychological Distress/	0
8	exp Anxiety/	71272
9	exp Depression/	25532
10	exp Emotional Adjustment/	21696
11	(psycholog* adj2 (distress* or adjust* or adapt*)). mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh]	31079
12	(emotional* adj2 (distress* or adjust* or adapt*)). mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh]	25711
13	(stress* or depress* or anxiety or distress*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh]	740154
14	7 or 8 or 9 or 10 or 11 or 12 or 13	759216
15	exp Neoplasms/	51727
16	exp “Head (Anatomy)”/	2050
17	exp “Neck (Anatomy)”/	1117
18	16 or 17	2882
19	15 and 18	239
20	1 or 2 or 3 or 19	617
21	exp Psychological Stress/	8877
22	exp Couples/	14263
23	exp Significant Others/	1353
24	exp Partners/	7452
25	exp Dyads/	6297
26	4 or 5 or 6 or 22 or 23 or 24 or 25	235070
27	14 or 21	759216
28	20 and 26 and 27	29

MEDLINE

	Searches	Results
1	(head and neck cancer).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	24686
2	exp “head and neck neoplasms”/	308243
3	(“head and neck” adj2 (neoplasm* or tumor* or tumour* or carcinoma*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	58730
4	HNC.mp. and exp/neoplasms/	1941
5	exp Spouses/	10072
6	exp Marriage/	23293
7	(couple* or spouse* or “significant other*” or partner* or dyad* or wife or wives or husband* or married).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	635930
8	1 or 2 or 3 or 4	315757
9	5 or 6 or 7	648439
10	8 and 9	1903
11	Psychological Distress/	510
12	exp Stress, Psychological/	130497
13	exp Adaptation, Psychological/	126509
14	exp Anxiety/	84548
15	exp Depression/	118231
16	exp Emotional Adjustment/	1186
17	(psycholog* adj2 (distress* or adapt* or adjust*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	113314
18	(emotional* adj2 (distress* or adapt* or adjust*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	9216
19	(stress* or depress* or anxiety or distress*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	1669292
20	11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19	1758663
21	10 and 20	153

CINAHL

	Searches	**Results**
S1	“head and neck cancer”	14561
S2	(MH “Head and Neck Neoplasms+”)	51249
S3	“head and neck” N2 neoplasm* OR tumor* OR tumour* OR carcinoma*	328575
S4	(MH “Spouses”)	11624
S5	(MH “Marriage”)	9377
S6	(MH “Significant Other”)	1374
S7	couple* OR spouse* OR partner* OR dyad* OR “significant other*” OR wife OR wives OR husband* OR married	159198
S8	S1 OR S2 OR S3	345612
S9	S4 OR S5 OR S6 OR S7	163261
S10	(MH “Stress”)	11676
S11	(MH “Stress, Psychological”)	53721
S12	(MH “Adaptation, Psychological”)	32493
S13	(MH “Anxiety”)	46816
S14	(MH “Depression”)	116735
S15	psychology* N2 distress* OR adapt* OR adjust*	346999
S16	emotional* N2 distress* OR adapt* OR adjust*	340651
S17	stress* OR depress* OR anxiety* OR distress*	489730
S18	S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17	771799
S19	S8 AND S9 AND S18	1143
S20	(MH “Squamous Cell Carcinoma of Head and Neck”)	156
S21	S1 OR S2 OR S3 OR S20	345612
S22	S9 AND S18 AND S21	1143

Appendix B: Adapted Quality Appraisal Tool (MMAT; Hong et al., 2018)

Criteria		Score
1.	**Are there clear research questions?** Further comments:	
2.	**Do the collected data allow to address the research questions?** Further comments:	
3.	**Is the sampling strategy relevant to address the research question?** Sampling strategy refers to the way the sample was selected. There are two main categories of sampling strategies: probability sampling (involve random selection) and non-probability sampling. Depending on the research question, probability sampling might be preferable. Nonprobability sampling does not provide equal chance of being selected. To judge this criterion, consider whether the source of sample is relevant to the target population; a clear justification of the sample frame used is provided; or the sampling procedure is adequate.	
4.	**Is the sample representative of the target population?** There should be a match between respondents and the target population. Indicators of representativeness include: clear description of the target population and of the sample (such as respective sizes and inclusion and exclusion criteria), reasons why certain eligible individuals chose not to participate, and any attempts to achieve a sample of participants that represents the target population.	
5.	**Are the measurements appropriate?** Indicators of appropriate measurements include: the variables are clearly defined and accurately measured, the measurements are justified and appropriate for answering the research question; the measurements reflect what they are supposed to measure; validated and reliability tested measures of the outcome of interest are used, variables are measured using ‘gold standard’, or questionnaires are pre-tested prior to data collection	
6.	**Is the risk of nonresponse bias low?** Nonresponse bias consists of “an error of non-observation reflecting an unsuccessful attempt to obtain the desired information from an eligible unit.” (Federal Committee on Statistical Methodology, 2001, p. 6). To judge this criterion, consider whether the respondents and non-respondents are different on the variable of interest. This information might not always be reported in a paper. Some indicators of low nonresponse bias can be considered such as a low nonresponse rate, reasons for nonresponse (e.g., noncontacts vs. refusals), and statistical compensation for nonresponse (e.g., imputation).	
7.	**Is the statistical analysis appropriate to answer the research question?** The statistical analyses used should be clearly stated and justified in order to judge if they are appropriate for the design and research question, and if any problems with data analysis limited the interpretation of the results.	
8.	**Are there complete outcome data?** Almost all the participants contributed to almost all measures. There is no absolute and standard cut-off value for acceptable complete outcome data. Agree among your team what is considered complete outcome data in your field (and based on the targeted journal) and apply this uniformly across all the included studies. For example, in the literature, acceptable complete data value ranged from 80% (Thomas et al., 2004; Zaza et al., 2000) to 95% (Higgins et al., 2016). Similarly, different acceptable withdrawal/dropouts rates have been suggested: 5% (de Vet et al., 1997; MacLehose et al., 2000), 20% (Sindhu et al., 1997; Van Tulder et al., 2003) and 30% for follow-up of more than one year (Viswanathan and Berkman, 2012).	
9.	**Have relational sample characteristics been fully reported?** These relational sample characteristics pertain to reported relationship status and length of relationship.	

JOURNAL PAPER

"This one is a bit of a taboo subject": A Mixed Methods Investigation into the Impact of Head and Neck Cancer upon Sexuality

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Abstract

Keywords: head and neck cancer, sexuality, coping styles, quality of life, oncology

Head and Neck Cancer (HNC) survivors are vulnerable to negatively impacted sexualities and impacts of HNC on sexuality are under-researched. Links exist between particular coping styles and levels of psychological distress which could be explored regarding sexuality outcomes. Additionally, professionals struggle to discuss sexuality: perceived support needs around sexuality are therefore poorly understood. This study investigated impacts of HNC upon sexuality, coping responses associated with sexuality outcomes, and perceived sexuality support needs. A mixed-method design was used: 60 individuals participated in a survey and 18 participants completed interviews. Quantitative data were analysed using descriptive statistics and correlational analyses. Qualitative data were analysed using thematic analysis with an inductive-deductive design. Findings support previous literature: for many participants, sexuality is negatively impacted by HNC, representing HNC-related deterioration for a large proportion. The themes developed illustrated a series of events where sexuality is deprioritised during treatment, sexuality remains undiscussed by professionals, altered sexual behaviour occurs and participants respond by rebuilding/renavigating sexuality. Significant relationships were not found between response styles and sexuality outcomes. The

sample was demographically limited with an over-representation of women and almost universally white ethnic backgrounds. Providing HNC-specific informational resources would benefit patients and assist professionals with sensitively-timed sexuality discussions.

Introduction

Background Information and Rationale

Over 30 areas in the head and neck can develop cancer (Macmillan Cancer Support, 2020). The experience of Head and Neck Cancer (HNC) encompasses HNC symptoms, diagnosis, curative treatment, survivorship, and associated phenomena. Globally, there are over 550,000 incidences of HNC and 300,000 HNC-related deaths each year (Fitzmaurice et al., 2017; Jemal et al., 2011). HNC is considered a particularly psychologically traumatic cancer due to its associated visible disfigurements and effects on life functions such as eating, speaking, breathing, and swallowing (Ledeboer et al., 2005; Millsopp et al., 2006). Relatedly, HNC is linked with psychosocial challenges, such as depression (Lydiatt et al., 2009), anxiety (Neilson et al., 2010), body image concerns (Fingeret et al., 2012), fear of cancer recurrence (Humphris et al., 2003), and sexuality/intimacy difficulties (Monga et al., 1997).

The World Health Organisation (WHO) defines sexuality as: "…a central aspect of being human throughout life [which] encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction.[5] Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships" (World Health Organisation, 2006). Sexuality is important to individuals regardless of age, health status, sexual orientation, or relationship status (Hughes, 2009; Kazer, 2003). Sexuality can be conveyed through interacting with another or individually expressed (Redelman, 2008; Rice, 2000). An individual's sexuality needs are dynamic and crucial to self-concept, supporting resilience and coping during challenging circumstances (Loehr et al., 1997).

Sexuality difficulties can affect cancer survivors, resulting in negatively altered sexuality (Ananth et al., 2003; Wright et al., 2002). Sexual function and satisfaction difficulties as an issue specific to cancer survivorship can include reduced libido, vaginal dryness, and erectile dysfunction (Hughes, 2009). However, the impact of cancer on sexuality encompasses both physiological and psychosocial symptoms,

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[5] See extended introduction (section 1.3) for further discussion of sexuality and its definition.

including reduced self-esteem, changes in body image, psychological distress, reduced self-confidence, and difficulties with relationships (Tierney, 2008). While the impact of cancer on sexuality has been cited extensively in extant literature, little research has theoretically considered how couples adjust to the challenges they face in adapting to sexual changes. This gap in knowledge has been addressed more recently by a theoretical framework which proposes three main pathways of adjustment to cancer for couples who face an impacted sexuality (Benoot et al., 2017).

HNC presents additional sexuality challenges for survivors (Jones, 2017; Rhoten, 2016), including functional barriers such as oral pain, reduced neck mobility, difficulty breathing, weakness, fatigue, and increased saliva secretions (Rhoten, 2016). There is a further psychosocial impact of HNC upon sexuality, as structures frequently affected by HNC facilitate relationships and both verbal/non-verbal communication (Rhoten, 2016; Rhoten et al., 2013). These include achieving desired facial expressions, speaking, seeing, smelling, and eating (Rhoten, 2016). Another potential barrier for HNC survivors is the anatomical site and degree of disfigurement associated with HNC (Moreno et al., 2012). If HNC survivors experience disfigurement, then this can be highly visible, which can undermine confidence, social engagement, and body image – all of which could impact sexuality (Chen et al., 2015; De Leeuw et al., 2000; Hassan & Weymuller, 1993; Rhoten et al., 2013). Despite the additional threats to sexuality identified for HNC survivors, there is little research investigating the experienced impact of HNC upon sexuality, and most existing research is quantitative/questionnaire-based, primarily focussing on a narrow physiological understanding of sexuality. One study conducted within HNC survivors indicates that one third of the sample experienced substantial problems with sexual enjoyment and interest (Low et al., 2009): however, there is limited further research regarding this impact within the HNC population. The broader psychosocial impact of HNC varies between survivors, and previous research has established the role of individual coping responses in shaping experiences of adjustment to HNC and its sequelae (Morris et al., 2018). Given the potential malleability of individual coping responses (relative to the demographic and clinical factors that can influence cancer adjustment; (Hulbert-Williams et al., 2012), understanding these responses/their influence on outcomes can usefully inform supports for individuals with HNC. Regarding impact on sexual functioning specifically, it is apt to examine whether and how any experienced impacts relate to ways of coping and therefore identifying coping responses that may facilitate better sexuality outcomes in the context of HNC.

Study of coping responses in cancer has been predominantly informed by the Lazarus and Folkman (1984) model: conceptualising cancer as a stressor, which is subject to evaluative cognitive appraisals (e.g., perceived threat and ability to cope) and coping responses (behaviours and strategies) that determine individual outcomes and adjustment to cancer. Empirical work arising from this model has established that negative cognitive appraisals (e.g., catastrophic perceptions of cancer) and avoidant coping responses (e.g., self-distraction, denial, and disengagement) are associated with poorer outcomes in various domains (Brabbins et al., 2020; Gillanders et al., 2015; Morris et al., 2018); one such domain which requires further exploration is sexuality outcomes for HNC survivors. Extant work suggests a need to identify and promote non-avoidant ways of responding that can potentially buffer against the detrimental impact of illness and illness perceptions. Testing associations between coping responses and HNC outcomes (including in the sexuality domain) may help to strengthen understanding of beneficial response-tendencies – and thereby highlight potential treatment targets.

Further to the appraisal and coping variables traditionally examined in the cancer-coping literature, there is emerging evidence for the potential role of psychological flexibility (PF) as an adaptive alternative to avoidant coping that can predict and influence positive outcomes in the context of cancer (Graham et al., 2016; McAteer & Gillanders, 2019). PF refers to the ability to mindfully attend and adapt to situational demands in the pursuit of personally meaningful longer-term goals (Dawson & Golijani-Moghaddam, 2020). PF is beneficial to overall psychological health (Kashdan & Rottenberg, 2010) and evidence indicates that increasing PF when working with cancer patients from an Acceptance and Commitment Therapy (ACT) framework – an interventional model that explicitly targets PF – predicts changes in quality of life (QoL), distress, and mood (Feros et al., 2013; Graham et al., 2016). Other research has demonstrated the predictive power of PF in accounting for psychological distress and QoL in individuals with cancer (McAteer & Gillanders, 2019; Montiel et al., 2016) – even after controlling for variance explained by the appraisals (illness perceptions) and cognitive-behavioural coping strategies (avoidant and approach-focussed responses) that are typically examined within the Lazarus and Folkman model (Brabbins et al., 2020). PF has also been shown to be positively related to sexual functioning specifically (Maathz et al., 2020). Taken together, emerging empirical evidence indicates that PF may be an important variable to examine in relation to the impact of HNC on sexuality.

Given that a skill such as PF – which supports the individual's ability to respond more openly and adaptively to distress – is potentially useful (Hulbert-Williams et al., 2015), it seems particularly pertinent to explore within HNC populations due to the heightened rates of distress this population experience, especially those receiving surgical treatment (Lang et al., 2013; Morris et al., 2018). A relationship between unmet support needs and psychological distress has been identified in cancer survivors (Rogers et al., 2014), including an unmet support need regarding sexuality during and after cancer (Henry et al., 2013). The negative impact on sexuality experienced by many cancer survivors is not routinely addressed by professionals (Park et al., 2009; Southard & Keller, 2009). Healthcare professionals report barriers to discussing sexuality, such as embarrassment (Penson et al., 2000), time pressure (Kotronoulas et al., 2009), and not knowing what to suggest for support (Katz, 2005). This is concerning as unattended sexuality issues can impact on a patient's QoL (Harrison et al., 2009; Tierney, 2008). Little attention has been paid to the support HNC survivors receive from cancer professionals receive in relation to sexuality; this is problematic considering the additional impact which HNC survivors may encounter in relation to sexuality (Rhoten, 2016). Furthermore, the extremely limited research that exists on this topic in this population has been conducted using quantitative methods involving problem checklists and single-item scaling of 'problems with intimacy' (Rogers et al., 2014); a limitation of this approach is that in-depth information about the potential barriers for individuals discussing their sexuality with professionals is lacking.

No study of the impact of HNC upon sexuality has been undertaken approaching this question from a mixed-methods perspective and including a broad definition of sexuality encompassing sexual function, satisfaction, identity, and relationships. The comprehensive definition of sexuality adopted by the current study seeks to address gaps in the literature as quantitative and qualitative data will be synthesised to achieve a fuller understanding of any sexuality issues for HNC survivors. Furthermore, examining how sexuality (in terms of sexual function and satisfaction) and QoL relate to coping responses – including PF – would inform understanding of individual differences in adjustment to HNC and identify potential targets for interventional support. For example, a positive relationship between PF and sexuality outcomes in HNC would imply that interventions targeting PF (such as ACT) may be beneficial for addressing sexual concerns in this population.

Research investigating what HNC survivors perceive to be their support needs surrounding sexuality from a qualitative perspective would also be beneficial to understanding what barriers, if any, HNC patients experience when discussing sexuality with professionals, as no qualitative literature exists on this subject. However, evidence shows that only 1 in 5 individuals who indicated sexuality concerns in advance of clinic appointments proceeded to raise these concerns in the appointment (Rogers et al., 2014). This merits further investigation, as sexuality is important to QoL, which is particularly salient for HNC survivors due to the rising rates of HNC, the younger average age of diagnosis and the improving survival rates. This research could influence clinical practice, by helping to determine the extent to which negatively impacted sexuality is an issue for HNC survivors which warrants specific intervention.

Aims and Purpose of Investigation

The primary aim of the study is to investigate the impact of HNC on sexuality in terms of sexual function, satisfaction, identity, and relationships. A secondary aim is to assess whether PF and other coping responses are associated with sexuality and QoL in the context of HNC. A tertiary aim is to explore what individuals with HNC see as their support needs in relation to sexuality.

Research Questions

1. What is the impact of HNC on sexuality in terms of sexual function and satisfaction, identity, and relationships?
2. Are PF and other coping responses associated with sexuality and QoL outcomes in the context of HNC?

3. What do people with HNC perceive to be their support needs surrounding sexuality?

Methodology

Study Design[6]

This study used a mixed methods convergent parallel design (Kettles et al., 2011). Quantitative survey data and qualitative interview data were collected simultaneously, after which both datasets were analysed separately, and then ultimately synthesised within the discussion section (Creswell et al., 2011). A mixed methods study design allowed this research to address its proposed aims, as both datasets could contribute to answering the research questions more completely than either dataset individually (Tashakkori & Creswell, 2007). Furthermore, this design supported the quantitative data to be understood in greater detail whilst also generating detailed qualitative data (Creswell & Plano Clark, 2011).

Epistemological Position[7]

This research was conducted from within a critical realist framework which aligns with the lead researcher's understanding of knowledge and its construction. This approach argues that objective ontological reality exists independently from knowledge or the knower and is concerned with the different experiences and realities experienced by individuals whilst acknowledging that individual epistemological realities are informed by different social contexts (Archer et al., 2013; Danermark et al., 2005).

Participants and Recruitment[8]

Online Survey.

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[6] See extended methodology (section 2.3) for critique of mixed methods approach and further rationale for the study design.

[7] See extended methodology (section 2.2) for further details on the epistemology of the study.

[8] See extended methodology (section 2.4) for further discussion on the sample size justification, recruitment challenges, and information about participants.

Participants were eligible for survey participation if they: a) were above the age of 18; b) had experience of or were currently experiencing HNC; c) were able to provide informed consent; d) could read and write in English; e) had internet access and access to an appropriate device. Screening to establish whether participants met inclusion criteria was included in the initial online questionnaire phase.

The survey was live for nine months and was advertised through social media, email dissemination through HNC charity mailing lists (The Swallows and Heads2gether), and through known clinicians providing information to patients at routine appointments. Opportunistic sampling was used to access a high number of eligible individuals. In order to achieve a description of sexual functioning, we calculated that a minimum of 43 participants would be needed to estimate sexual functioning to within ±15% of 'true' population values [with 95% certainty]).

Semi-Structured Interviews.

Participants who had participated in the online survey and consented to a semi-structured interview were interviewed either through an online, video-recorded interview, a telephone, audio-recorded interview, or through an email exchange in the case of one participant. The a priori minimum target for interview recruitment was 12 participants, based on guidelines by Braun and Clarke (2013). Originally, a maximum variation sampling strategy was employed as a purposive sampling strategy to allow a heterogenous group of individuals to be intentionally selected to verify the study's findings, based on variables such as sex, ethnicity, sexual orientation, age, cancer-site, prognosis, and relationship status (Miles & Huberman, 1994). However, after interviewing initially selected participants, recruitment continued as others had expressed a wish to participate in interviews and new potential themes were still being developed from later interviews.

Eligible participants were contacted via email or phone number, depending on the contact details they had provided.

Measures[9]

An online survey which could be accessed through a web-link was designed to collect quantitative data using five sequentially administered validated measures and one adapted measure (Appendices W-AA display these measures). These questionnaires were administered to address three key domains: background variables (e.g., demographic information, cancer-specific information, and threat appraisals of illness), response-style variables (participant responses to aforementioned appraisals), and psychological outcome variables (e.g. sexual function and satisfaction and QoL). The measures are detailed below:

Illness Appraisal Measure

Brief Illness Perception Questionnaire (Brief IPQ). The Brief IPQ measures appraisals of illness with a nine-item self-report questionnaire (Broadbent et al., 2006).

Response Style Measures

8 Item Comprehensive Assessment of Acceptance and Commitment Therapy Processes (CompACT-8). The CompACT-8 is a shortened version of the CompACT and measures psychological flexibility (Francis et al., 2016); it is psychometrically robust and possesses good internal reliability and validity (Morris et al., 2019).

Brief Coping Orientation to Problems Experienced Inventory (Brief COPE). The Brief COPE is a shortened version of the COPE and is a self-report questionnaire which assesses varied coping responses (Carver, 1997).

Psychological Outcome Measures

Patient-Reported Outcomes Measurement Information System® Sexual Function and Satisfaction Brief Profile self-report questionnaire which is composed of multiple domains which can be customised to measure sexual function and satisfaction (PROMIS SexFS) (Flynn et al., 2013). For each domain, a T-score

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[9] See extended methodology (section 2.4) for further information regarding measures used.

metric exists where a score of 50 relates to the mean of the population of adults with cancer from the United States. Lower scores indicate poorer function and/or satisfaction. For the present study, a score which was one standard deviation (SD) below 50 – namely 10 points - was considered to represent impaired function at an individual level, in line with previous interpretation of this questionnaire and the advised scoring of the domains (Ljungman et al., 2019). At a group-level, impairment was considered to be represented by mean scores of 0.5 SD (5 points) below 50 which generally corresponds to a clinically meaningfully difference at this level.

Alongside each validated question on this measure, participants were asked to complete a second response scale, as devised by the present study's researchers, which asked 'how does this compare to before your HNC?'. Participants were provided with three options per question, such as 'more interested now', 'less interested now' and 'as interested now as before'. This has been adapted to capture how the participant's current score compares to their pre-HNC experience.

Functional Assessment of Cancer Therapy-Head and Neck Version 4 (FACT H&N). The FACT H&N is a 39-item self-report measure which assesses QoL in HNC populations (D'Antonio et al., 1996).

Table 5

Theoretically informed measurement framework

Theoretical Category	**1) Background Variables**	**2) Response Style Variables**	**3) Outcome Variables**
Conceptual Targets	Cancer-related appraisals; individual and clinical characteristics	Response-focussed Measures	Psychological Outcome Measures
Measurement Targets	Demographic and clinical variables; cancer characteristics and beliefs	Acceptance and alternative coping/response styles	Quality of life and sexuality
Measures Employed	Brief IPQ Biological sex Sexual orientation Age Ethnicity Years since diagnosis Cancer site/s Current HNC treatments Past HNC treatments Cancer status Psychological therapy Relationship status	Brief COPE CompACT-8	FACT H&N PROMIS SexFS

Note. Brief IPQ = Brief Illness Perceptions Questionnaire; Brief COPE = Brief Coping Orientation to Problems Experienced; FACT H&N = Functional Assessment of Cancer Therapy-Head and Neck Version 4; PROMIS SexFS = Patient-Reported Outcomes Measurement Information System® Sexual Function and Satisfaction; CompACT-8 = 8-item version of Comprehensive Assessment of Acceptance and Commitment Therapy Processes

The measures were presented in the following order: PROMIS Sex FS, FACT H&N, Brief IPQ, CompACT-8, and Brief COPE. Due to the sexuality outcomes being central to the study's primary aim one, this was presented first. Whilst still considered important, the CompACT-8 and Brief COPE were positioned at the end of survey as the exploration of coping responses was a secondary aim. The survey was piloted with a service-user with HNC experience who advised on the survey design and language. The online questionnaire asked respondents to indicate their willingness to participate in an interview. The interview schedule was created and discussed with the same HNC expert by experience to seek feedback.

Ethics[10]

This research was given ethical approval by the Cambridge South Research Ethics Committee (REC) and the National Health Service (NHS) Health Research Authority (HRA) provided governance and legal compliance approval. Ethical approval documentation is displayed in Appendices E-I. Participants all provided informed consent and participated voluntarily. Appendices J-O show the consent forms, information sheets, and debriefing documents. Participants had the opportunity to enter a prize draw to win either one £100 or one £50 Amazon voucher in recognition of their participation.

Analysis[11]

Online Survey.

Descriptive statistics and correlation analyses (Pearson's *r*) were produced from the quantitative survey data using IBS SPSS Statistics Version 27. Correlation analyses were conducted to investigate relationships between time since diagnosis, participants' appraisal of their illness, response styles, and psychological outcome variables (sexual function and satisfaction and QoL). Background variables of age and years since diagnosis were selected analytically for inclusion within the matrix by running exploratory correlations between outcomes of interest and background/clinical variables. Results report any such correlations that showed

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[10] See extended methodology (section 2.5) for further information regarding ethical approval and considerations.

[11] See extended methodology (section 2.6) for further analysis information.

statistically significant association >.10. This is an approach consistent with those used in previous research (Brabbins et al., 2020).

One set of correlations was run without either of the sex-specific variables (erectile dysfunction and vaginal lubrication) to ensure that the largest available *n* was used for these correlations. Separate correlation matrices were run for sex-specific variables and values are presented below from these latter matrices for variable pairs that specifically involve one of these sex-specific variables. A deterioration variable was added into the correlation matrix to pick up on the aspect of perceived change/impact of HNC and whether any variables buffered against this – this was coded by identifying participants who had identified deterioration in any domain.

Semi-Structured Interviews.

Interviews were transcribed verbatim by the first author (LM) and thematic analysis (Braun & Clarke, 2006). was used to analyse the qualitative data and develop themes based on common patterns across the data that were pertinent to the research questions and not captured by more circumscribed quantitative measures. A mixed deductive-inductive semantic approach to thematic analysis – as employed in other research (Fereday & Muir-Cochrane, 2006) - was adopted. This approach allowed the researcher to work at the level of what the participants said, before interpreting the data in a way that was informed by relevant theories – such as the Sexual Adjustment Process of Cancer Patients and Their Partners (Benoot et al., 2017) - while also allowing for unexpected insights and patterns to be identified.[12] This study is the first to apply the aforementioned theoretical model as part of the deductive coding framework within a solely HNC population.

Synthesis of Results.

The quantitative and qualitative data were analysed and reported separately but the integrative analysis surrounding the first aim and the synthesis of quantitative and qualitative findings is reported in the discussion section to develop a higher-order understanding of how HNC impacts upon sexuality. Research aims two and three were considered solely using quantitative and qualitative analysis respectively and

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[12] See extended methodology (section 2.6) for further information surrounding the deductive coding framework.

therefore were not explored using the same mixed-methods approach as deployed for aim one.

Reflexivity[13]

As a quality assurance measure[14], the first author (LM) kept a reflective diary throughout the research process and used supervision to continually reflect on how her judgements, practices and beliefs could be affecting data collection and subsequent analysis (Watt, 2007): one such belief related to the researcher's assumption that sexuality would be negatively affected by HNC and this was noted prior to data collection and analysis. It is considered good practice to consider reflexivity to limit researcher biases unduly shaping the research (Watt, 2007).

Results

Participant Characteristics – Online Survey

60 participants completed a questionnaire battery. Participant demographics are available in Table 6. These appear to correspond with available figures on the UK HNC population (e.g., modal age range; 55-64). However, more females were recruited than the national average.

Table 6

Characteristics of overall sample

Sample Demographics	Response Options	Sample (N=60)	Percentage %
Biological Sex	Male	23	38.3
	Female	37	61.7
Age Range	18-24	0	0
	25-34	1	1.7
	35-44	10	16.7
	45-54	17	28.3
	55-64	21	35
	65-74	9	15

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[13] See extended methodology (section 2.9) for further reflexivity information including information surrounding the lead researcher's judgments, beliefs, and practices**.**

[14] See extended methodology (section 2.7) for further quality assurance details,

	75+	2	3.3
Sexual Orientation	Heterosexual/Straight	54	90
	Bisexual	2	3.3
	Homosexual/Gay	1	1.7
	Pansexual	1	1.7
	Other	1	1.7
Ethnicity	White British	42	70
	White Irish	3	5
	Any other white ethnic background	14	23.3
	Any other ethnic background	1	1.7
Years Since Diagnosis	0-1	12	20
	1-2	9	15
	2-3	10	16.7
	3-4	10	16.7
	4-5	2	3.3
	5-10	13	21.7
	10+	2	3.3
Relationship Status	Single	4	6.7
	In a relationship	13	21.7
	Co-habiting	2	3.3
	Engaged	1	1.7
	Civil Union	1	1.7
	Separated	2	3.3
	Married	35	58.3
	Divorced	1	1.7
Cancer Status	Not yet started treatment	2	3.3
	Currently receiving treatment	7	11.7
	In Remission	51	85
	Surgery	35	58.3
Treatments Received	Radiotherapy	40	66.7
	Chemotherapy	28	46.7
	Physical Therapy	10	16.7
	Immunotherapy	2	3.3
	Targeted Therapy	2	3.3
Received Psychological Therapy	Yes	20	33.3
	No	39	65

On an individual level, the largest clinical impairment was reported in relation to the ‘interest in sex’ domain, with 44.8% (*n* = 26) of the sample endorsing responses which were classified as clinically impaired. Furthermore, this was reported to be a post-HNC deterioration for 92.3% (*n* = 24) of the clinically impaired group. ‘Interest in sex', 'sex life satisfaction', and 'vaginal lubrication' were reported as significantly more impaired on a group level than the study's normative reference data for a general cancer population. Orgasm ability is not highlighted as meeting clinical impairment at a group level, but 37.0% (*n* = 14) of participants met the individual clinical impairment criterion for this, which was reported to be a post-HNC deterioration for 78.6% (*n* = 11) of those. As Table 7 indicates, for those who meet the clinical impairment criterion – either at a group or individual level – this is experienced by large proportions of the sample as a negative change.

Table 7

Proportions of study participants meeting clinical impairment criteria

PROMIS SexFS Domain	*n* Responders	*M* T-Score (SD)	*n* Clinically Impaired [CI] (%)	Of CI, *n* deteriorated post-HNC (%)
Interest in Sex Life	58	**40.5 (11.7)**	26 (45.0)	24 (92.3)
Sex Life Satisfaction	38	**44.9 (7.3)**	10 (26.0)	9 (90.0)
Orgasm Pleasure	36	47.2 (9.1)	5 (14.0)	4 (80.0)
Orgasm Ability	38	46.8 (11.2)	14 (37.0)	11 (78.6)
Erectile Function	14	50.1 (8.3)	2 (14.0)	2 (100)
Vaginal Discomfort	22	55.3 (13.1)	0 (0.0)	0 (0.0)
Vaginal Lubrication	22	**42.4 (10.7)**	10 (45.0)	6 (60.0)
Labial Discomfort	22	55 (10.7)	0 (0.0)	0 (0.0)
Clitoral Discomfort	22	54.1 (10.2)	0 (0.0)	0 (0.0)

Note 1: At a group (aggregated) level, mean T-scores ≤ 45 (i.e., ≥0.5 SD lower than the normative average [50]) were classed as 'clinically impaired'. At an individual level, T-scores ≤ 40 (i.e., ≥1 SD lower than the normative average) were considered 'clinically impaired'.

Note 2: Emboldened mean t-scores represent those which meet the group-level clinically impaired criterion.

Note 3: The final column describes deterioration for those within the clinically impaired subset rather than the responders in general.

Correlational Analyses

Correlations between years since diagnosis, age, response styles, cancer appraisal, and psychological outcome variables of interest are depicted in Table 8.

Response style variables relate to wellbeing, as measured through psychological outcome variables, in expected ways e.g., emotional wellbeing was found to be negatively associated with avoidant coping responses to HNC (*r* = -.52) and positively associated with psychological flexibility (*r* = .64). Other than this, none of the variables reflecting sexual functioning (current sexual functioning or post-HNC deterioration) were significantly associated with any response-style variables (avoidant coping, approach coping, or psychological flexibility) – although there were some non-significant relationships of small-to-moderate magnitude e.g., orgasm ability was shown to be significantly and negatively correlated with avoidance coping (*r* = -.355) and erectile function was shown to be positively associated with psychological flexibility (*r* = .449).

Table 8

Bivariate correlation matrix between background, response style, and outcome variables

	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18
1 Years since Diagnosis	-.034 [-.413, .356]	.047 [-.286, .414]	-0.10 [-.391, .415]	.142 [-.142, .414]	.041 [-.367, .455]	-.263 [-.514, .063]	-.250 [-.553, .066]	-.435* [-.674, -.149]	-.250 [-.850, .320]	-.141 [-.675, .507]	-.141 [-.459, .273]	.199 [-.158, .519]	-.016 [-.430, .383]	-.213 [-.594, .287]	-.291 [-.616, .138]	.173 [-.189, .586]	.295 [-.048, .606]
2 Brief IPQ		.414* [.051]	.135 [-.304, .507]	-.440* [-.672, -.174]	-.228 [-.541, .102]	-.315 [-.602, .004]	-.194 [-.585, .186]	-.055 [-.499, .766]	-.512 [-.822, .005]	.066 [-.425, .520]	-.195 [-.532, .139]	-.686** [-.821, -.537]	-.705** [-.818, -.559]	-.47** [-.730, -.126]	-.370* [-.724, -.015]	.020 [-.337, .346]	.058 [-.302, .398]
3 Avoidance Coping			.396* [.033, .699]	-.56** [-.749, -.330]	.183 [-.246, .356]	-.221 [-.577, .132]	-.355 [-.619, -.070]	-.228 [-.569, .192]	-.426 [-.871, .188]	.466 [-.096, .803]	-.087 [-.400, .229]	-.52** [-.781, -.163]	-.354* [-.618, -.087]	-.379* [-.701, -.031]	-.439* [-.727, -.057]	-.301 [-.580, .071]	.151 [-.211, .495]
4 Approach Coping				.116 [-.205, .413]	.129 [-.173, .413]	-.066 [-.348, .242]	.119 [-.207, .427]	.046 [-.379, .465]	-.355 [-.734, .252]	.131 [-.411, .643]	.270 [-.091, .559]	.150 [-.265, .522]	.069 [-.266, .401]	-.049 [-.436, .362]	-.319 [-.581, .044]	-.101 [-.458, .256]	.074 [-.254, .429]
5 Psychological Flexibility					-.109 [-.438, .224]	.296 [-.010, .630]	.290 [.005, .597]	.222 [-.069, .503]	.449 [-.099, .905]	-.473 [-.729, -.061]	.600** [.338, .794]	.640** [.337, .823]	.452** [.241, .656]	.351* [.061, .640]	.147 [-.187, .553]	.257 [-.075, .552]	-.210 [-.572, .120]
6 Interest in Sex						.252 [-.119, .591]	.353* [-.010, .634]	.374* [.019, .659]	.471 [-.028, .792]	.447 [-.051, .790]	-.143 [-.507, .175]	.085 [-.217, .395]	.216 [-.188, .581]	.352* [.074, .624]	.032 [-.307, .449]	-.167 [-.451, .175]	-.252 [-.531, .103]
7 Orgasm Pleasure							.595** [.272, .827]	.421* [.106, .661]	.663* [.067, .932]	.437 [-.071, .791]	.307 [-.033, .632]	.213 [-.096, .576]	.170 [-.175, .518]	.394* [.047, .671]	.264 [-.123, .650]	-.067 [-.462, .353]	-.570** [-.780, -.296]
8 Orgasm Ability								.541** [.237, .753]	.877** [.660, .995]	.252 [-.278, .669]	.333 [.030, .633]	.162 [-.137, .521]	.360* [.040, .657]	.547** [.326, .717]	.376* [.077, .650]	.066 [-.264, .420]	-.69** [-.865, -.473]
9 Sex Life Satisfaction									.568* [-.249, .897]	.262 [-.267, .693]	.416* [.037, .682]	-.007 [-.322, .356]	.213 [-.137, .521]	.213 [-.116, .523]	.205 [-.098, .465]	-.154 [-.414, .148]	-.499** [-.746, -.225]
10 Erectile Function											.332 [-.274, .724]	.053 [-.364, .792]	.213 [-.445, .748]	.655* [.287, .917]	.300 [-.189, .786]	-.395 [-.763, .177]	-.919** [-1.000, -.777]
											.113	-.292	.048	.083	.083	-.275	-.376

Table 8

Bivariate correlation matrix between background, response style, and outcome variables

	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18
11 Vaginal Lubrication											[-.448, .651]	[-.718, .314]	[-.497, .563]	[-.485, .548]	[-.485, .548]	[-.685, .214]	[-.754, .045]
12 SWB												.165 [-.217, .503]	.494** [.200, .742]	.287 [-.122, .611]	.117 [-.172, .427]	-.110 [-.387, .198]	-.400* -.691, -.064
13 EWB													.537** [.269, .772]	.291 [-.045, .658]	.068 [-.280, .525]	.283 [.025, .554]	.043 [-.311, .353]
14 FWB														.492** [.096, .797]	.276 [-.007, .585]	-.003 [-.359, .381]	-.200 [-.542, .160]
15 PWB															.601** [.399, .794]	.285 [-.133, .631]	-.488* [-.692, -.134]
16 HNCS																.030 [-.458, .493]	-.291 [-.578, .042]
17 Age																	.099 [-.273, .452]
18 Deterioration																	

*p < 0.05, **p < 0.01

Note 1: Rows *1-2* = background variables, Rows *3-5* = response style variables, and Rows *17-19* = outcome variables

Note 2: Background variables showing ≤1 significant association with response-style and outcome variables were excluded

Note 3: Brief IPQ = Brief Illness Perceptions Questionnaire; SWB = Social/Family Wellbeing; EWB = Emotional Wellbeing; FWB = Functional Wellbeing; PWB = Physical Wellbeing; HNCS = Head & Neck Cancer Subscale

Note 4: Confidence Intervals (based on 1,000 bootstrap samples) are reported in square brackets.

Note 5: The coding for the deterioration variable was derived from those who endorsed a deterioration on any of PROMIS Sex FS domains.

Participant Characteristics – Interviews

Eighteen participants who expressed interest at the survey stage undertook semi-structured research interviews. Table 9 outlines the interview sample's characteristics.

Table 9

Interview participant demographics

Interview Number	Participant Pseudonym	Sex	Age	Ethnicity	Head & Neck Cancer Site	Time since diagnosis	Treatment Type	Interview Format	Interview Length
1	Hannah	F	41	White	Tongue	1 Year, 7 Months	Chemotherapy, Physical Therapy, Immunotherapy, Radiotherapy and Surgery	Video Call	42m
2	Andrew	M	64	White	Tongue	5 Years, 2 Months	Chemotherapy, Radiotherapy	Telephone Call	39m
3	Scott	M	47	White	Tonsil	1 Month	Surgery	Video Call	31m
4	Lisa	M	42	White	Tonsil	2 Years, 1 Month	Chemotherapy, Radiotherapy	Video Call	1h 15m
5	Sandra	F	62	White	Mouth	2 Years, 6 Months	Surgery	Telephone Call	16m
6	John	M	70	White	Mouth	5 Years, 5 Months	Radiotherapy, Surgery, Physical Therapy, and Targeted Therapy	Video Call	59m
7	Patricia	F	63	White	Salivary gland in tongue	1 Year, 5 Months	Surgery	Video Call	52m
8	Rick	M	56	White	Throat	3 Years, 1 Month	Chemotherapy, Physical Therapy, Radiotherapy,	Video Call	1h 7m
9	Rebecca	F	49	White	Right cheek	12 Years, 6 Months	Surgery	Video Call	53m
10	Sam	M	46	White	Neck, tongue, and left tonsil	2 Years, 4 Months	Chemotherapy, Radiotherapy	Video Call	34m

Table 9

Interview participant demographics

Interview Number	Participant Pseudonym	Sex	Age	Ethnicity	Head & Neck Cancer Site	Time since diagnosis	Treatment Type	Interview Format	Interview Length
11	Danny	M	51	White	Unspecified	1 Year, 6 months	Chemotherapy	Video Call	1h 9m
12	Carol	F	59	White	Parotid gland	1 Year, 9 Months	Surgery, Radiotherapy	Video Call	42m
13	David	M	68	White	Pharynx	6 Years, 0 Months	Chemotherapy, Radiotherapy, Surgery, and Physical Therapy	Video Call	36m
14	Bert	M	80	White	Neck and throat	0 Years, 5 Months	Surgery, Radiotherapy	Email	N/A
15	Paul	M	62	White	Throat	3 Years, 6 Months	Chemotherapy, Radiotherapy	Video Call	34m
16	Timothy	M	55	White	Tonsil and neck gland	0 Years, 7 Months	Chemotherapy, Radiotherapy, Surgery	Video Call	15m
17	Jim	M	62	White	Throat	10 Years, 0 Months	Chemotherapy, Radiotherapy, Surgery, and Physical Therapy	Video Call	23m
18	Ruth	F	53	White	Jaw	0 Years, 5 Months	Surgery, Physical Therapy	Telephone Call	53m

Themes

Four themes were developed with the third theme containing subthemes: ‘Sexuality on hold during treatment’; ‘Sexuality not discussed by healthcare professionals (HCPs)’; ‘Impact: Altered sexual behaviour’, and ‘Response: Renavigating/rebuilding sexual intimacy’.[15]

Sexuality on hold during treatment

Everyone alluded to sexuality being deprioritised during their treatment to facilitate recovery. John described how “*the idea of having sex was in my head because it's never out of my head but it was not a priority. My priority was to get walking, get thinking, getting talking”.*

This deprioritisation of sexuality by individuals undergoing treatment was almost exclusively described as necessary, allowing them to focus on their treatment and recuperation. It appeared that participants generally were understanding of the reasons for changed sexuality during treatment and did not feel unduly distressed by this, conceptualising it as an inevitable aspect of their experience:

> *I found that I wasn't particularly interested in sex drive during the treatment part, I absolutely got it, I understood why, but during my treatment, absolutely, my sex drive just dried up, wasn't interested… I wanted to sleep, and I wanted to recover*.
>
> Sam

Participants differed in the length of time they experienced disruption to their sexuality as a result of cancer treatment, with some describing a more minimal change: Scott describes how “*the only real disruption [to sex life] would have been for the 10 days or so after the surgery where I was not in a fun place and lots of painkillers*”. However, some described a more extensive period of sexuality change during treatment: Danny explained that “*sex was the last thing on my mind… and…*

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[15] See extended results (section 3.1.2) for a more detailed description of themes with further quotes

from an actual physical point of view, there's not a chance I could, and it was the best part of a year until we could".

As detailed by all participants, considerations regarding sexuality ceased, briefly at least, during HNC treatment.

Theme 2: Sexuality not discussed by HCPs

The majority of participants stated that sexuality was not discussed by HCPs at any point during their treatment journey. Several reflected on this as a key discussion point that was missed:

> "*I find it so weird that there's a lot of talk about… how I can improve my saliva, this is how you can improve your eating, here you go, here's a menu, here's a bloody sauce, do this, but who's talking to you about this huge impact it's going to have, because we all have sex, and all enjoy sex… But nobody ever mentioned it to me… not one person has gone, how's your swallowing, how's your saliva, how's your neck. Nobody's ever said, "and how's your sex life?". Nobody's ever said that to me*". Lisa

Some made sense of this as a topic that was sacrificed due to the staff's priorities in helping them to survive cancer: Rick explained his opinion that "*if it's between me surviving and the treatment working and me having a great sex life, they are going to deprioritise my sex life in the short amount of time*".

Three participants reported that they did not feel that an HCP discussing their sexuality with them was a priority throughout their cancer treatment and therefore did not mind that it had not been raised. Similarities between two of these participants included extremely minimal treatment sequelae from HNC.

While most participants described that sexuality was not raised by either them or the HCP, two participants detailed experiences of actively raising the topic of sexuality with HCPs with different professional roles and the topic either not being engaged with or inappropriately managed:

> "*I tried to raise it…I spoke to a SLT (Speech and Language Therapist) first because obviously oral sex is about using your mouth, and so I asked about how that would work and they laughed, they thought it was, they were*

> *embarrassed and then they laughed and thought it was really funny… there was a serious question behind that which was never answered, and then when I suggested that I ask the consultant, everybody was, they just thought that was hilarious and said, can we be there when you ask him? Because the consultant… he's great at his job but he's not necessarily the most easy person to talk to*".
>
> Ruth

A reluctance to engage was additionally described in relation to a nurse by a second individual:

> "*She sat down, and I asked about sexuality, and I can always remember what she turned round and said, "…I don't want to give the wrong information. I don't want to give something that might mislead you or get missen [myself] into trouble, so I'd rather refrain from answering the question" which I could understand*".
>
> Paul

Evidently, HCPs do not appear to routinely raise or discuss sexuality with HNC patients and if a patient does initiate a conversation surrounding this topic, there seems to be a reluctance - which one participant understood as embarrassment - to engage or provide advice. However, it is salient to note that some participants reported that their sexuality was not impacted at all, to the extent of expressing curiosity about the reason for the study.

Theme 3: Impact: Altered sexual behaviour

It was clear that for many participants, their sexual behaviour was altered following HNC; which was commonly experienced as a loss, consistent with the pathway of grief and mourning outlined as common in the sexual adjustment process following cancer (Benoot et al., 2017). These alterations to sexual behaviour were conceptualised as involving both physical and psychological barriers.

Subtheme 3a: Physical barriers.

Practical barriers were indicated by participants which produced altered sexual behaviour. One such physical barrier was post-treatment pain:

> "…*there's a fissure at the end [of my tongue] where they cut it out and sort of sewed it back underneath itself, which is very sore… it feels as though I have stinging nettles in my mouth… I cannot imagine kissing anybody now… except very chastely, just with lips*".
>
> Patricia

Post-treatment pain was not the only physical barrier reported. Structural changes following surgery had impacted on the feasibility of sexual acts involving the mouth:

> "*My mouth opening is slightly restricted, and I can't open it as wide… so I mean kissing is fine but it's just a little bit more, um, difficult because you're not opening your mouth as wide, and also, the thing with oral sex really is I can't open my mouth as wide, so, it's possible, but it is a little bit more, awkward*".
>
> Sandra

Another commonly reported post-treatment effect which proved a physical barrier to previous sexual activity was "*a huge drop-off in the volume of saliva that's produced, which again, is quite important in a sex life*" (Andrew). This was echoed by other participants, reporting that "*the ultimate thing is the lack of saliva*" (Lisa). This was reported to impede the performance of oral sex as "*saliva substitutes… they've not really been developed… for a long period of licking*" (Andrew).

Subtheme 3b: Psychological barriers.

Psychological barriers caused alterations to sexual behaviour: these have been conceptualised as the participant's own fears and the fears of the partner.

The fear of cancer reoccurrence from performing oral sex was a fear expressed by one participant:

> "*I really enjoy giving oral sex to my partner…Obviously I don't do that anymore because that could cause HPV… I'll do anything I can to prevent any reoccurrence, whether that would make much difference or not I don't know, but clearly in both of our minds that's now out of bounds*".
>
> Sam

Another prominent fear which emerged related to participants' diminished view of their own attractiveness following HNC and related treatment:

> "*(I) would have been more interested a couple of years ago before the operation… I don't look the same as what I did back then… I was much better looking… I think some of your sexuality is coming from within, how you feel about yourself, you know how you feel pretty*".
>
> Carol

While this quote indicates that the participant's own perception of their attractiveness inhibits their personal sense of sexuality, another participant expressed concern about their partner's perception of them: Ruth explained that "*if I open my mouth, if I happen to be expressive during sex, if he's [partner] looking down on me, what he's seeing is all this metal framework and no teeth*".

Partners' fears of contracting cancer through sex were outlined by participants: Danny reflected that "*the hardest thing what's happened… is my wife doesn't kiss me anymore… I always loved kissing and it's something I miss… I think she's, she's conscious of catching something*". Jim shared his understanding of his partner's reservation, stating that "*if you go on Google, it says it's sexually transmitted, soon as you see that, then why would she want to be intimate with me in case I give her cancer*?".

Another fear expressed by partners related to hurting their partner: "*My wife was very worried about causing further pain or discomfort*" (Andrew). This idea appeared in other interviews, capturing the difficulties partners had in transitioning from a carer role back to a sexual partner role:

> "*My husband… he's been used to having to take my feeding tube out and change my PICC line and he's been my caregiver to suddenly he has a wife*

> *who is… feeling so much better…and wants to start from where we left off two years ago*”.

Hannah

Regarding the physical apparatus connected with HNC treatment, thoughts about the feeding tube demonstrated that this presented a psychological barrier for participants to engaging with their sexuality.

Evidently, both physical (predominantly experienced by the patient) and psychological barriers (experienced by both patients and partners) led to altered sexual behaviour following HNC.

Theme 4: Response: Renavigating/rebuilding sexual intimacy

The majority of participants described a process of renavigating and rebuilding a sexual intimacy with their partner which had been affected by their experience of HNC. Some detailed how their sexual experiences with their partner had been affected in practical terms and explained how they had used particular behavioural and physical modifications to rebuild sexual intimacy between them. An application of the deductive coding framework to the inductive data found this to be consistent with the sexual rehabilitation theoretical literature described by Benoot et al (2017):

> “*We've now found other ways through trial and error, which was great, and actually was quite a bit fun, but through trial and error we’ve found other ways to, for us to both get a climax again, which is great, but it took that kind of, let's start with this, let's start with that….it was a bit like a check sheet, let’s try this, let’s try this, let’s try that. And eventually we found stuff that worked and that’s now what we do*”.
>
> Sam

Additionally, some participants referred to an experience of rebuilding sexual intimacy which involved cognitive adjustments to how they viewed sexuality within their relationship and discovering new ways of expressing closeness and intimacy. These accounts appeared to fit with extant theoretical literature around a cognitive pathway of sexual restructuring which differed from the previously mentioned sexual rehabilitation pathway (Benoot et al., 2017):

> "…*before sex used to be… we'd both have to have an orgasm, job done. I'm very much trying to work on now, right, so, we call it naked time… more about just intimacy and more about like, we are married… we can just be together in a sexual way, it doesn't have to have the end result. Yeah, that's quite a change of mind… for me… so, I think we're working… more on the intimacy side of it more, like we'll take baths together and you know just try and get around it in that way, yeah*".
>
> Lisa

The concept of intimacy being fostered even when a couple's sexual expression had changed considerably was additionally highlighted by another participant:

> "…*I feel like my closeness to my partner has increased but our physical, our sexual activity has, I would say almost ceased, like we kiss, and we hug, we're physically close but we are not having sex now, after, post-treatment*".
> Rick

Just one participant described no changes/re-navigation to his sexuality following HNC, but almost all detailed sexual adjustment following their HNC at either a behavioural or cognitive level.

Discussion

This study primarily aimed to investigate the impact of HNC upon sexuality. It addressed three questions, outlined below with associated discussion of the findings. The limitations are considered before clinical implications and future directions are provided.

What is the impact of HNC on sexuality in terms of sexual function and satisfaction, identity, and relationships?[16]

Consistent with other research, the integrated quantitative and qualitative findings indicate that sexuality is adversely impacted by HNC for a large proportion of HNC survivors within the current sample across multiple domains of sexuality including function, satisfaction, identity, and relationships. Subjective appraisals (e.g., interest

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[16] See extended paper section 4.1 for further discussion of this research question

in sex, sex life satisfaction) of sexuality as diminished were reflected in both phases of the study and appeared more prominent within the data than functional impairments to sexuality, although these were also mentioned as adversely impacted by a significant minority. Qualitative findings offer a nuanced understanding of why participants may display less interest in sex and overall reduced satisfaction with their sexuality due to the altered sexual behaviour reported by many in relation to multiple physical and psychological barriers.

The findings obtained from the current sample in both study phases showing that sexuality is negatively impacted within HNC populations supports extant literature. The present study found that sexuality could be impacted in terms of both functional/physical and more psychological aspects, as previously highlighted (Rhoten et al., 2019); novel perspectives on this were elicited through a triangulation of methods which captured the significant impact on orally-related sexual activities such as kissing and performing oral sex. Furthermore, findings that more subjective appraisals of deteriorated sexuality (e.g. interest in and satisfaction with sexuality) following HNC were common and echoed previous findings that the domain of sexual enjoyment is frequently negatively affected by HNC (Moreno et al, 2012).

Study findings in relation to the frequently mentioned renavigation of sexual intimacy partially correspond with the sexual adjustment to cancer framework (Benoot et al, 2017) which suggests three main adjustment processes to altered sexuality following cancer. This study is the first to apply this theoretical model as part of the deductive coding framework within an exclusively HNC population. This supports the model's generalisability to different cancer presentations and demonstrates that even when individuals do experience a deterioration in sexuality post-HNC, there are multiple approaches to navigating these difficulties which can occur at either a behavioural or more cognitive level.

Are PF and other coping responses associated with sexuality and QoL outcomes in the context of HNC?[17]

Quantitative results show that while response style variables - such as PF and other coping responses are related to overall wellbeing – as measured by QoL – strong

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[17] See extended paper section 4.2 for further discussion of this research question

relationships were not detected between measures of sexual function/satisfaction and response style variables. This latter relationship was the novel focus of the study.

In terms of how threatening the cancer is perceived to be and how participants made sense of cancer as a stressor, this was inversely related to PF. In terms of general wellbeing and coping with the threat of an illness, PF appeared to be important, whereas avoidant coping appeared to be unhelpful. This resonates with the extant literature (Brabbins et al., 2020; Gillanders et al., 2015). Findings relating to sexual function and response styles were not clear within the data. This can be partly attributed to sample size, as the relationships within the correlation analyses do display moderate correlations but this is less pronounced in comparison to what is indicated in the relationships between response style variables and overall wellbeing, as measured by QoL.

These results were not as expected, as previous longitudinal literature found that lower levels of psychological flexibility were associated with reduced sexual functioning, therefore providing initial evidence that PF is related to sexual adjustment (Maathz et al., 2020) whereas our study did not compellingly show this. However, this was in a health context of vulvovaginal pain rather than cancer – it is possible that the vulvovaginal pain could have more directly impacted sexual function. The study findings did not convincingly connect with extant literature showing that cognitive appraisals and avoidant coping responses are associated. Therefore, despite negative cognitions/avoidant coping having been associated with poorer functioning in various QoL domains in other research (Brabbins et al., 2020; Gillanders et al., 2015), this has not been generalised to sexuality outcomes for HNC survivors in the current study. As previously noted, the lack of significance could arguably be partially accounted for by sample size.

What do people with HNC perceive to be their support needs surrounding sexuality?[18]

Results from the current sample show that there are support needs for people with HNC in terms of psychological, informational, practical, and physical support around

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[18] See extended paper section 4.3 for further discussion of this research question

sexuality. Results indicated that sexuality support is poorly integrated into wider healthcare structures for HNC survivors. Large proportions of participants experience a negatively impacted sexuality following HNC - as evidenced by those who described sexual deterioration - and a significant minority of participants indicated that they would have benefitted from support provision regarding their sexuality which could have included psychological support around sexuality. These support needs included normalising and permission-giving to raise the topic of sexuality with HCPs, as well as sexual psychoeducation and in some cases, couple-level psychological support to re-navigate sexual intimacy.

Results indicated that negatively impacted sexuality is a common problem that is not being raised by professionals, consistent with extant literature (Haboubi & Lincoln, 2003). If such a discussion is not initiated by a HCP at any stage, then it is possible that a person may not receive any information at all. It was a relatively rare report within the qualitative interviews, but salient findings showed that some participants had met with unprofessional and invalidating responses (e.g. laughter, conversational shutdowns) when they raised the topic of sexuality with HCPs: this fits with literature showing that cancer patients overwhelmingly report that HCPs are unwillingly to openly discuss this topic (Hordern et al., 2009). While extremely unprofessional behaviour appears to be a rare occurrence, it suggests a training need for HCPs around sensitively and appropriately discussing sexuality with patients to cultivate a perception of them as reliable and trustworthy sources of information.

These findings are consistent with extant literature suggesting that sexuality difficulties are rarely discussed in routine appointments (Low et al., 2009; Rogers et al., 2014) and that patients would appreciate more time in appointments with HCPs for discussing difficulties relating to sexuality difficulties (Rhoten et al., 2019). However, the present findings extend previous literature, highlighting that sexuality should be discussed beyond purely functional sexual difficulties and that suitable informational resources should be made for professionals and patients to avoid HNC patients - who are vulnerable to experiencing deteriorated sexuality - being left with no information and/or support around this topic.

Limitations[19]

Recruitment in the quantitative survey stage was a challenge, despite multiple recruitment attempts across various timepoints and the development of good relationships with recruiting clinicians, charities, and social media group administrators. Despite the wish to recruit higher numbers of participants, the recruitment of 60 participants in relation to a socially sensitive phenomenon within a circumscribed population still compares favourably to similar research conducted within this field.

Another limitation pertains to the demographic limitations of the sample, more specifically the higher than average representation of women and the almost universally white backgrounds of participants.. While efforts were made to recruit from a diverse range of channels and therefore capture a more ethnically diverse sample by including clinics, charities, and support groups within the recruitment plan, this did not result in a more ethnically heterogenous sample. This is problematic as research shows that ethnic minorities are under-represented within cancer research and that any differing cancer outcomes for ethnic minorities are poorly understood (Knobf et al., 2007).

In relation to the questions within the questionnaire phase which invited participants to consider how their current sexual function and satisfaction compared to their pre-HNC sexual function and satisfaction, it is important to note that this is still cross-sectional research despite being phrased longitudinally. Therefore, it is important to consider the data generated by this in an appropriately critical manner as it will be vulnerable to recall bias as it has not been collected at two separate timepoints.

A final key limitation relates to the mechanical and embodied nature of some items within the sexual function and satisfaction questionnaire which arguably may have required a high level of literacy and anatomical knowledge from survey participants, especially women who were asked to differentiate between sensation within the vagina, clitoris, and labia. Furthermore, it is possible that ways of thinking and acting (e.g., response styles) would not be directly related to such items as erectile function and vaginal lubrication. However, other items within the survey accessed more

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[19] See extended paper section 4.4 for extended discussion of the limitations and strengths of this study.

subjective participant appraisals of their sexuality by asking about such topics as interest in sex and sex life satisfaction. Additionally, the mixed methods nature of the study allowed for further detail surrounding a higher-order understanding of the impact of HNC upon sexuality to be gained in the qualitative stage.

Clinical Implications and Future Directions[20]

Difficulties with sexuality following HNC demonstrably affect a number of individuals. It would be advantageous for HCPs to raise this topic with patients at an appropriate stage of treatment (given deprioritisation during treatment) to normalise the experience of negatively impacted sexuality and to support patient concerns (Park et al., 2009). However, it is important that concerns are not just validated and normalised but that appropriate signposting and advice can be provided. Again, this importance of HCPs discussing sexuality is likely to increase with the increasing number of HNC cases caused by HPV and its associated connotations of sexual transmission (Farsi et al., 2015).

Furthermore, as previously noted, it was generally subjective (e.g. sexual interest and satisfaction) rather than functional (e.g. erectile function, vaginal discomfort) appraisals of diminished sexuality that were reported by participants. This suggests that professionals should ask about a broadly defined impact rather than focussing on the more mechanistic, physical aspects of sexual function. Whilst it is not anticipated that an HCP such as a CNS would be trained to administer a specialist psychological intervention around supporting an individual’s adjustment to an impacted sexuality and supporting them to renavigate and/or reappraise intimacy, informational resources to support frontline HCPs to identify those in need of access to practitioners who could offer more specialised psychological interventions would be beneficial. These informational and support needs are increasingly highlighted in connection with cancers related to sexual organs but little literature addresses this in relation to HNC (McCaughan et al., 2020).

Future research in this area could usefully triangulate the perspectives of the HNC patients with HCPs to deepen the understanding of the barriers to discussing sexuality for staff, particularly with a population for whom it would be such a pertinent

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[20] See extended paper section 4.5 for extended discussion of the clinical implications and future directions of the study.

topic. Relatedly, the production and dissemination of clearer guidance on the topic of raising sexuality with patients, when sexuality can safely be re-engaged in again from a practical and emotional perspective, why there might be impacts specifically for a HNC population to be aware of (e.g. infection concerns), and who it is useful to speak to if a patient does have questions or problems.

This project contributes to the existing literature but also extends our understanding of the impact of HNC on sexuality. A clearer understanding has been achieved which clarifies that changes to sexuality are typically experienced as attributable to HNC rather than other factors. Furthermore, it appears that subjective appraisals of sexuality – such as interest – are more vulnerable to deterioration than more functional aspects, highlighting this as something that HCPs could usefully ask about. The study findings show that sexuality is extremely rarely raised with HNC patients and yet HNC survivors are likely to have additional queries about sexuality e.g., infection control, HPV risk, and impaired saliva production. From this, the development of guidelines and informational resources for HCPs in relation to this topic is clearly indicated.

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EXTENDED PAPER

1. Extended Introduction

1.1. Head and Neck Cancer

Head and Neck Cancer (HNC) - sometimes referred to as head and neck squamous cell carcinoma - is a broad term that can refer to in excess of 30 cancers in the head and neck. The majority of head and neck cancers originate within the mucosal epithelium in either the pharynx[21] , larynx[22], or oral cavity[23] (Leemans et al., 2011). Risk factors for head and neck cancers deriving from the larynx or oral cavity include tobacco or alcohol consumption, whereas pharynx-related head and neck cancers have been associated with infection with the Human Papillomavirus (HPV), most typically HPV-16 (Johnson et al., 2020). The tumours which occur as a result of HNC display considerable heterogeneity, leading to a wide range of prognoses and therapeutic options for patients (Chow, 2020).

1.1.2 Epidemiology

Data from 2018 shows that HNC is the seventh most common cancer globally with 890,000 incidences and 450,000 deaths (Bray et al., 2018). HPV-associated cancer rates (most commonly the HPV-16 subtype) are increasing: this is most noticeable amongst relatively younger individuals in North America and Northern Europe (Chow, 2020; Mourad et al., 2018). This epidemiological change is considered to be linked to a latency period of 10-30 years after exposure to the carcinogen of oral sex (Gillison et al., 2015): Gillison (2015) hypothesises that this is partially linked to the increased proportion of men and women reporting engagement in oral sex in successive birth cohorts. A latency period refers to the amount of time which occurs between exposure to the carcinogen and cancer diagnosis (Gillison et al., 2015).

Within the United Kingdom, HNC is the eighth most commonly occurring cancer and accounts for 3% of new cancer cases, with 12,400 incidences and 4077 deaths

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[21] The pharynx includes the nasopharynx (behind the nasal cavity), oropharynx (comprising the tonsillar area, tongue base, soft palate, and posterior pharyngeal wall), and hypopharynx (comprising the pyriform sinuses, posterior surface of the larynx and post-cricoid area, and inferior posterior and inferolateral pharyngeal walls) (Chow, 2020, p.61).

[22] The larynx includes the supraglottic larynx, glottic larynx (true vocal cords and anterior and posterior commissures), and subglottic larynx (Chow, 2020, p.61).

[23] The oral cavity includes the lips, buccal mucosa, anterior tongue, floor of the mouth, hard palate, upper and lower gingiva, and retromolar trigone (Chow, 2020, p.61).

annually (Cancer Research UK, 2018). Men are four times more likely to be diagnosed with HNC than women (Bosetti et al., 2013) and HNC occurs more commonly in individuals over the age of 50 (Macmillan, 2018) with the highest incidence in those aged 65 and over (Orlandi et al., 2019).

HNC is typically diagnosed for an individual after a comprehensive history had been taken, they have received a physical examination, radiologic imaging has occurred, and a biopsy is performed (Chow, 2020; Tandon et al., 2008). Other possible diagnostic procedures include a nasendoscopy, examination under anaesthetic, or a trans-nasal flexible laryngo-oesophagoscopy (Macmillan, 2018).

Following a diagnosis, the cancer is staged: this refers to a process where the size of the cancer and whether it has spread from where it originated is considered (Macmillan, 2018). Typically, the Tumour, Node, Metastases (TNM) staging system, or the Number Staging System is used (Macmillan, 2018; Shah, 2018). Within the TNM system framework, the T can be graded on a 0-4 basis: T0 representing no tumour but possible pre-cancerous cells and T4 describing a tumour which has spread into surrounding tissue (Macmillan, 2018). The N references the node, namely whether the cancer has progressed to lymph nodes: N0 would refer to no affected lymph nodes whereas N1-4 would describe that there are cancer cells in the lymph nodes (Macmillan, 2018). Finally, the M indicates the extent of the cancer's spread around the body, with M0 referencing no cancer spread and M1 showing that cancer has spread: this is also known as metastatic cancer (Chow, 2020; Macmillan, 2018). The Number Staging System ranges from Stage 1 (early stage cancer which has not spread) to Stage 4 (more advanced cancer which has progressed to more distant parts of the body) (Macmillan, 2018).

1.1.3 HNC Treatments and Related Sequelae

A number of considerations inform decisions regarding the most appropriate treatments, decided through discussion by a multidisciplinary professional team. Factors that should be contemplated alongside the nature of the cancer include a patient's age, co-morbidities, and support structures (Orlandi et al., 2019). Some individuals may have multiple treatments, whereas others may only require single modality treatment e.g. surgery or radiotherapy (Macmillan, 2018).

1.1.3.1 Surgery

Surgery is a commonly used treatment for HNC and aims to wholly remove the cancer whilst still aiming to reduce the impact of surgery upon processes such as speaking, breathing, and swallowing (Macmillan, 2018). Recent surgical advances have allowed surgeons to both perform the removal of more complex tumours and more precisely perform any necessary reconstructive surgery (Homer & Fardy, 2016). Due to the site of many HNC surgeries, a feeding tube - also known as a percutaneous endoscopic gastrostomy (PEG) or radiologically inserted gastrostomy (RIG) tube - may be required to allow the site of the operation to heal: this often requires the feeding tube to be inserted into the stomach (Macmillan, 2018).

Side effects of surgical treatment can include tissue loss, pain, scarring, a change to appearance, and either a temporary or permanent loss of sensation in a particular area/areas depending on the location of the cancer in relation to a nerve (Macmillan, 2018).

1.1.3.2 Radiotherapy

In radiotherapy, high-energy cells are used with the aim of gaining control of the tumour whilst causing minimal damage to surrounding organs (Macmillan, 2018; Song, 2014). Radiotherapy may be used as a single modality treatment approach if the cancer is small with no spread but is likely to be used as part of a wider multi-modal treatment approach if the cancer is larger or is affecting surrounding local tissue (Macmillan, 2018). Adjuvant radiotherapy refers to radiotherapy that is administered after surgery, usually for further progressed cancer (Macmillan, 2018).

Due to the extremely high doses of radiation used in typical head and neck radiotherapy, severe and persistent treatment sequelae frequently occur. These sequelae are likely to develop because several areas of tissue are impacted by the radiation dose (González-Arriagada et al., 2018). The impact experienced by the individual will vary based on treatment-related factors, such as the dose of radiation and individual factors such as the patient’s overall health and whether they currently smoke or drink alcohol (González-Arriagada et al., 2015). Side effects of radiotherapy include tissue swelling in mouth (oral mucositis), an unpleasant taste in the mouth (dysgeusia), swallowing difficulties (dysphagia), pain when opening the jaw (trismus), skin irritation (dermatitis), and thrush (candidiasis) (González-Arriagada et al., 2018). These side effects, whilst acute, can often be addressed after treatment concludes. However, a commonly reported side effect which can persist after the radiotherapy finishes a lack of saliva which can lead to patients experiencing a dry mouth, discomfort in their mouth, and difficulties chewing, swallowing, and speaking (Macmillan, 2018).

1.1.3.3 Chemotherapy

In chemotherapy, cytotoxic (anti-cancer) drugs which disrupt how cancer cells grow are administered to the patient (Macmillan, 2018). Chemotherapy is not used as a treatment in insolation to treat HNC but is instead dispensed in conjunction with other treatments including surgery and radiotherapy to enhance treatment outcomes (Kelly, 2016). When chemotherapy is administered in combination with radiotherapy, this treatment approach is referred to as chemoradiation (Macmillan, 2018).

Chemotherapy is typically given intravenously over multiple treatment sessions: the patient is provided with rest breaks to allow them to recover prior to the next treatment cycle (Macmillan, 2018).

Side effects of chemotherapy can include nausea, an intensification of radiotherapy-related side effects, a painful mouth, hair loss, and fatigue: these side effects can all affect an individual’s quality of life (Macmillan, 2018).

1.2. Psychological Impact of Head and Neck Cancer

The prevalence of psychological distress for individuals experiencing HNC is high: this is commonly thought to be related to the considerable physical and mental challenges faced by those undergoing HNC treatment (Neilson et al., 2010). It is estimated that approximately 33% of HNC patients show symptoms of depression and/or anxiety (Rogers et al., 2006). Rates of depression are higher in patients with HNC (22-57%: Massie, 2004) even in comparison to other cancer populations (0-38%: Massie, 2004) and this elevated psychological distress is additionally reflected in the increased suicide risk for HNC patients, again, even when compared to other cancer populations and the wider population (Frampton, 2001; Sun et al., 2020; Zeller, 2006).

HNC commonly necessitates prolonged, multi-modal treatments (typically some combination of surgery, chemotherapy and radiotherapy) which are physically exhausting for the patient and generally lead to multiple side effects (Badr et al., 2019). Research literature suggests that a contributing factor to the psychological distress experienced by HNC patients is the nature of areas affected by the cancer and treatment e.g. the mouth, throat, and nose which resultantly can impair vital life functions such as breathing, swallowing, and eating (Ledeboer et al., 2005; Millsopp et al., 2006).

Alongside profound physical treatment sequelae, HNC survivors experience worries around their cancer returning, which it is statistically more likely to do as compared to other cancers due to poorer prognosis outcomes (Milette et al., 2010). Potential physical alterations following treatment include radiotherapy-related skin pigmentation changes, swelling, and fibrosis and/or surgically-related scarring, affected facial contour/expression, or an amputated facial area (Hung et al., 2017; Rhoten et al., 2014). Concerns about an altered physical appearance are commonly reported in HNC survivors, with prevalence rates estimated to range between 25-77% (Melissant et al., 2021). These body image fears are understood as particularly prominent in this population as compared to other cancers because the disfigurement HNC survivors experience is harder to conceal (Fingeret et al., 2012).

Another contributor to the psychological distress experienced by individuals with HNC is cancer stigma (Threader & Mccormack, 2016; Tseng et al., 2021). Research suggests a twofold stigma experienced by HNC patients (Threader & Mccormack, 2016): one area of stigmatisation putatively pertains to the lifestyle factors associated with contracting HNC (e.g. alcohol consumption, smoking, and the human papilloma virus (HPV)) and the second aspect of stigma relates to the possibly “visually confronting” altered facial appearance an individual with HNC may have following treatment (Threader & Mccormack, 2016, p.1). Experiencing such stigma can compound experiences of social isolation and psychological distress for individuals with HNC and further impact on quality of life, in addition to the distress experienced by the cancer diagnosis and treatment alone (Threader & Mccormack, 2016; Tseng et al., 2021).

1.3. Sexuality and its Definition

Sexuality is a term that has been variously - some have argued inadequately (Goettsch, 1989) – defined (Tolman & Diamond, 2013): more contemporary understandings view the term ‘sexuality’ as a broad multidimensional construct which includes a range of ideas such as relationships, gender, and dress (Singer et al., 2008; Tierney, 2008). Sexuality can also be defined more specifically in relation to sexual activity[24], sexual orientation[25], or sexual identity[26] (Ridner et al., 2007). While sexuality can encompass a wide range of concepts, not all individuals will express all concepts e.g. a person’s sexual orientation might not be reflected in their sexual activity. Due to the multidimensional nature of sexuality, it is recommended that research investigating sexuality offers a clear definition of sexuality which is appropriate for the scope of their study (Ridner et al., 2007). Furthermore, research shows that due to sexuality being a multidimensional construct, it should be assessed as such in the context of cancer care (Cleary & Hegarty, 2011). This translates into professionals considering aspects of sexuality beyond merely physical sexual functioning and also taking into account areas such as intimacy, sexual self-concept, and sexual response (e.g. desire, orgasm, and arousal) (Cleary & Hegarty, 2011).

Due to the multiple interpretations of the term ‘’sexuality”, participants were oriented to the semi-structured interview and online questionnaire with the WHO definition of sexuality, namely that sexuality is:

“…a central aspect of being human throughout life [which] encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles, and relationships”(World Health Organisation, 2006).

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[24] Sexual acts or behaviours conducted individually or with another/others (Ridner et al., 2007).

[25] Sexual orientation refers to “the organisation of an individual’s eroticism and/or emotional attachment with reference to the sex and gender of the partner involved in sexual activity”(World Health Organisation, 2000).

[26] The way that individuals define themselves sexually which may or may not reflect the sexual activity they engage in (Moser, 2016).

Research shows that sexuality is a crucial aspect of a person's life irrespective of their age, health status, relationship status, or sexual orientation (Tierney, 2008): this is particularly salient to consider in relation to older adults, around whom a narrative of asexuality exists (Kenny, 2013).

1.4. Psychological Theory Related to the Impact of Cancer upon Sexuality

There is a growing awareness of the impact of cancer upon sexuality in research literature which recognises that both the cancer itself and the treatment can cause disruption to an individual's sexuality (Fischer et al., 2019; Southard & Keller, 2009). It is probable that a patient will have experienced at least one of the following: a surgery, radiotherapy, chemotherapy, or hormonal treatments. The side effects of treatment can be permanent and include hair loss, vaginal dryness, erectile dysfunction, and structural changes to the body (Gilbert et al., 2009; Perz et al., 2013; Southard & Keller, 2009). While a consideration of the physical areas of sexuality affected by cancer is important, an exclusive focus on the physical neglects to understand the "subjective meaning and consequences of sexual changes" for the individual (Ussher et al., 2015, p.1). It is therefore advisable to consider how sexuality can be psychosocially impacted as well as physically altered (Gilbert et al., 2009). Research suggests that multiple domains of sexuality are affected by cancer and its treatment: these include self-esteem, body image, self-confidence, and interpersonal issues (Tierney, 2008).

1.4.1 A Theoretical Model of the Sexual Adjustment Process of Cancer Patients and Their Partners

Through a meta-ethnographically informed synthesis of 16 qualitative research studies from a purposeful sample, a theoretical model outlining the process of sexual adjustment during cancer was developed by Benoot et al (2017) to explain the processes of adjustment couples might experience when faced with an altered sexuality following cancer. The model outlines three theoretically-informed pathways of sexual adjustment for couples. Each pathway is multi-phasal, outlining the initial phase of that specific pathway, the associated sexual difficulties, and ultimately, the mechanism of sexual adjustment: insight is also provided into why couples may take which pathway e.g. a couple with sexual difficulties prior to cancer may find it easier to adapt to altered sexuality post-cancer (Benoot et al., 2017). However, a limitation of the paper relates to the minimal consideration of gender theory within this model which might aid understanding of the different responses of couple members depending on their gender identity.

1.4.1.1 The Pathway of Grief and Mourning

Within this pathway, any sexual alterations following cancer are framed as a loss and the adjustment to these changes can be understood in terms of classical grief and mourning theory (Kübler-Ross, 2008; Schut & Stroebe, 1999). Features of this pathway include concepts such as denial, anger, bargaining, depression, and ultimately, acceptance of the new reality (Benoot et al., 2017). However, it is important to consider that classical grief and mourning theory was not traditionally developed to be applied to couples experiencing sexual adjustment which could arguably make this slightly less relevant to this population.

1.4.1.2 The Pathway of Restructuring

The restructuring pathway suggests that couples flexibly adapt to the new reality of their altered sexuality post-cancer at a more cognitive level than proposed in the Mourning/Grief pathway. It is possible that this adaptation could lead to the couple questioning dominant socio-sexual discourses regarding the importance of sexuality or particular sexual activity or, indeed, that this questioning/change in meaning could produce flexible adaptation. This could also be reflected in couples considering the meaning of sexuality differently in relation to how they did pre-cancer (Benoot et al., 2017).

1.4.1.3 The Pathway of Sexual Rehabilitation

This pathway varies from the previous two in that the adjustment processes places less emphasis on psychological processes but instead highlights that the sexuality changes as a result of cancer are considered in terms of physical dysfunction. These changes which are considered in physical terms are understood as requiring specific behavioural treatment approaches rather than psychological/cognitive adaptations. The aim of the adjustment process is to re-achieve a sexuality that is the same as pre-cancer rather than focussing on emotions or cognitions about the experience (Benoot et al., 2017).

A strength of this theoretical model is the clinical utility it offers in helping healthcare professionals understand the difficulties with sexuality a couple may be experiencing prior to using a strengths-based approach to support their adjustment to their altered sexuality following cancer. Another benefit of this model relates to the author's recommendations that the three pathways can be integrated to inform a personalised approach to facilitating a couple's sexual adjustment. The recommendations of this model are endorsed by results from other research studies (Canzona et al., 2019; Jonsdottir et al., 2021).

1.5. Measuring Sexuality and Quality of Life Outcomes

Sexuality can be measured in a number of ways: however, consistent with the difficulties in defining such a multidimensional construct, the various scales developed to measure sexuality can vary significantly. A useful way of measuring sexual outcomes is through self-reported measures of sexual function and satisfaction as it allows individuals to report outcomes regarding a socially sensitive phenomenon without being directly asked by others (Weinfurt et al., 2015). A challenge associated with the use of sexual self-report measures is the socially sensitive nature of the topic (Fenton et al., 2001). It is therefore important that steps – such as service-user involvement when designing the questionnaire - are taken to reduce the risk of measurement error which may occur through social desirability bias and participants experiencing difficulties in understanding the questionnaire items (Fenton et al., 2001).

Sexual self-report measures are beneficial for research purposes to understand the needs of specific populations but can also be employed in clinical settings to evaluate interventions (Weinfurt et al., 2015). Within cancer populations where patients are vulnerable to experiencing a negatively impacted sexuality, it is particularly useful to have measurement tools to gain insight into a patient's sexuality and, if required, this may indicate particular supportive interventions (Flynn et al., 2013).

The Patient-Reported Outcomes Measurement Information Sexual Function and Satisfaction measures (PROMIS SexFS) were developed based on thorough quantitative and qualitative data collection and analysis (Flynn et al., 2013). This measure is useful in that it can be answered regardless of relationship status, as it captures both solo and partnered sexual activity. The measures possess well-documented validity and reliability for a broad range of cancer patients, albeit with an over-representation of highly-educated, ethnically homogenous participants which is reflective of wider diversity issues in cancer research (Flynn et al., 2013). Further information about the psychometric properties of this measure can be found in Table 7.

Similar to the challenges faced in measuring sexuality, measuring quality of life (QoL) can also pose difficulties for researchers. Quality of life has been defined as "the difference, or the gap, at a particular period of time between the hopes and expectations of the individual and that individual's present experiences" (Calman, 1984, p.124). Measuring health-related quality of life is an increasingly important task as more individuals are surviving chronic illnesses such as cancer (Pequeno et al., 2020). Commonly, self-report measures are used to gauge a measure of an individual's quality of life. Two frequently used measures of quality of life for the HNC population are the Performance Status Scale for Head and Neck Cancer (PSS-HN) and the Functional Assessment of Cancer Therapy-Head and Neck Scale (FACT-H&N) (List et al., 1996). Both the PSS-HN and the FACT-H&N have demonstrable validity and reliability in application to HNC patients (List et al., 1996). However, it is crucial to consider the potentially reductionist nature of such measures which can leave unanswered questions surrounding individual meaning and sense-making: this is an advantage of mixed-methods approaches.

1.6. Existing Literature on HNC and Sexuality

There are reasons why HNC could impact on sexuality to an even greater extent than other cancers, which is reflected in an emergent evidence base. Recent research suggests that 24-100% of HNC patients have reported a negative impact on their sexuality as a result of their cancer and treatment, with higher impacts reported by women and individuals who are single (Melissant et al., 2018; Rhoten, 2016). The difficulties with sexuality that patients with HNC are vulnerable to have a wide-ranging impact and are associated with reduced quality of life and health outcomes (Low et al., 2009; Rhoten, 2016).

The nature of HNC treatment presents an increased risk of survivors experiencing a profoundly altered sexuality: HNC is frequently not diagnosed until it has reached a more advanced stage (Rhoten et al., 2019). The impact of this is that patients are more likely to require a multi-modal treatment approach, namely some combination of surgery, chemotherapy, and radiotherapy which can often be extensive, leading to extremely noticeable facial alternations (Rhoten, 2016). The highly visible head and neck area means that any alterations are prominent: these could include facial scarring due to surgery, skin changes as a result of chemoradiation, or a stoma in the neck for patients who have experienced laryngectomies (Melissant et al., 2018). Evidence suggests that HNC patients are vulnerable to experiencing reduced body image and decreased sexual attractiveness, with rates of body image distress estimated to be between 13-20% (Melissant et al., 2021).

HNC treatment sequelae can also profoundly impact the oral area: HNC survivors report that the potential loss of tongue and lip functioning can impact on the ability to kiss, perform oral sex, and resultantly enhance sexual arousal (Rogers et al., 2014). These difficulties can be compounded by further functional difficulties which can arise following treatment and interfere with sexuality both practically and in relation to an individual’s sexual self-confidence (Singer et al., 2008). These can include either excessive or reduced salivation, oral pain, sticky saliva, bad breath, a cough, and/or a restricted mouth opening (Macmillan, 2018).

Another consideration surrounding sexuality that is relatively unique to the HNC population is the rising number of cases that are related to HPV. Evidence shows that the identification of a sexually transmitted infection as a contributing causal factor to a person’s cancer can elevate distress levels (Dodd et al., 2019). HNC patients and their partners are understandably likely to wish to understand how and when they contracted HPV and whether their current or future partners are at risk of contracting HPV from them (Dodd et al., 2019; Richardson et al., 2015). Research shows that sexual relationships can be affected due to worries about sexually transmitting HPV to the partner without cancer (Taberna et al., 2017). A study investigating changes to sexual behaviour following diagnoses of both HPV positive and negative oral cancer found that half of the participants were worried about HPV transmission between partners through oral and vaginal sex (Taberna et al., 2017). While this is an under-researched topic, there are clear indications that the sexuality of HNC survivors can be affected by concerns about the potential health risk the individual may pose to their partner through sexual activity.

Despite the myriad ways an HNC survivor's sexuality could be affected by the cancer and related treatment they have experienced, it is less likely that discussions will be had surrounding this with them due, in part, to HNC not being related to reproduction which is considered further in Section 1.8.

1.7. Psychological Theory relating to Coping and Psychological Flexibility

An extended description of the following psychological theories will contextualise the focus on appraisal and coping which has informed this study's design and deductive analysis.

1.7.1 Acceptance and Commitment Therapy (ACT)

ACT is considered third-wave Cognitive Behavioural Therapy (CBT) and its philosophical underpinnings lie within Functional Contextualism which considers how an individual's thoughts, feelings, and behaviours function within contexts rather than assuming that specific ones are faulty/dysfunctional (Hayes, 2016; Petkus & Wetherell, 2013). A core principle of ACT is that psychologically distressing experiences are a universal aspect of being human (Hart, 2016). ACT distinguishes between pain and suffering: pain is considered a universal aspect of the human life-course whereas suffering is the extra stress experienced when attempting to avoid/control pain (Luoma et al., 2007). ACT theory proposes that increasing our attempts to control or avoid pain commensurately increases our suffering: this is referred to as psychological inflexibility (Levin et al., 2014). ACT aims to increase psychological flexibility, partially by supporting willingness to experience private events whilst not increasing suffering by attempting to push pain away (Hayes et al., 2006). The ACT model rests on the concept of 'workability': if actions move one towards a personally meaningful life, then those actions are 'workable'. If they do not, then the actions are 'unworkable' (Harris, 2019). Evidence supports the use of ACT within cancer populations (Graham et al., 2016; McAteer & Gillanders, 2019).

Psychological inflexibility involves six processes as depicted in the ACT hexaflex (Table 10). These processes are interconnected and can be represented through a triflex (Harris, 2019).

Table 10

The six components of psychological inflexibility, their psychologically flexible alternatives, definitions, and the related triflex aspect (Harris, 2019; Hart, 2016).

Component of Psychological Inflexibility	Psychologically Flexible Alternative	Definition	Triflex Component
Experiential avoidance	Acceptance	Attempts to control/avoid internal/external private events.	Opening up
Cognitive fusion	Defusion	Becoming entangled with thoughts and firmly believing them.	
Unworkable action	Valued action	Not acting according to one's values.	Doing what matters
Detachment from values	Insight into values	Lack of insight into values.	
Self-as-content	Self-as-context	Fixed view of 'who' oneself is, often fused with cognitions about being flawed.	Being present
Dominance of attention to past and/or future	Contact with present moment	Overwhelming focus on past or future	

1.7.2 A Cognitive Model of Adjustment to Cancer

Moorey and Greer's (2011; 2002) cognitive model of adjustment to cancer represents classical second-wave CBT. A key tenet of the model - consistent with cognitive theory (Beck et al., 1979)– is that adjustment to cancer is influenced by individual appraisals of the cancer. This is reflective of other cognitive models of adjustment and coping which suggest that the interpretations made about challenging incidents shape how we react to them (Folkman & Greer, 2000; Lazarus & Folkman, 1984). When a person is given a cancer diagnosis, their assumptions about their life are compromised and they experience a threat to their survival; following a cancer diagnosis, patients must confront three questions (Moorey & Greer, 2011):

(1) How great is the threat?

(2) What can be done about it?

(3) What is the prognosis?

There are four putative interpretations to the threat of cancer: the cancer can be perceived as a challenge, a significant threat with the power to destroy or overwhelm the person, a harm/loss/defeat, or it can be denied entirely and therefore not perceived as a threat at all. The patient's adjustment style is closely linked to the degree of control they believe that they have. Five main adjustment styles have been identified by Greer and Watson (1987):

(1) *Fighting spirit*: the individual perceives the illness to be a challenge over which they do have some control and they are likely to have an optimistic appraisal of the diagnosis.

(2) *Avoidance or denial*: the individual denies the seriousness of the illness and the resultant threat, rendering questions of perceived control over illness irrelevant. The prognosis is therefore also viewed as positive due to an under-estimate of the disease's threat.

(3) *Fatalism*: within this adjustment style, the threat of the illness is understood as relatively little, the patient does not see themselves as having control over the situation, and active strategies for improving their prognosis are not employed.

(4) *Helplessness or hopelessness*: this style represents the individual as overwhelmed by their cancer, with a view of the cancer as an extremely serious threat over which they have no control. Resultantly, the patient perceives the prognosis as extremely negative.

(5) *Anxious preoccupation*: this style of adjustment understands the diagnosis to represent a serious threat, with an accompanying sense of uncertainty about the level of control the patient can exert over the situation. Regarding the prognosis, this too is considered to be very uncertain.

This model has been supported in the cancer-coping literature through the association between psychological adjustment style and coping (de Ridder et al., 2008; McCabe et al., 2004). However, the application of CBT-informed understandings to cancer-related distress can be critiqued for potentially undermining individuals' realistically negative appraisals of threatening situations (Hulbert-Williams et al., 2015).

1.8. Healthcare Professionals' Discussion of Sexuality

Despite the evidence indicating that HNC survivors are especially vulnerable to experiencing a negatively impacted sexuality following their cancer and treatment, the topic of sexuality is not routinely addressed with patients by healthcare professionals during appointments (Rogers et al., 2014; Tierney, 2008). A recent quantitative study reported that more than 80% of HNC patient participants thought that they should receive information about sexual difficulties from their healthcare providers at the time of their diagnosis of HNC (Rhoten et al., 2020). Further, 50% of participants endorsed discussions with professionals as the most appropriate channel for the communication of information regarding sexuality (Rhoten et al., 2020).

Literature suggests that a contributing factor to the neglect of the sexuality needs of HNC patients is healthcare providers not considering it a priority to discuss sexual issues with individuals experiencing a cancer that does not directly affect reproductive organs (Ussher et al., 2015). However, as previously discussed, this is problematic as HNC can affect patients across multiple areas of sexuality and yet professionals are not typically addressing this unmet need (Rogers et al., 2014). The rising number of HNC cases associated with HPV necessitates more discussion of sexuality with patients due to the aetiology of the cancer and queries patients might have about how their future sexuality might be impacted by this specific cancer (Dodd et al., 2019). Literature suggests that healthcare professionals may be unclear about the association between HNC and HPV and this may impact how able they feel to discuss it with patients (Dodd et al., 2016).

However, even within non-HPV related HNC, there is a lack of comfort with discussing sexuality matters. While research indicates that healthcare professionals believe that a discussion of sexuality is important, this commonly held attitude has not translated into changes in practice (Dizon et al., 2014; Krouwel et al., 2020). Healthcare professionals experience barriers to discussing sexuality with patients which helps to account for the incomplete integration of sexuality into oncological care (Flynn et al., 2012). Frequently reported barriers by clinicians include time pressures (Krouwel et al., 2015), lack of training (Hautamäki et al., 2007), and feeling that discussing sexuality was irrelevant and/or inappropriate for some groups (Ussher et al., 2013). Consequently, patients' sexual difficulties often remain unaddressed, and they are dissatisfied with their sexual health care (Albers et al., 2020). Recent recommendations state that the communication around sexuality issues for cancer survivors should be improved, whilst accounting for the fact that not all patients will require the same level of information and/or intervention (Albers et al., 2020).

1.9 Extended Rationale

The extremely limited research that exists on this topic in this population has been conducted using quantitative methods involving problem checklists and single-item scaling of 'problems with intimacy' (Rogers et al., 2014); a limitation of this approach is that in-depth information about the potential barriers for individuals discussing their sexuality with professionals is lacking.

The rationale for investigating response styles such as PF alongside other health belief and behaviour change models in a cancer population is due to the emphasis PF places on tolerating realistic appraisals of distressing situations (Hulbert-Williams et al., 2015). PF is associated with actively accepting potentially challenging experiences to prevent them from interfering with living a life congruent with values; this is again relevant to a cancer population, as individuals may need to adapt how they have previously connected with their values (González-Fernández et al., 2017). Conversely, approaches aimed at challenging or altering 'faulty' cognitions, as might be supported by traditional problem-focussed approaches such as CBT, may be less effective in a cancer population where the experience of distress and ‘negative’ thoughts is arguably an appropriate response (Graham et al., 2016; Hulbert-Williams et al., 2015).

2. Extended Methodology

2.1. Method Overview

The lack of literature on the current research topic with its associated broadly defined understanding of sexuality motivated the decision to adopt a mixed methods convergent parallel design (Fetters et al., 2013). The quantitative aspect of the study sought to gain data regarding the impact of HNC on sexuality in terms of sexual function and satisfaction, as well as investigating whether psychological flexibility and other coping responses predicted sexuality and quality of life in HNC patients. The quantitative phase also functioned practically to identify participants for the qualitative interview phase. The qualitative component of the study aimed to gather detailed data regarding the impact of HNC upon sexuality, with a greater focus on the identity and relationship aspect of sexuality. The qualitative interviews were also intended to collect information regarding any clinical need for HNC survivors in relation to their sexuality. In line with the principles of the convergent parallel design, qualitative and quantitative data was collected concurrently before both data sets were analysed separately and ultimately synthesised to achieve a fuller understanding of the research questions (Fetters et al., 2013).

2.2. Epistemological Stance

A critical realist epistemological stance was adopted for this study. The critical realist approach argues that objective reality exists independently from knowledge or the knower and is concerned with the different experiences and realities experienced by individuals whilst acknowledging that these realities are informed by different social contexts (Archer et al., 2013; Danermark et al., 2005). This study aims to investigate the impact of HNC upon sexuality from both a qualitative and a quantitative perspective due to the lack of research conducted in this area, despite evidence suggesting that this is a significant concern for HNC survivors. It is therefore appropriate to operate within a framework which allows for methodological heterogeneity, such as critical realism.

Critical realism as a philosophical stance developed as an alternative to the two dominant philosophies of science, namely positivism and interpretivism (Gorski, 2013). Critical realism proposes that the world is created through individual perceptions but that there is a ‘true’ reality which exists outside of knowledge (John Creswell et al., 2011).

A stated advantage of critical realism is its ability to generate novel theoretical insights in ways which traditional approaches – such as positivism – cannot (Modell, 2009). Adopting a critical realist stance in mixed methods research can support a range of perspectives to be incorporated with the caveat that no one of these various viewpoints offers a full representation of reality (Modell, 2009). Critical realism can helpfully be used when conducting both mixed methods research and data triangulation as it is appropriate for both quantitative and qualitative approaches whilst recognising the limitations of each (Maxwell & Mittapalli, 2015). In response to those who say that combining quantitative and qualitative is incompatible due to differing philosophical positions, critical realists would argue that a research approach can be informed by at least one paradigm (Pitman & Maxwell, 1992).

2.3. Mixed Methods Research

Mixed methods research is thought to be the third major research model after quantitative and qualitative research paradigms (Giddings & Grant, 2007; Johnson et al., 2007). Quantitative approaches typically use measurable questions to quantify variables of interest. This usually involves gathering numeric data which can be statistically analysed and is often associated with (Howitt & Cramer, 2008). Qualitative approaches collect data in the form of words, usually to seek the views of participants prior to searching for themes in the data and is more exploratory in nature (Hayes, 1997). Mixed methods approaches can therefore be understood as research where the researcher uses both quantitative and qualitative methods within a single study during data collection, analysis, interpretation, and ultimately, synthesis (Tashakkori & Creswell, 2007).

Mixed methods research possesses advantages. One such benefit is its ability to use both quantitative and qualitative approaches to generate a richer understanding of the question than using either quantitative or qualitative would if used independently (Ivankova & Wingo, 2018). A qualitative component within a research study can help contextualise/explain the findings of a quantitative survey phase or inform the development of a specific survey instrument, depending on the structure of the two phases (Fetters et al., 2013). A quantitative component can support recruitment for the qualitative phase as well as enriching the understanding of the qualitative data (Fetters et al., 2013).

A limitation traditionally mentioned in relation to associated with mixed methods research is its design complexity and the time-consuming, intensive nature of research phases being conducted simultaneously (Creswell et al., 2011) – namely simultaneous triangulation – as was the case in the present study (Whitehead & Schneider, 2007). However, arguably the time consumption/intensity of any research, including single-method research, is dependent on the question, design, and resources of the project timeline. Nonetheless, this was considered, and any potential issues were mitigated through the creation of a research design plan prior to data collection, regular consultation with research supervisors, and rigorous adherence to the research timeline.

Mixed methods research has been criticised for privileging quantitative aspects of the study above qualitative components which can be perceived as lesser (Morse, 2003) and therefore privileging quantitative approaches (Giddings & Grant, 2007). When planning mixed methods research, it is crucial to consider whether the research will be equally mixed, with both quantitative and qualitative research having equal prominence, or whether either the quantitative or qualitative component will have a greater weighting (Almalki, 2016). At the beginning of this study, it was agreed that both aspects would receive equal status, and this was considered at regular points throughout the study.

The growing use of mixed methods research has occurred in response to concerns around the use of more than one paradigm in a research study (Tashakkori et al., 2015). Traditionally, quantitative approaches are associated with a postpositivist ontological paradigm – which believes that there is one knowable reality - and qualitative approaches involve a constructivist ontological paradigm which considers that there is no one ‘true’ reality but that it is variously socially constructed by different individuals (Johnson et al., 2007). The online questionnaire employed in the initial research phase would typically be associated with postpositivism and the qualitative interviews traditionally might be linked with a constructivist approach: however, within a critical realism approach which assumes all knowledge is imperfect in its capture, this methodological heterogeneity does not produce paradigm incompatibility regarding ontology (Shannon-Baker, 2016).

2.4. Study Design

2.4.1. Online Survey

For the quantitative phase, an online survey, accessible through a web-link, was used to collect data from a wide range of participants. The first researcher (LM) designed the questionnaire, which combined 5 validated measures and one adapted measure, in collaboration with the third author (NM). Feedback regarding the structure and language was sought from a HNC survivor recruited by the fourth author (SB): feedback from this consultation (e.g. having “next” on buttons instead of arrows to move to the next page) was implemented.

Online questionnaires offer numerous advantages: they are cost-effective and allow for participants to be recruited from an extremely wide geographical range (Sue & Ritter, 2012), as demonstrated by participants in the current study who lived in Canada and the United States of America. This was important for this study, which sought to gain a large sample size and obtain a diverse range of viewpoints (Mann & Stewart, 2001). The anonymity with which participants could participate in this online survey provided another advantage due to the socially sensitive nature of the questionnaire (Sue & Ritter, 2012), particularly around questions focussed on sexual function and satisfaction. Arguably if there had been a researcher or clinician supervising the completion of the questionnaire, this may have restricted the participant’s ability to answer candidly or participate at all. The online questionnaire was designed to ensure that participants were not shown questions that were irrelevant to them, saving them the time and fatigue burden of reading over extraneous questions: an example of this was that if a participant selected that they had not had sexual activity in the past thirty days, then several follow-up questions, contingent on having had sexual activity, would not be displayed. This is a salient consideration when working with cancer populations who are likely to experience higher levels of fatigue than observed in the general population (Jones et al., 2016).

A disadvantage of online questionnaires is a lower response rate (Evans & Mathur, 2005), which was considered in the current study and managed by widely disseminating the survey web-link through several different channels, including social media, clinicians, and charity mailing lists.

2.4.2. Semi-Structured Interviews

Semi-structured interviews were used to gather data for the qualitative phase and to elaborate on the information gained from the quantitative survey. The use of semi-structured interviews was compatible with the chosen qualitative analysis approach, namely thematic analysis (Braun & Clarke, 2006). Another approach to gather qualitative data is focus groups: these were considered inappropriate due to the research aims of gathering detailed understandings of individual experiences. If several participants took part in such a focus group and all attempted to share their experiences, it could produce multiple disjointed accounts which were difficult to fully analyse (Barbour, 2008). Furthermore, it is possible that due to the sensitive nature of the topics, participants might be less likely to participate in focus groups for this research. Semi-structured interviews are carried out in a conversational style with one participant at a time and aid the exploration of a participant’s experiences, typically through a mixture of questions which involve asking follow-up questions which can lead to unanticipated topics arising (Adams, 2015; Braun & Clarke, 2013).

Within semi-structured interviews it is important for the interviewer to be extremely focussed to ensure that they capture moments which warrant further sensitive questioning, requiring extensive preparation. The interviewer within the current study has considerable experience of questioning in their clinical role and had familiarity with the topic area due to previous research, mitigating against the drawbacks associated with this approach. However, semi-structured interviews are considered particularly beneficial in eliciting novel insights due to their flexible and open-ended nature which was relevant to the aims of the current research (Braun & Clarke, 2013).

All questionnaire participants who expressed an interest in being interviewed for the qualitative phase were offered the opportunity to be interviewed through either video call, telephone call, or using email. Research supports the conduction of qualitative interviews over telephone (Cachia & Millward, 2011), video-conferencing software (Nehls et al., 2014), and through email exchange (Hawkins, 2018) . Due to the Coronavirus pandemic, it was considered inappropriate to conduct face-to-face interviews, especially when interviewing a population with potentially compromised immunity to infection. While face-to-face interviews have traditionally been regarded as the gold-standard of qualitative research (Mccoyd & Kerson, 2006), online and telephone interviews were particularly helpful for research within the HNC population. Email interviews allow the inclusion of people who cannot speak due to the effects of cancer or surgery and telephone interviews can allow individuals who experience distress in social situations due to visible difference to focus on the interview. Eighteen semi-structured interviews were therefore conducted remotely: one occurred over email, three using the telephone, and 14 were performed using video-conferencing software, specifically Microsoft Teams. The length of the interviews ranged from 15-75 minutes. The number of interviews would have been significantly lower if face-to-face interviews had been used as the remote nature of the interviews facilitated participation across a wide geographical spread.

2.4.3. Inclusion and Exclusion Criteria

The journal paper describes the inclusion criteria and an explanation of the decision-making around some of these choices is provided here.

The study did not exclude participants who could not verbally communicate in English, as treatment for HNC may affect a person's ability to speak. If the participant's level of written English allowed communication, the interview could still occur e.g. in the form of an email exchange. However, if the participant could neither speak, read, nor write in English, then this constituted exclusion criteria from the study. Screening to assess whether participants meet the inclusion criteria was included in the initial online questionnaire phase.

The current study adopted broad inclusion criteria to capture a range of participants. Excluding participants based on the terminal nature of their HNC was considered unnecessary, as it was thought unlikely that anyone with terminal HNC would participate. However, no participants ultimately did declare end of life HNC in the survey data collection.

2.4.4. Sample Size

2.4.4.1. Online Survey

There was a target number of participants of 96 participants, based on a sample size calculation which judged that a sample size of 96 participants would be sufficient to address analyses – and afford sufficient power for secondary regression analyses. For the quantitative component of the study, the primary analyses pertain to the question of "What is the impact of HNC upon sexuality in terms of sexual function and satisfaction, identity, and relationships" with a particular focus on quantifiable indices of function and satisfaction. There are two analyses of interest here: (1) examining the impact of HNC by testing whether respondents with HNC have levels of sexual function and satisfaction that differ statistically from those of the general population (one-sample t-test on standardised scores); and (2) accurately estimating the proportion of those with HNC who perceive that HNC has impacted on their sexual function and satisfaction.

Appropriate sample sizes differ for these two analyses: (1) tests a hypothesis, and numbers required depend on sufficiency of power for hypothesis-testing (balancing false-negative versus false-positive rates); (2) estimates a quantity, and numbers required depend on sufficiency of precision for accurate estimation (limiting the margin of error; (Hickey et al., 2018). For (1), a practically meaningful difference on the measure of sexual function and satisfaction (described below) would be 5 points (corresponding to a half-SD/Cohen's d of 0.5; (Rothrock et al., 2010). To detect a difference ≥5 points from 50 (the normative population average for this standardised measure), we would need 34 participants (providing 80% power with a two-sided alpha criterion of .05). For (2), we aim to estimate proportions with a margin of error ≤10% and confidence level of 95% (i.e., if 40% of our sample perceive that HNC has negatively affected their sexuality, we could be 95% certain that the 'true' proportion perceiving this in the broader HNC population is between 30% and 50%). We would need 96 participants to enable this level of precision.

For our secondary regression analyses: given that planned models will contain up to 10 predictor variables, 63 participants would provide sufficient power (80%, with a two-sided alpha criterion of .05) to detect predictive relationships of a magnitude (r2

= .13) previously observed in studies regressing functional outcomes onto PF and other coping responses (Brabbins et al., 2020).

Due to the multiple recruitment channels, no figures exist to determine how many participants were approached and offered the opportunity to take part. Furthermore, data was not routinely collected to understand why potential participants chose not to participate, meaning that drawing inferences about participants' representativeness of the wider HNC population is not possible. However, when the researcher asked a recruiting clinician why they thought survey uptake was so limited, the clinician shared that the patients they saw in outpatient clinics were experiencing severe treatment side-effects, including fatigue and nausea, which could make it too burdensome to participate in research.

2.4.4.2. Semi-Structured Interviews

No standardised limits exist within qualitative research to dictate the required sample size for the study but the sample sizes in qualitative research are typically smaller than quantitative research to allow for detailed yet manageable data analysis (Vasileiou et al., 2018). Qualitative research has traditionally aimed to recruit enough participants that data saturation is reached within the interviews, namely when no further themes or codes emerge from the data (Fusch & Ness, 2015; Guest et al., 2006). Data saturation, sometimes referred to as information redundancy (Braun & Clarke, 2021), is derived from grounded theory analysis which simultaneously collects and analyses data, meaning that pre-determining the number of participants logically cannot be done prior to data being collected (Braun & Clarke, 2021; Hennink et al., 2017; Vasileiou et al., 2018).

The term 'data saturation' has been questioned in recent years due to its ambiguous operationalisation and its implication that a full understanding of the research question has been achieved and further data would not be able to meaningfully add to the data (Braun & Clarke, 2021; Thorne, 2020). Alternatives have been suggested such as theoretical sufficiency (Dey, 1999) or conceptual density/depth (Nelson, 2016) to reference the point at which the researcher possesses enough high-quality qualitative data to answer their research question, without purporting to have completely gathered all relevant information (Braun & Clarke, 2021).

2.4.5. Recruitment

2.4.5.1. Online Survey

The online survey was recruited to through several different channels. The social media advert text (Appendix Q) was shared to several social media pages, predominantly on Facebook, by the group administrators of the pages after the researcher (LM) had contacted them and asked them if they would be able to share it. These social media pages were all used for the purposes of supporting HNC survivors which ensured that the study advert was being displayed to a relevant audience. If individuals were interested in participating in the study, a web-link was shared within the advert text through which they could access the survey, ensuring that anonymity could be preserved, and no direct contact was required between potential participant and researcher: this was deemed appropriate due to the socially sensitive nature of the research. The survey was also disseminated through the HNC charity mailing lists of The Swallows and Heads2gether: furthermore, the researcher attended support virtual group meetings for these charities and was kindly granted a time slot to discuss the research study before sharing a link to the research in the group chat for any interested participants.

Finally, participants were recruited from three general hospitals within two NHS trusts in the East Midlands by clinicians who agreed to recruit and display a study poster within the waiting rooms (Appendix R). The clinicians who agreed to recruit to the study included a Macmillan clinical psychologist, a Macmillan consultant radiographer, and two speech and language therapists working with HNC survivors. The clinicians explained the purpose of the study to eligible participants, stressing to them that this had no impact on their care and that their participation within the study was voluntary. If participants did express interest within the study, they were provided with the web-link through which they could access the online questionnaire.

2.4.5.2. Sampling

2.4.5.2.1. ***Semi-Structured Interviews***

Purposive sampling is a type of sampling strategy which is often used within qualitative research to gather information-rich cases which necessitates sampling participants who have experience of the studied topic (Emmel, 2014; Patton, 2002). Maximum variation sampling was initially employed as a type of purposive sampling used to recruit participants to the qualitative interview phase of the study. In maximum variation sampling, the researcher will decide upon variables that lead to variation in the study phenomenon (Schreier, 2018). Following this, the researcher will aim to sample participants with as much variety in relation to the identified variables as possible (Schreier, 2018). In relation to the current study, participants who had expressed interest in being interviewed were selected based on a diverse range of characteristics including sex, sexual orientation, and age. After the first 12 interviews occurred using this sampling strategy, it became clear that there were still several participants who wished to be interviewed alongside new themes and insights emerging from the data. At this point, the research team decided to offer interviews to all remaining participants who had expressed interest in taking part to achieve greater conceptual depth and in order not to exclude anyone. This was felt to optimise the results of the study by ensuring broad representation due to a diverse range of participants across the final six participants.

2.4.6. Data Collection

2.4.6.1. Demographics

The study asked participants to provide demographic information including age, sexual orientation, gender, nationality, ethnicity, and relationship status. Demographic information was collected to describe the sample, enabling researchers to understand the generalisability of the quantitative results (Hughes et al., 2016) and transferability of qualitative results (Krefting, 1991). Participants were asked about their HNC type, treatment stage, and time since diagnosis. Collecting these demographics was important to both control for their impact when conducting secondary analyses and to investigate how the demographic variables, and the interaction between them, affected the outcome variables of interest.

2.4.6.2. Instruments

2.4.6.2.1. Online Survey

The survey was created using Qualtrics, a website used to create online surveys. The survey consisted of five validated questionnaires, with one of these measures featuring adaptations designed by the lead researcher and a co-author (NM) to capture information about the participants' sexuality prior to HNC. Table 11 summarises the psychometric properties of the validated measures. The survey also contained questions surrounding the participants' demographics to contextualise the sample. Brief versions of the questionnaires were used where possible in order to minimise participant burden and information about the questionnaires contained within the online survey is listed below:

8-Item Comprehensive Assessment of Acceptance and Commitment Therapy Processes (CompACT-8). The 8-item CompACT (Francis et al., 2016; Morris et al., 2019) assesses PF. The CompACT-8 (Appendix Z) has a good model fit with the three-factor structure reflecting three dyadic processes outlined in the CompACT (Morris et al., 2019); openness to experience and detachment from literality, self-awareness and perspective taking and motivation and activation (Francis et al., 2016).

Brief Coping Orientation to Problems Experienced Inventory (Brief COPE). The Brief COPE (Carver, 1997) investigates coping strategies when experiencing stressors (Carver, 1997). The Brief COPE (Appendix X) consists of 14 scales, as measured by 2 items (28 items overall), which represent a particular coping strategy. Factor analysis indicates that the response styles within this questionnaire reflect two core factors of 'avoidant coping' and 'approach coping' (Eisenberg et al., 2012).

Functional Assessment of Cancer Therapy-Head and Neck Version 4 (FACT H&N). The FACT-H&N (D'Antonio et al., 1996) assesses QoL in HNC patients. The FACT-H&N items (Appendix Y) indicate functioning in six areas (physical well-being, social and family well-being, relationship with doctor, emotional well-being, functional well-being, and HNC-related symptoms; D'Antonio et al., 1996).

Brief Illness Perception Questionnaire (Brief IPQ). The Brief IPQ assesses an individual's cognitive appraisals of their illness (Broadbent et al., 2006). Each Brief IPQ item (Appendix AA) measures one dimension of illness perception (consequences, timeline, personal control, treatment control, identity, coherence, emotional representation, and illness concern).

Patient-Reported Outcomes Measurement Information System® Sexual Function and Satisfaction questionnaire (PROMIS SexFS). The PROMIS Brief Profile Sex FS (Flynn et al., 2013) assesses sexual function and satisfaction in cancer populations. Participants completed the validated Brief Profile questionnaire (Appendix W), answering questions such as "How interested have you been in sexual activity?" on a variable response scale. Alongside each validated questionnaire question, participants were asked to complete a second response scale, as devised by the present study's researchers, which asks 'how does this compare to before your HNC?'. Participants were provided with three options per question, such as 'more interested now', 'less interested now' and 'as interested now as before'. This has been adapted to capture how the participant's current score compares to their pre-HNC experience.

Table 11

Questionnaires used and their psychometric properties

Measure	Function	Information and Data
Outcome Variables		
PROMIS SexFS (14 items for women, 10 items for men)	Measure of Sexual Function and Satisfaction, Subjective	Participants answered questions such as "How interested have you been in sexual activity?" on a variable response scale. The PROMIS SexFS has good reliability for both the male and female questionnaire profiles (α =.87-.95) and the test-retest reliability is also satisfactory, as measured by ICCs ranging from 0.71–0.87 [1]. Strong construct validity has been reported.[2] This measure is an appropriate choice as it does not reference specific sexual activities, allowing answers based on either solo or partnered sexual activity.[3] This ensures that the questionnaire is neutral in respect to the participant's sexual orientation which is important for preventing the questionnaire from being heteronormative.[4]
FACT-H&N (39 items)	Measure of Quality of Life, subjective	Five-point Likert scale: 'Not at all' (0 points) to 'Very much' (4 points). Higher scores on an item reflect increased quality of life. Construct validity reported for the FACT-H&N through correlations in the expected directions with the subscales of the Performance Status Scale for Head and Neck Cancer Patients (ρ = .16-.66) .[5] Below recommended internal consistency, α = 0.63.[6] However, it is an appropriate choice due to its wide use in clinical practice, relative brevity and its HNC-specific questions, which allows for a detailed understanding of HNC-specific sequelae that the participant may experience.
Predictor Variables		
CompACT-8 (8 items)	Measure of Psychological Flexibility, Subjective	Seven-point Likert scale: 'Strongly disagree' (0 points) to 'Strongly agree' (6 points). Higher scores reflect increased psychological flexibility.[7] The measure is robust with good internal reliability, concurrent and convergent validity.[8] The questionnaire identifies a broad range of core ACT processes, making it an appropriate choice for the study as it will provide a comprehensive overview of the participant's psychological flexibility.

Brief COPE (28 items)	Measure of Coping Styles, subjective	Four-point Likert scale: ‘I haven’t been doing this at all’ (1 point) to ‘I’ve been doing this a lot’ (4 points). Higher scores on an item indicate an increased use of that coping style. Evidence for convergent and discriminant validity has been reported.[9] Wide-ranging internal consistency (α =.50-.92 with one outlier of .25). This questionnaire is appropriate as its item load is lower, reducing participant burden. The issues surrounding content validity can be managed by using a contemporary scoring strategy which does not include the items with questionable properties. Finally, the Brief COPE measures both situational and dispositional coping, allowing for a comprehensive assessment of the participant’s coping styles.
Brief IPQ (9 items)	Measure of an individual’s cognitive and emotional representations of their illness, subjective	Ten-point Likert scale: example item – ‘absolutely no control’ (0 points) to ‘extreme amount of control’ (10 points). A higher score indicates a more threatening perception of the illness. Evidence for discriminant and predictive validity has been reported.[11] Good test-retest reliability has also been reported, *r* =.42-.75. The questionnaire is an appropriate choice for the study due to its psychometric properties, its brevity considering that it is being administered alongside several other measures and its ability to support the study’s understanding of moderating influences upon outcome variables.

Note. Data**:** α = Cronbach’s alpha, ρ = Spearman’s Correlation Coefficient, *r* = Pearson’s Correlation Coefficient, ICC – Intraclass Correlation Coefficient

Reference. [1]Flynn et al., 2013; **[2]**Flynn et al., 2014; [3]Flynn et al., 2013; [4]Flynn et al., 2013; [5]List et al., 1996; [6]List et al., 1996; [7]Morris et al., 2019; [8]Morris et al., 2016; [9]Yusoff et al., 2010, [10]Yusoff et al., 2010, [11]Broadbent et al., 2006

2.4.6.2.2. Development of Interview Schedule

Little qualitative research had been conducted considering a broadly operationalised definition of sexuality, therefore the interview schedule (Appendix P) was developed after the researcher had conducted a literature review on HNC and sexuality and then discussed the provisional interview schedule with the fellow researchers during supervision alongside consideration of the research questions. The interview schedule was refined by consultation with an HNC survivor who advised predominantly on phrasing and useful prompt questions.

The questions outlined in the interview schedule were typically worked through in a linear fashion although the semi-structured nature of the interviews was beneficial in allowing the researcher (LM) to follow up on any new topics raised by participants. Participants were welcomed to the interview, provided with relevant information surrounding such topics as confidentiality and data withdrawal before being oriented to the research interview by being provided with a definition of sexuality. Participants were told that “people describe sexuality in lots of different ways, including being about relationships, intimacy, and sex.” After this definition was supplied, the interview schedule’s first section contained questions asking participants about how they understood sexuality and whether they had experienced any changes or similarities to their sexuality following HNC. Experiences surrounding similarities were deliberately sought to ensure that any assumptions of a negatively impacted sexuality did not introduce bias to the interview.

Before the second section of the interview schedule, participants were advised that “people describe their sexual identity in lots of different ways, including how they see and express themselves as a sexual person”. Following this, participants were asked about any changes or similarities to their sexual identity and relationships following HNC. The third and final section of the interview schedule was intended to draw out participant experiences of how healthcare professionals had engaged or not with the topic of sexuality. At the close of the interview, participants were supplied with relevant ethical information (e.g. debriefing form), thanked for their participation, and encouraged to ask any questions they had, either now or at a later date.

2.4.6.2. Recording and Transcription

All interviews were either audio recorded - having been conducted and recorded over the telephone using a telephone pick-up device - or digitally audio recorded using Microsoft Teams software. The one interview which was conducted over email did not need to be recorded or transcribed due the nature of data collection and so the email responses were copied into a Microsoft Word document. Raw audio data resulting from qualitative interviews was recorded using the built in audio-visual recording function in Microsoft Teams, logged in through a University of Nottingham account. Recordings conducted over Microsoft Teams were automatically transcribed using Microsoft Teams software before their accuracy was checked by the lead researcher (LM) and saved within a Microsoft Word document. Recordings gained from audio recording using the telephone pick-up device and a secure Dictaphone accessible only to the research team were played back and transcribed by the lead researcher (LM). Transcriptions were checked at least once for accuracy.

2.5. Ethical Considerations

2.5.1. Ethical Committee and Regulatory Approval

This research protocol, participant information sheets and consent forms were submitted to the Research Ethics Committee (REC) and National Health Service Research and Development trusts for approval prior to the initiation of the study. No protocol amendments were requested. The application to conduct research through NHS organisations necessitated the submission of an Integrated Research Application System (IRAS) form alongside the supporting documentation. The study was approved by the Cambridge South Research Ethics Committee.

This study adhered to recommendations described in the British Psychological Society (BPS) report (BPS, 2014), the recommendations of the Declaration of Helsinki, 2013 and the UK Policy Framework for Health and Social Care Research, 2017. Salient ethical issues are addressed below.

2.5.2. Incentives and Reimbursement

The study offered each questionnaire participant the opportunity to enter a prize draw to win either a £100 or £50 Amazon voucher in recognition of their participation.

Experts by experience were offered reimbursement at £10 per hour for their consultancy. No travel expenses were incurred by service-users or interview participants due to the interviews being conducted virtually.

2.5.3. Publication and Dissemination Policy

The findings from the proposed research were submitted to the Trent Doctorate of Clinical Psychology Course in February 2022. It is intended that the journal paper will be submitted to a peer-reviewed journal, presented at the 2022 International Head and Neck Cancer Conference in Sunderland, and summaries distributed to supporting charities and participants who requested research findings.

2.5.4. Informed Consent and Participant Information

Once the participant opened the web-link to access the questionnaire and/or attended their qualitative interview, they were required to read the participant information sheet (Appendix J; Appendix K) before providing consent. Participants received information about the purpose of the study, its procedure, withdrawal information, the risks and benefits associated with participation and email contact details. When completing the online questionnaire, participants were required to select a box indicating their understanding of the information sheet and providing participation consent (Appendix L).

The participant was required to sign and date the consent form before the interview began (Appendix M). Due to participants participating in telephone or video-call interviews, they were emailed out the consent form in advance which they were asked to electronically sign and return to the interviewer prior to the interview. The original copy of this form will be securely stored in the study records at the University of Nottingham (UoN). The participant retained a copy of this consent form through the email exchange.

2.5.5. Participant Withdrawal

The participant information sheet and consent form informed the participant of their right to withdraw from the study for up to a week after completion. The information sheet explained that they had received unique identifiers for the questionnaire battery so they could retrospectively withdraw their data for a week after participation. The debriefing message appeared on the participant’s browser, regardless of when they exited the survey (Appendix N).

Participants received verbal and written reminders of their right to withdraw at any time during the interview and have the data associated with their interview destroyed. Participants were also able to retrospectively withdraw their interview data for up to a week post interview. Following this, they were unable to withdraw due to the data having been transcribed. This was explained on the information sheet and consent form. However, no participants requested to withdraw any data.

2.5.6. Sensitive Topic

This was sensitive research due to the topic of sexuality and participants being asked to recall their potentially traumatic experience of cancer. The participant information sheet clarified that the participant could withdraw without consequence at any time during either the survey or the questionnaire. Furthermore, participants could skip questions during the questionnaire. During the interviews, the interviewer monitored the participant and stopped if the participant appeared to be upset, verbally reminding them of their right to stop either temporarily or permanently. The debriefing form reminded participants to contact their GP or a helpline if they experienced difficulties following the study (Appendix N; Appendix O).

2.5.7. Debriefing

A debriefing page appeared when the participant exited the online questionnaire and was emailed to all participants at the end of the interview. This reminded participants of their rights around data withdrawal, supplied support information, and provided contact details for the chief researcher and their supervisor if they had queries.

2.5.8. Data Protection and Storage

In accordance with the Data Protection Act (2018) and General Data Protection Regulation (2018), all involved staff strove to safeguard the information and data of the participants. Identifiable data such as signed consent forms, participant names and the contact details were securely stored electronically on the chief researcher’s OneDrive account. Anonymised data such as interview transcriptions was also stored here. Interviews were either audio recorded using a digital recorder prior to transcription or video recorded using secure software. All electronic files were stored on the chief researcher’s OneDrive account, which is securely password protected.

2.5.9. Confidentiality

All data was carefully handled to ensure confidentiality. Participants were assigned pseudonyms so that if they chose to withdrew their data from the study, this data could be accordingly destroyed. Any identifiable information within the interview transcripts was anonymised. An Automated Transcription Service was used to generate an initial transcription of the interview, following which the chief researcher checked the accuracy of this transcription, editing accordingly.

2.5.10. Sponsorship and Indemnity

The research study was sponsored by the University of Nottingham, with Angela Shone as the named representative. The insurance providers of the University of Nottingham provided indemnity.

2.6. Analysis

2.6.1. Online Survey Data

Descriptive statistics in relation to participant demographics and the frequencies for the pre-HNC comparison questions to assess change were produced from the quantitative questionnaire data using IBM SPSS Statistics Version 27.

The PROMIS SexFS questionnaire data was hand-scored to produce *t*-scores which had been normed against a general cancer population (*n*=819) and descriptive statistics were produced to analyse the sample results.

A correlation matrix – available as Table X in the journal paper - was developed in relation to the quantitative questionnaire data to discover what variables were associated and in which direction. Additional to the general deterioration variable described, a subjective satisfaction variable was produced – coded for by identifying participants who reported deterioration in relation to their sex life satisfaction.

2.6.2. Interview Data

Reflexive thematic analysis was employed to analyse the data generated by the semi-structured interviews using the six-step process outlined by Braun and Clarke (2006). A hybrid inductive-deductive approach was used to analyse interview data: this was employed practically by reading over transcripts several times, producing initial codes, and searching for initial inductive themes. Following this, the deductive coding framework (Table 13) was applied to the data and considered alongside the inductive themes to consider whether any changes to theme names were indicated.

2.6.2. Qualitative Methodologies

When deciding which approach would be most appropriate to address the qualitative research aims of the current study, several different qualitative analysis approaches were appraised to determine their suitability. The researcher considered all options and sought supervision from research supervisors to determine the most suitable choice. The alternative qualitative methodologies that were considered are described below and an explanation is offered to explain why they were not selected for conducting the analysis. The approach to qualitative analysis that was selected, namely thematic analysis, is then justified.

2.6.2.1. Grounded Theory

A grounded theory approach explicitly seeks to generate a theory through constant movement between data collection and data analysis (Bryant & Charmaz, 2007; Glaser & Strauss, 1967). When applied practically, this could involve conducting interviews, analysing the data, and then re-shaping the study’s interview schedule (Strauss & Corbin, 1997): this aspect of grounded theory distinguishes it from other qualitative methods. Grounded theory is an inductive approach as it begins by solely considering the data and then progressing towards the development of a theory (Bryant & Charmaz, 2007). A crucial aspect of traditional grounded theory is that the researcher should remain independent from the existing theoretical literature by avoiding conducting a literature review prior to data collection to ensure that the theory arises from the data without the researcher enforcing their theoretically-influenced ideas upon it (Glaser & Strauss, 1967). The notion of pre-data collection independence from the data has, however, been critiqued in recent years (Charmaz, 2014).

Grounded theory was not deemed suitable for the current study as the aim was not to inductively generate a theory from data which is the central aim of grounded theory. Furthermore, due to the selection of measures for the quantitative phase of the current mixed-methods study, the researcher had established a significant level of familiarity with related theory prior to data collection which would compromise researcher independence from the data.

2.6.2.2. Interpretative Phenomenological Analysis (IPA)

IPA seeks to develop a thorough and detailed understanding of an individual's lived experience of a particular phenomenon and the sense the individual makes of this phenomenon (Smith et al., 1999). Researchers pursuing an IPA approach consider that their own biases and preconceived ideas are inevitable and aim to actively manage these by consistently engaging in a reflexive examination of how their prejudices and assumptions could be interacting with the participant's description of their experience (Smith, 1996). IPA does not aim to establish an objective truth regarding events which have occurred and has been described as involving double hermeneutics, namely the concept that the researcher is interpreting the participant's interpretation of their experience (Smith et al., 2009). Resultantly, the process of analysis in IPA is iterative and laborious with an aim to fully appreciate and reflect each participant's case (Pietkiewicz & Smith, 2014). Qualitative projects using IPA typically seek to recruit small (between two and six participants (Braun & Clarke, 2013)), homogenous samples to characterise in detail the experiences of a circumscribed group (Noon, 2018).

IPA was not considered appropriate for the present study due to the small, homogenous sample necessitated. The current study sought out a larger, heterogenous sample of participants with HNC to establish representativeness across a diverse demographic group. This was particularly relevant considering the present study's focus of interest – sexuality - as if the interviewed individuals all came from a homogenous age group or biological sex, this would arguably create ambiguity about whether identified changes were caused by other factors, such as ageing.

2.6.2.3. Discourse Analysis (DA)

Discourse analysis is concerned with the analysis of written or spoken language, how this relates to social context, and therefore how particular concepts are constructed (Paltridge, 2021). Discourse analysis proposes that the language people use does not merely reflect reality but constructs it (Willig, 2015). Discourse analysis can therefore be described as having a social constructionist epistemological position (Potter & Wetherell, 1987).

The current research wished to explore and elaborate on the impact of HNC upon a broadly defined understanding of sexuality, therefore a very close focus on language would have been misaligned with the research aims. Furthermore, the application of discourse analysis to interview data - as would be required in the current study - would be criticised by some discourse analysts who would view interviews as a non-naturally occurring form of text which the interview had unduly imposed their own meaning and assumptions on and therefore inappropriate for discourse analysis (Potter & Hepburn, 2005).

2.6.2.4. Thematic Analysis

Reflexive thematic analysis was the method selected for qualitative analysis for the present study and an approached outlined by Braun and Clarke was followed (Braun & Clarke, 2006). Thematic analysis is a frequently used method for analysing qualitative data which seeks to identify, analyse, and interpret patterns of meaning – often referred to as themes – within qualitative data (Braun & Clarke, 2006). An area where thematic analysis diverges from other qualitative analytic approaches, such as grounded theory or interpretative phenomenological analysis, is in its classification as a technique or method, as opposed to a methodology (Clarke & Braun, 2017). Thematic analysis is considered a method in contrast to a methodology as it is not constrained by a specific theoretical framework and principles but is instead composed of theoretically distinct qualitative analysis tools (Clarke et al., 2015). Braun and Clarke (2013) outline three main approaches to thematic analysis: the coding reliability approach, the codebook approach, and the reflexive thematic analysis approach.

A strength of thematic analysis is its flexibility across many areas: thematic analysis is not attached to any one specific theoretical framework, epistemological position, or form of data collection, allowing it to be applied across various research paradigms and theoretical positions (Clarke & Braun, 2017). This is particularly relevant for the critical realist stance adopted by the researcher in the current mixed-methods study.

In a thematic analysis, the data can be coded at either a semantic or latent level of analysis (Willig, 2013). Semantic coding/theme-searching requires the researcher to explicitly code what is obvious at a surface level in contrast to latent coding/theme-searching which necessitates the researcher identifying more subtle, interpretative patterns within the qualitative data (Willig, 2013).

Thematic analysis can be conducted either inductively, deductively or through a combination of both (Braun & Clarke, 2013). An inductive thematic analysis, sometimes referred to as a ‘bottom up’ approach allows the researcher to be led up by the data which subsequently informs the themes. A deductive thematic analysis is an equally plausible approach which requires the researcher to analyse the data through the lens of a theoretical framework (Braun & Clarke, 2006). A hybrid inductive-deductive thematic analysis approach can also be adopted, allowing the data to be analysed inductively before being interpreted in a theoretically informed way (Joffe, 2012): this approach was most appropriate for the current research as it allowed the researcher to work directly with what the participants reported before using relevant theories to inform further analysis. Theories around post-cancer sexuality, psychological flexibility, and a cognitive understanding of adjustment to cancer were considered especially relevant to appraise alongside the data-driven codes that were inductively developed.

Thematic analysis is considered helpful when used to understand the perspectives of several participants to identify similarities and differences between them and capture unexpected insights (Braun & Clarke, 2006; Nowell et al., 2017). Furthermore, thematic analysis can be usefully applied to depict the most salient aspects of a large dataset – as was the case in the current study – as the researcher needs to take a clearly-defined approach to manage and describe the data (King, 2004;

Nowell et al., 2017). However, a disadvantage of thematic analysis pertains to its flexibility: novice researchers may experience uncertainty about the most appropriate way to conduct a thematic analysis due to the relative lack of guiding literature in comparison to other approaches (e.g. discourse analysis, interpretative phenomenological analysis) (Nowell et al., 2017). This was managed in relation to this study by regular consultation with the second researcher (AT) and peer supervision. Additionally, qualitative analysis using a thematic analysis approach can be critiqued for being largely descriptive of themes rather than providing a compelling analytic narrative (Braun & Clarke, 2013). This study took precautions against this risk by frequent supervisory consultation and the use of a mixed inductive-deductive approach to ensure that what was described by participants was critically considered alongside extant theoretical literature.

2.6.2.4.1. Thematic Analysis Process

Thematic analysis was applied to the interview transcripts using the six-phase process described by Braun and Clarke (2006) and depicted in Table 12 below.

Table 12

Phases of Thematic Analysis (Braun & Clarke, 2006, p.87)

Phase	Description of the Process
Familarising yourself with the data	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.
Generating initial codes	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
Searching for themes	Collating codes into potential themes, gathering all data relevant to each potential theme.
Reviewing themes	Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic ‘map’ of the analysis.
Defining and naming themes	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.
Producing the report	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

Familiarisation with data: the researcher began to become familiar with the data during the process of data collection through transcribing the data. For those interviews conducted using Microsoft Teams, it was possible to process raw audio data through automated transcription software. However, there were many inaccuracies within this data which was exacerbated in this study population due to some having had surgeries and treatments which changed the usual rhythm and sound of their speech: the automated transcription software therefore inaccurately transcribed substantial sections of interviews. For interviews conducted over the telephone, the process of transcription required the researcher playing the recordings back and transcribing verbatim. Despite the time-intensive nature of this process, the researcher's familiarity with the data was greatly enhanced and this was further increased by the researcher reading over the transcripts in full. Any ideas which occurred to the researcher during this process were noted down in a reflective document together with any sections which evoked particularly strong emotions. Research supervision was also used as a space to share these thoughts and discuss any particular reactions from the researcher.

Generating initial codes: initial codes were generated inductively prior to the researcher selecting final deductive codes to be included in the deductive coding framework. The 'object: descriptor' (e.g. Cancer Nurse Specialist: could be trusted) coding style was generally used with an emphasis on being faithful to the language and salience expressed by participants. Despite deductive codes being determined after the initial inductive code generation phase, the researcher was aware that prior familiarisation with the cancer and sexuality literature, as well as researcher assumptions, could influence results. The researcher sent an initially coded transcript to the supervisor (please see Appendix S for sections of this transcript) to ensure that the initial codes were consistent with the language and context expressed by participants.

Searching for themes: a Microsoft Excel spreadsheet was used to track the inductive codes and similar inductive codes were clustered into themes on a transcript-by-transcript basis before being gathered into overarching themes across transcripts. An initial inductive map was created at this stage, as displayed in Appendix T. Following the inductive initial code generation, the deductive coding framework (see Table 13) was created which incorporated relevant sections of theoretical literature. This deductive coding framework was discussed with the supervisor as a quality assurance measure and then was applied to the interview transcripts (see Appendix U) in a secondary coding process. Prominent ideas which emerged from the application of the deductive coding framework were noted onto the original inductive theme diagram, but this was not found to alter any thematic categories but rather to nuance it and lend theoretical support to key concepts.

Reviewing themes: the process of reviewing themes was not linear and occurred throughout the analysis process which was aided by research supervision and re-checking both initial codes and raw participant data. This is advised to ensure that the final themes are appropriately data-driven and reflect the sentiments of the interview participants (Lincoln & Guba, 1985).

Defining and naming themes: at this stage, the process diagram of the interaction between thematic categories was clarified and a cogent narrative was finalised. This process diagram was discussed in peer supervision with a fellow trainee clinical psychologist with an equivalent level of training who was also conducting a thematic analysis. They provided feedback that the themes were clear and that the process diagram had a coherent narrative.

Producing the report: after sufficient time had been taken to reflect upon and finalise the themes, the production of the report began. Participant quotes are an important part of qualitative research (King, 2004) and were a key aspect of the written report and overall narrative. Pseudonyms were used throughout the overall narrative to evidence to the reader that a diverse array of participant perspectives had been used. The report considered the qualitative interview results alongside the quantitative survey findings, noting down areas of convergence and divergence before ultimately synthesising the results of the two datasets. Within the discussion section of the report, the results and interpretation of both the quantitative and qualitative data were considered in relation to extant theoretical literature.

2.6.3. Deductive Analysis

After themes had been searched for in the data (Phase Three) but prior to reviewing themes (Phase Four), the deductive coding framework (as shown in Table 13) was used whilst examining the data to see if it was consistent with theoretical literature outlined in the deductive framework. Any data that was deemed to fit with theoretical literature was then linked to it: this was done by assigning a number to each aspect of the framework and then noting the relevant number next to the data if it was considered to fit with it. An example of how this was carried out is displayed in

Appendix U. It is noteworthy that participants were not asked specific questions based on these theories, so it might be that the questions asked did not elicit information that would fit with these deductive codes, rather than an absence of these codes being reflected in the data disconfirming the theory or definitely indicating that these were not relevant to participants' overall experiences of cancer and sexuality. The application of the deductive coding framework did not indicate the need to modify any themes but was useful in adding nuance to the researcher's understanding of the data and provided theoretical support to inductively identified themes.

Table 13

Deductive Coding Framework

Deductive Coding Framework	**Theory**	**Theoretical basis**	**Framework Aspect Number**
Does the data support or contradict this?		*Literature suggests that…*	*Number corresponding to theory will be noted next to relevant data*
The Pathway of Grief and Mourning	Sexual Adjustment Process of Cancer Patients and their Partners	This theory builds on grief theory to consider sexual changes as a loss and the subsequent adjustment to this occurs in terms of *grief* and *mourning*, moving through denial, anger, and acceptance (Benoot et al., 2017). At first, individually-based reactions may involve minimising the significance of any changes to sexuality as compared to living through cancer (Hartman et al., 2014). Relationally, individuals on this pathway may avoid the subject and activity of sexuality (Walker & Robinson, 2011, 2012). -*Do participants minimise the importance of sex and avoid the topic/act with partners? Do participants report anger, depression, or ultimately an acceptance of 'the new normal'?*	1
The Pathway of Restructuring	Sexual Adjustment Process of Cancer Patients and their Partners	This theory follows restructuring theory (Benoot et al., 2017) where the patient and partner adjust to the sexual impact of cancer at a cognitive level in a psychologically flexible way and possibly interrogate dominant social sexuality discourses (Beck et al., 2013; Perz et al., 2013). *-Do participants describe new ways of expressing their sexuality, hold a different view of what sexuality means, or now question the socially-dictated importance of sexuality?*	2

Table 13

Deductive Coding Framework

Deductive Coding Framework	**Theory**	**Theoretical basis**	**Framework Aspect Number**
Does the data support or contradict this?		*Literature suggests that…*	*Number corresponding to theory will be noted next to relevant data*
The Pathway of Sexual Rehabilitation	Sexual Adjustment Process of Cancer Patients and their Partners	This theory emphasises that post-cancer sexual changes are framed in terms of physical dysfunction necessitating particular behavioural strategies and treatment approaches rather than any cognitive alterations or psychological modifications (Benoot et al., 2017). This pathway positions the process of adaptation as leading to the resumption of pre-cancer levels/manners of sexual activity with less emphasis on emotions/cognitions about the experience (Hartman et al., 2014; Ramirez et al., 2009). *-Do participants describe resuming/aiming to resume their sexual activity with the use of specific sexual techniques/aids but without describing a reframing of their understanding of sexuality?*	3
Openness to Experience	Acceptance and Commitment Triflex (Psychological Flexibility)	Openness to experience encompasses the psychological flexibility hexaflex components of ‘defusion’ and ‘acceptance’, namely being able to notice meta-cognitive processes rather than becoming entangled in cognitive content and practising non-judgmental awareness of internal and external events (Harris, 2019; S. C Hayes et al., 2004). *-Do participants express insight into the thoughts they have regarding their post-cancer sexuality and are they willing to make room for different internal and external events in terms of sexual changes? Or do participants describe being very resistant to their altered sexual experiences?*	4

Table 13

Deductive Coding Framework

Deductive Coding Framework *Does the data support or contradict this?*	**Theory**	**Theoretical basis** *Literature suggests that…*	**Framework Aspect Number** *Number corresponding to theory will be noted next to relevant data*
Valued Action	Acceptance and Commitment Triflex (Psychological Flexibility)	Valued action encompasses the psychological flexibility hexaflex components of ‘values’ and ‘committed action’ which involves establishing what is most personally meaningful and working towards living life in line with these values (A. M. Beck et al., 2013; Graham et al., 2016). *-Do participants report greater awareness of and action in line with what is most important to them regarding sexuality and intimate relationships following their Head and Neck Cancer e.g. greater appreciation for intimate relationship? Or is their behaviour less in line with their values due to changes to sexuality?*	5
Behavioural Awareness	Acceptance and Commitment Triflex (Psychological Flexibility)	Behavioural awareness encompasses the psychological flexibility hexaflex components of ‘self-as-context’ and ‘present moment awareness’ which refers to being able to mindfully observe your thoughts, feelings, and actions and being able to pay attention to senses in the moment (Harris, 2019). *-Do participants report a greater awareness of the internal events they experience in connection with their post-cancer sexuality, and do they describe greater sensory awareness in connection with their potentially altered sexuality? Or do they engage in reduced behavioural awareness, suppressing thoughts and feelings regarding changes to sexuality?*	6

Table 13

Deductive Coding Framework

Deductive Coding Framework	**Theory**	**Theoretical basis**	**Framework Aspect Number**
Does the data support or contradict this?		*Literature suggests that…*	*Number corresponding to theory will be noted next to relevant data*
Fighting Spirit	A Cognitive Model of Adjustment to Cancer	Moorey et al (2011) define fighting spirit as one of the five common adjustment style to cancer (originally described by Greer and Watson, 1987) where individuals perceive the disease to be a challenge and hold positive attitudes towards the outcome. *-Do participants report seeing cancer as a challenge? Do participants show a positive attitude towards the outcome of their cancer? Do participants perform behaviours in line with the fighting spirit e.g. seeking appropriate information and taking an active role?*	7
Avoidance or Denial	A Cognitive Model of Adjustment to Cancer	This adjustment style to cancer occurs when individuals avoid/deny the serious nature of the disease and downplay the seriousness of the diagnosis (Moorey & Greer, 2011). *-Do participants minimise the impact of the cancer? Do participants seek to carry on with life as normal without considering or thinking about the cancer?*	8
Fatalism	A Cognitive Model of Adjustment to Cancer	Fatalism as an adjustment style describes the individual perceiving themselves to have no control over the situation and passively 'accepting' the cancer (Moorey & Greer, 2011) *-Do participants demonstrate no sign of trying to 'fight' the cancer? Do participants express beliefs that are consistent with the cancer being completely out of their control?*	9
Helplessness and Hopelessness	A Cognitive Model of Adjustment to Cancer	If an individual displays a 'helplessness and hopelessness' adjustment style, the threat of the cancer will be all-consuming and they may appear to have given up (Moorey & Greer, 2011).	10

Table 13

Deductive Coding Framework

Deductive Coding Framework	**Theory**	**Theoretical basis**	**Framework Aspect Number**
Does the data support or contradict this?		*Literature suggests that…*	*Number corresponding to theory will be noted next to relevant data*
		-Do participants focus on their imminent death? Do participants feel that they have no control of the situation? Does the participant engage less in other activities as a result of the cancer?	
Anxious Preoccupation	A Cognitive Model of Adjustment to Cancer	The final of the five putative adjustment styles to cancer, an anxious preoccupation adjustment style will involve high levels of anxiety and extremely frequent preoccupation with cancer, physical symptoms, and the fear of it returning (Moorey & Greer, 2011). *-Does the individual habitually seek reassurance? Does the individual worry very frequently about the cancer returning? Do participants perform behaviours in line with the anxious preoccupation style e.g. compulsively seeking information about cancer or using alternative medicines?*	11

2.7. Quality Assurance

The topic of ensuring quality in mixed methods research has become more prominent in recent years to ensure that this type of research design is appropriately planned and well-integrated (Fàbregues & Molina-Azorín, 2017). Recommendations from a systematic search of the literature suggest that mixed methods research has a various specific features which mean that it should be evaluated with its own set of criteria rather than merely a set of quantitative criteria and a set of qualitative criteria (Fàbregues & Molina-Azorín, 2017). The Mixed Methods Appraisal Tool (MMAT) is a checklist which is intended to supply quality appraisal for quantitative, qualitative and mixed methods studies (Pluye & Hong, 2014) and was created following a thematic analysis of quality appraisals of 17 mixed methods studies (Hong et al., 2018).

Quality assurance will be considered through the use of a Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2018). The Mixed Methods study design category methodological quality criteria (Hong et al., 2018) were considered by the lead researcher - as displayed in Appendix AB with the relevant items included - to critically appraise the quality of the present study's overall mixed methods study design. A fellow trainee clinical psychologist with research published in a peer-reviewed journal also completed a checklist of the same criteria once the write-up was completed to gain another perspective on the research quality – this can be seen in Appendix AC.

Discussions were also conducted verbally at an earlier point with the aforementioned trainee clinical psychologist which produced further reflection and critical judgment surrounding the quality's project. The same colleague also provided consultation on the coherence of the initial themes, leading to revised themes as displayed in Appendix V. Supervision was frequently conducted with two academic supervisors (AT and NM) through a combination of in-person, video conferencing, and email discussions. After each supervision session, logs were written up by the lead researcher, checked for accuracy with the supervisor/s present, and sent to the University of Nottingham for their own records. The lead researcher also kept reflective journals to ensure that they considered their own position in relation to the research regarding both thoughts/emotions that occurred throughout the research and the rationale for research decisions.

2.8. Service-User Involvement

Service-user involvement is argued to produce higher quality research which can more effectively engage research participants (Beresford et al., 2007) although much of the literature surrounding involvement is based on opinion pieces rather than empirical evidence. However, service-user involvement was beneficial for the current study. Initial discussions around project feasibility were conducted with two HNC survivors running HNC charities. Both individuals offered support for project recruitment and reflected their thoughts that this topic lacked attention, further validating the rationale for the study. Furthermore, an HNC survivor was recruited by a clinician to consult on the adapted questionnaire and interview schedule: this resulted in feedback which ranged from altering the survey format (adding ‘next’ buttons rather than merely arrows) to considering the role of stigma in a cancer that is often contracted through the Human Papilloma Virus (HPV).

2.9. Reflexivity

In qualitative research, the lead researcher can be considered as the main instrument of data collection and analysis (Watt, 2007). Due to the potential for the biases and assumptions of the researcher to affect both data collection and analysis, researcher reflexivity – where the researcher critically reflects on their own position in relation to the research – is important (Braun & Clarke, 2006). Reflective diaries are often used by researchers to enhance the quality of studies (Ortlipp, 2015); the primary researcher ensured that they used this as a tool to reflect upon their assumptions (such as an assumption that sexuality would be impacted by HNC) and how they could mitigate this throughout the research (e.g., using supervision to consider the data from a critical standpoint – asking questions such as what else could have impacted this aspect of sexuality, is there anything about the recruited population that may increase the likelihood of difficulties or lack thereof?) Without researcher reflexivity being intentionally addressed in these ways, it is possible that the biases of the researcher could have affected future interviews or the overall interpretation of data (Willig, 2013).

2.10. Researcher’s Statement of Perspective

A researcher statement of perspective is advised as a measure that can support the consumer of the research to understand the researcher’s perspective and support understanding of how the research was interpreted and resultantly analysed (Elliott et al., 1999). Although designs which employ thematic analysis from a critical realist position do not commonly include a researcher statement of perspective, one is included here to support transparency about the researcher’s position in relation to the research and improve quality (Joffe, 2012). Therefore, relevant information regarding the primary researcher is included below to facilitate transparency surrounding the present research.

The current research was undertaken in partial fulfilment of gaining a doctorate in Clinical Psychology (DClinPsy) and was predominantly written during my final year of training to become a Clinical Psychologist.

I am a 27-year-old White British woman who has not experienced HNC or any other cancer, nor has anyone who I am personally close to during my lifetime: both my age and my lack of cancer experience are variables which perhaps distance me from the characteristics of the current study participants. This could arguably have the impact of allowing me to take a more neutral, curious stance towards the studied phenomenon. Prior to training, I worked as an Improving Access to Psychological Therapies Psychological Wellbeing Practitioner in a Long-Term Conditions service which initially established my interest in and compassion for those who experience serious illnesses such as cancer. Having worked clinically with several individuals with cancer, I was aware that I might find myself drawn into a position of clinical interviewing during research interviews which would have the potential to alter participants’ responses. At the outset of my research into this topic, I was aware of my assumption that participants would experience a negatively impacted sexuality at both an individual and interpersonal level following their experience of HNC. Furthermore, I anticipated that clinicians would not be routinely discussing sexuality with their patients.

3. Extended Results

1.1 Survey Results

The survey was accessible from 30.01.21 to 08.11.21. In total, 83 individuals accessed the survey, with 23 disengaging after they had completed the screening questions and provided consent having accessed the participant information sheet.

1.1.1 Participant Characteristics

To help characterise the sample regarding those participants who met criteria for clinical impairment, average years since diagnosis was calculated for those who were impaired as compared to the average years since diagnosis for the overall respondents. The results of this are displayed in Table 14.

Table 14

Clinical impairment criteria and years since diagnosis.

Domain	M Years since Diagnosis for Clinically Impaired Subset	M Years Since Diagnosis for overall respondents
Interest in Sex	3	2.98
Sex Life Satisfaction	4.22	2.98
Orgasm Pleasure	4	2.98
Orgasm Ability	3.92	2.98
Erectile Function	5.5	3.36
Vaginal Lubrication	4	2.75

Note 1: Two out of 60 participants did not provide the number of years since diagnosis, so the averages were calculated from the available data for 58 participants.

These results demonstrate that those within the clinically impaired subset are typically representative of the wider participant sample, and in no domains appear to characterise a subset that is closer in time to diagnosis and active treatment. Conversely, in all domains where individuals within the sample met clinical impairment criterion, the average number of years since diagnosis was greater than for the average number of years of all respondents within that domain.

1.1.2 Correlational Analyses

Based on the deterioration variable (coded by representing a negative post-HNC change on one or more items), associations with ways of responding were small and non-significant e.g., avoidant coping was associated with greater deterioration [r = .151] and PF was associated with less deterioration/preserved function [r = -.210]. The correlations coded for and run to capture subjective satisfaction deterioration yielded similar results for coding *any* deteriorative change.

1.2 Interview Results

1.2.1 Sexuality on hold during treatment

As described earlier, participants appeared accepting of sexuality being on hold during treatment, but one participant did allude to concerns developing as the impact of the cancer clearly began to extend past the active treatment phase, saying that:

> *"…before I had cancer, we had a good sex life and then obviously I got the cancer treatment… we didn't have sex… chemo and radiotherapy as well… that just killed everything… there was no sex there. And that was fine at the beginning, but… even when I finished the cancer treatment and…. the all-clear, I think the harm was already started there… the downfall of the marriage*".
>
> Paul

Another participant highlights that even after active treatment has ceased, the sequelae of treatment can continue to inhibit sexuality:

> *"Full sex with a naso-gastro tube in probably isn't going to happen anyway, if that had been removed, I then had what they call a pack, so a pack over the right hand side of my gum that was made out of my leg and it means you were only allowed to have water, then I thought, and even now I've said, I don't know how we, what we do about that because the worry is around infection and given that I'd had this horrendous infection, and that put paid to sex for a long time as well".*
>
> Ruth

1.2.2 Sexuality not discussed by HCPs

Participants shared that although they had experiences of HCPs discussing sexuality, these were not instigated by the HCP, and they perceived them to have a lack of knowledge during these times. Some participants indicated their perception that staff had inadequate knowledge regarding the impact of HNC upon sexuality: Lisa located this more broadly, saying that "*there's a lot of things about cancer and the aftercare that I think is just really lacking in the knowledge*". Participants who had attempted to seek support around sexuality following cancer reported their sense that professionals lacked knowledge and highlighted a training need for professionals:

> "*I think it was the lack of knowledge… that's how it come across to me. So when we walked out the meeting… we both said, what a waste of time… I'd like the consultant and nurses to have a little bit of training, you know, on how to give you information on sexuality. I think they should have more knowledge*".
>
> Paul

Another participant implied that this was a seldom raised topic which they believed reflected a lack of professional knowledge about the topic.

> "…*I think that they'd never had a conversation with anybody about it either [with professionals] above them or a patient, I think that neither of them [the staff] had ever come across anybody who had ever asked that question before*".
>
> Ruth

These experiences suggest that if individuals do ask professionals for guidance or advice surrounding their potentially impacted sexuality, HCPs do not have the experience or training to satisfactorily validate and support patients with difficulties.

1.2.3 Impact: Altered Sexual Behaviour

1.2.3.1 Physical barriers

Pain acted as a barrier for another participant to engaging in sexual activity with their partner in areas beyond the direct cancer site:

> "*I hurt so much you couldn't just twist me around now like I was able to be twisted before… I have a bulging disc on my neck on account of radiation… I just wouldn't like anybody twisting or turning me or even somebody to hug me hurts me… it's nice to get in a hug… (but) you know you are going to get some bloody pain somewhere*".
>
> Carol

Carol's account highlights the far-reaching treatment effects and highlights a sense of fragility within her body which she perceives would prevent her from engaging in the sexual activity she participated in prior to her HNC.

However, there was some data which highlighted that sexual behaviour had been altered in ways experienced by the participant as positive, such as weight loss. Andrew described how:

> "*It's really been an absolute upswing in my general physical health. I lost six and a half stone, 40 kilos… so that actually makes… intercourse a lot easier. Because without the huge belly stuck on the front, it does make everything easier, less sweaty, just better… there's a positive that came from it*".
>
> Andrew

1.2.3.2 Psychological barriers

The fear of an intimate partner's perception of the HNC patient post-treatment was elaborated on by several participants and a concept of not wishing to impose sexually on partners was voiced by two male participants because of feeling less attractive following treatment for HNC:

> "*The treatment, particularly having a plastic tube stuck in my tummy and… feeling unattractive was the main thing. I felt so unattractive, and I didn't like… imposing on her to have sex with my tube (in), I didn't even want to ask*".

> Rick

This is echoed by another male participant who also had a feeding tube in during his treatment:

> "*That was hard from the point of view of looking at myself going, that doesn't look good… So even when you've got a bit more strength to think that you wanted to (have sex), you were like, ooh… I was too conscious of kind of putting myself in that position, really*".
>
> Danny

These accounts further nuance the reasons behind the frequently prolonged cessation of sexual activity following HNC. As voiced by both participants, even if the physical strength and inclination to be sexually intimate was present, the sense of themselves as sexually unappealing prevented them from initiating sex. It is interesting to note that both participants who report this experience did have plastic feeding tubes inserted and Rick even names this in relation to a sense of his own unattractiveness. This leads to a question around the possibility that the physical presence of a feeding tube might compound a participant's sense of sexual unattractiveness. This line of thought evokes comments from another participant who described struggling to understand how her partner could still find her attractive because:

> "*She… became my carer… and… after as I was recovering from the treatment… I also had a feeding tube, a stomach feeding tube and… it's not attractive is it, that's not sexy, this big, massive tube sticking out and… I struggled confidence wise with that*".
>
> Lisa

Some participants also highlighted a stigma surrounding HPV which appeared to contribute to psychological barriers which altered their sexual behaviour. In some accounts, this was at the level of partner's attitude, with one participant describing how when he was told that sexual behaviour could have led to him contracting cancer, "*my wife was looking at me and wondering what the hell I was up to when I was younger*" (Timothy).

Another participant reflected that if he had wanted to be sexually intimate with his wife following his HPV-related cancer, it would have been a "*problem*" for her (Jim). Jim also shared that:

> **"**…*that's what I've got, and I'm… not dirty, I've just been given cancer that is HP related and it's not until … we'd done a lot of research that… you can be with one partner all your life and still have HPV*".
>
> Jim

Jim's comments appear to suggest that there is a perception of having HPV-related cancer as being associated with being dirty and furthermore, that there is an initial assumption of multiple sexual partners associated with HPV-related cancer which could be associated with greater feelings of stigmatisation for some.

In relation to his HPV-related cancer, another participant described how his future sexual behaviour could be affected due to his understanding of how he contracted cancer, as he explained how:

> "…*giving oral has always been a large part of my sexuality … so now the added symbolism of… this is the act… that gave me cancer…and with… any future partners I will undoubtedly be thinking about it in the moment and how this is likely how I got HPV cancer*".
>
> Scott

It appeared from these three participants that the potential stigma associated with HPV-related cancer could pose additional challenges in terms of psychological barriers which could impact sexual behaviour.

1.2.4 Response: Rebuilding/Renavigating Sexual Intimacy

The suggestion that the shared experience of dealing with cancer as a couple had enhanced the couple's closeness even if it had impacted upon intimacy was highlighted by several participants:

> “*Beforehand we used to kiss and cuddle a lot and we were very touchy-touchy with each other but…. since the cancer that has stopped… so I think that's the main difference, but we find other ways, so we will have a cuddle. But it's not like it used to be and… we hold hands all the time now but… that's as much as our touching goes, which again isn't a problem for us… with us we've come to accept that, and that's our life now… But we don't have to do that (touching) now because I know nothing can come between us*”.
>
> Jim

The increased relationship closeness post-cancer is highlighted by another participant who describes the process of renavigating as positively impacting upon the relationship:

> “*…as we experimented, things started to work… and then you find something that works for both of you, and you think great because you've done it together. I think that helped us gel as a couple a bit better as well. We are certainly a lot closer than we were… we’ve always been close, but I think we’re closer in a different way now, because we’ve… gone through, not just the cancer obviously, but the follow-on stuff like the intimacy*”.
>
> Sam

While Jim refers to an acceptance-based response of when renavigating sexual intimacy with his partner, Sam refers to an approach to rebuilding sexual intimacy focussed around making behavioural changes and experimentation. However, similarities between the two accounts appear to relate to a sense of increased relational closeness.

However, this response of rebuilding sexual intimacy within a strengthened relationship was not universally experienced, with one participant sharing that the impact on sexuality had contributed to “*the downfall of the marriage*” (Paul), demonstrating that the stressor of the cancer and its resultant impact on sexuality within his marriage was perceived to have significantly damaged it.

4. Extended Discussion

4.1 What is the impact of HNC on sexuality in terms of sexual function and satisfaction, identity, and relationships?

To expand further on the table describing clinical impairment criteria and years since diagnosis, it is important to note that these findings represent a deterioration within those who reported a deterioration from before cancer which is not explained by the recency of diagnosis as those with more preserved sexual function and satisfaction did not appear to be further from diagnosis. Indeed, more time since diagnosis was generally correlated – albeit with a small magnitude – with lower functioning and significantly correlated with lower satisfaction. This does not appear to be a function of age as age shows smaller/limited correlation with sexual outcomes apart from the sex-specific physical outcomes. These results would make sense in the context of being close to and focussed on treatment, and qualitative data supports that sexuality is deprioritised during active treatment, but the quantitative data suggests that this effect continues on beyond the initial treatment phase for some. Therefore, it appears that the deprioritisation of/interruption to sexuality which occurred for some participants is often connected with active treatment and recovery, consistent with extant literature (Benoot et al., 2017), but this is not fully explanatory: for others - as indicated by both study phases – it is the treatment sequelae which are leading to impaired sexual function and/or satisfaction and resultant intimacy changes. Therefore, any disruption of sexuality does not appear to be about the immediate/survival stage – as participants are often past this phase – and outcomes appear to be worse further from diagnosis without being confounded by age of participants.

4.2. Are PF and other coping responses associated with sexuality and QoL in the context of HNC?

The one other study which investigated the association between sexual function and PF did find a small relationship over time, namely between PF at timepoint one and sexual functioning at timepoint three (Maathz et al., 2020). However, the magnitude of the relationship was the same as that found in the relationships within the current study: the current study did not have the number of participants to detect this as significant. In the Maathz et al (2020) study, at a comparable cross-sectional stage, PF and sexual function were not correlated: this suggests that the current study's findings support the existing evidence base.

As briefly referenced in the journal paper, it is relevant to expand further on the failure to detect significance in relation to associations between sexual function variables and response style variables. Although there were small trends – e.g., between more avoidant coping/lower PF and greater sexual satisfaction – the small *n* in this study means that the confidence intervals around these estimates are wide, including the possibility of no association. Whilst this could form the basis for further exploration, relationships do seem less pronounced than those for wellbeing outcomes. Arguably, this implies that supporting flexible/less avoidant coping might help to support wellbeing overall, but it is less clear that this would be beneficial in the sexuality domain.

Finally, although it was intended that aim two of this project would solely be addressed by the quantitative data, it is possible that limitations of the measure – e.g., the highly embodied nature of the questions – and the resultant non-significant findings may occlude the results to some extent. Arguably, there is indirect evidence in the qualitative data that some people are able to be more adaptive/flexible in enacting intimacy with associated helpful consequences.

4.3 What do people with HNC perceive to be their support needs surrounding sexuality?

The study findings highlighted that for the current study participants, conversations are not routinely occurring within cancer care for HNC patients which is consistent with research described in the journal paper (Badr et al., 2016; Haboubi & Lincoln, 2003; Park et al., 2009). The difficulties associated with infection risk, feeding tubes, and saliva production were raised from the qualitative data and suggest a clear area of focus for future informational resources which should be elicited with service-user involvement at the heart. A final point relates to the concerns expressed by participants about the views of partners in relation to rebuilding intimacy. The qualitative data gathered on this topic is consistent with extant literature which indicates that partners experience self-blame, rejection, and sexual non-fulfilment following alterations to sexuality post-cancer (Hawkins et al., 2009). This is relevant to consider, as the improvement of support around sexuality for survivors is likely to have positive systemic implications for couple-level functioning.

4.4 Strengths and Limitations

A strength of this study was the mixed-methods framework employed to collect and analyse data. The online questionnaire sought to gather a range of information which included data surrounding sexual functioning and satisfaction, while also gaining insight into participants' use of particular response styles. Due to the relatively limited descriptive analyses that were employed within the current study – consisting of descriptive statistics and correlational analyses – the qualitative data was especially helpful for enriching the research team's understanding of the study questions. This is the first known study to triangulate an understanding of how HNC affects sexuality with such a broadly operationalised definition of sexuality, as well as looking at individual-level variables e.g. response styles and more systemic factors such as how HCPs approach (or choose not to approach) the topic of sexuality in clinical practice. These insights are especially valuable due to the growing understanding that individuals are likely to need support/guidance across a broad range of domains that contribute to QoL, particularly with rising numbers of individuals living longer following HNC diagnosis and an increasing number of HPV-related HNC diagnoses.

It is possible that a study such as this would be more likely to recruit participants who find the research topic more salient due to changes in sexual functioning: however, while impaired sexuality was described by several individuals, there were also participants who said that they did not feel their sexuality had deteriorated whatsoever, therefore demonstrating that not everyone who came forward for the study did so because they were struggling. Conversely, it did not appear that all participants who took part in the research held untypically positive attitudes towards sex, as evidenced by the high number of skipped items on more intimate questions on the questionnaire. In terms of general representativeness within the study, it was not possible to establish how many participants saw the survey link and their reasons for not participating. However, the lead researcher asked the recruiting clinicians why people generally declined to participate and was told that the participants often felt extremely unwell when they were seen by HCPs in the late effects clinics following active treatment. This may mean that the study has not fully captured the views of those who are at a lower level of functioning to ensure representativeness, as has been recommended by previous literature (Andrews Rhoten et al., 2019).

In relation to the thematic analysis, the current survey did not have a second coder, which is recommended as a technique to enhance data trustworthiness by reducing bias (Church et al., 2019) although whether this is recommended is arguably influenced by a researcher's epistemological position. To mitigate the risk of reduced data trustworthiness, the researcher who coded the interview transcripts sent a whole coded interview transcript to a research supervisor (AT) and incorporated feedback. However, the supervisor stated that broadly they agreed with the coding and provided advice to ensure that the emphasis of the data was preserved. A final strength of this research was the valuable input from service-users/experts by experience: this was achieved by having involved HNC charities and, separately, a HNC survivor consulting on the online survey and interview to provide feedback on accessibility and readability, following which, changes were made to the online survey.

4.5 Clinical Implications and Future Directions

The current research study indicates several clinical implications, some of which have already been outlined. However, professional guidance would be beneficial for professionals at a range of levels within the system ranging from Clinical Nurse Specialists and Speech and Language Therapists, who are very likely to be involved in a HNC patient's care pathway to Clinical Psychologists and other mental health professionals such as counsellors. For those who are likely to be involved more frequently across several domains, primarily involving a patient's physical health, training and guidance could focus on initiating and facilitating conversations around sexuality with patients, as well as having clarity on specialist referral pathways for those with sexuality difficulties. For those more specialist services/professionals who work with HNC patients, it would be useful to ensure that they have access to training/understanding about the specific ways that HNC may affect sexuality and how to tailor support to incorporate these concerns. It is likely that all professionals may need reassurance/empowerment to feel that discussing sexuality with patients is appropriate and that implicit biases we are all vulnerable to experiencing can lead individuals to think that particular groups are not interested in sexuality. However, this research study, along with several others, has demonstrated that individuals spanning a broad range of ages, health statuses, and sexual orientations are interested in sexuality and HCP assumptions about who this is relevant for are likely to prevent individuals from gaining valuable information and/or support.

Future research could usefully explore the relationship between subjective appraisals of sexuality (e.g. interest in sex and sex life satisfaction) and particular response styles as, while the current research did find correlations in expected directions, these were not prominent enough to achieve more than moderate associations. Arguably, this could be mitigated in future research by using a longitudinal study design, attending clinics in person to be on standby if prospective participants had questions about the study, and developing stronger community links to better represent those from culturally and ethnically minoritised populations. The benefit of examining particular coping styles and psychological flexibility as potential buffers against a detrimentally affected sexuality is that if it were found that PF and/or coping styles accounted for variation in the sexual experience of living with HNC, third-wave approaches - such as ACT - which have a burgeoning evidence base in relation to cancer survivors could be helpful for this population.

Furthermore, mixed-methods research investigating HNC professional perspectives on navigating conversations relating to sexuality could prove beneficial. This could usefully elicit HCP opinions on whether they feel that it falls within their remit to have these conversations with patients, as it is possible that if no-one is having such conversations with patients, as results from this study suggest, then patients will be left with minimal information and/or support regarding sexuality issues. Future research could also elicit HCP perspectives on whether there would be particular issues relating to sexuality which they would be more aware of in a HNC population as compared to other cancers e.g. infection control in relation to sexual acts involving the mouth – such as kissing and/or performing oral sex - following treatment, as well as information to address concerns patients may have about future sexual behaviour if they have HPV-related cancer. If professionals do have this information, then it would be helpful to investigate why this information does not typically appear to reach patients. If they do not have such information/training, then this highlights a significant informational need in relation to supporting HNC patients’

QoL. Future research could also usefully capture partner perspectives on altered sexuality and possible unmet support needs in this domain as change is something that is adjusted to at a couple-level for those HNC patients who are in relationships.

5. Extended Reflection

This section provides reflections that I experienced throughout the process of conducting the research project which range from initially conceptualising the research to considering the clinical implications of the research. To provide context to these reflections, excerpts from my reflexive reflective journal have been included where appropriate to illustrate challenges around specific sections around the research and how issues were resolved.

5.1 Planning and Making Decisions about the Research Process

The idea for this research project was within a handbook of research ideas that was sent out to trainee clinical psychologists prior to the start of the doctoral training. I was drawn to the research due to prior clinical work with those experiencing cancer and a genuine interest in the topic which grew as I researched more into the topic. Having approached two research supervisors and a field supervisor who were happy to support with the project, we began to develop a firmer idea which extended to adopting a mixed methods approach which allowed us to investigate broadly into this under-researched topic.

I had not formally started writing a reflexive journal at this time, but I noted in an email to a colleague an anxiety that occurred frequently at this time, namely that *“something I am hearing a lot when I tell people about the research is “oh, that’s such a niche topic”. Whenever people say this, it makes me think that I have chosen to pursue a topic that is too specific and maybe I won’t find any meaningful results!”* This was a concern that remained until the interview stage, at which point a participant said to me that “we don’t feel like a niche group of people”: I held onto this comment throughout and also critically interrogated my opinion of what ‘meaningful’ research meant as I believe that I had a positivist and inflexible understanding of the term, rooted in detecting large effects within large sample sizes.

I sought out the expertise of a clinician working in the field and also experts by experience to shape my understanding of the topic and decisions around areas such as the online survey. These conversations helped me to gain a more nuanced understanding of the topic: initially, I had held the assumption that much disrupted sexuality would be related to possible facial disfigurement and amputated features. However, clinicians within the field supported my understanding that medical treatments had progressed significantly in recent years meaning that the majority of patients would not experience such a severe level of facial disfigurement and potential disruption could relate to other more nuanced considerations.

5.2 Using a Mixed Methods Approach

I was pleased by the prospect of using a mixed methods approach, especially as it would allow me to use a triangulation of methods to consider my research question. However, prior to doctoral training, I had conducted very little research, meaning that the prospect of employing both quantitative and qualitative in one project was worrying. This is captured in my reflexive journal when I wrote *"I am becoming concerned that my position as a relatively inexperienced researcher means that this project will feel extremely difficult, as I do not have much familiarity with either approach on its own, let alone both of them together!"* These reflections were triggered by a research panel presentation where I was asked helpful but detailed questions which highlighted to me that I had much to learn about both approaches.

These concerns about inexperience and lack of knowledge were compounded at this time by concerns about managing workload and resources, as outlined by this excerpt from my journal where I describe how *"on the one hand, I am really glad that my project is mixed-methods as I think it will enhance the overall quality and meaningfulness of the research. On the other hand, I have had a couple of qualified clinical psychologists making jokes about my project showing that I am a "glutton for punishment" due to the heavy workload associated with it."*

With these concerns in mind, I found it extremely helpful to use research supervision to discuss areas of confusion and speak to trainees who were using similar methodologies to manage my workload and the resource-intensive nature of the mixed methods approach. This was of particular benefit at times when I was synthesising the results from both the quantitative and qualitative datasets which had different epistemological positions and required me to remain aware of my own critical realist approach to the data.

5.3 Reflection on the Ethics Process and Recruitment

The ethical approval application process and subsequent recruitment were areas of challenge within this research project. It had seemed appropriate to pursue an NHS ethics route to aid recruitment, as I had concerns that this could be difficult as the research was investigating a socially sensitive issues within a circumscribed population. However, the Covid-19 pandemic impacted the speed with which research projects were approved and it took several months from my initial ethics proposal being submitted to recruiting clinicians being allowed to mention my research project to participants. These feelings of stress are noted in my reflexive journal when I describe how *"I am finding it really stressful that it is taking so long to get ethical approval. I appreciate that there is an increased strain on services at the moment due to the Covid-19 pandemic, but I feel frustrated as I know that clinicians are happy to help me recruit and I am on a tight timeline – it feels like as time goes by, I am missing opportunities for participants to be recruited".* The Covid-19 pandemic also impacted recruitment in other ways, as health services – especially cancer services – were under extreme pressure due to the backlog of appointments which were cancelled or postponed during the first lockdown meaning that even when the project received ethical and management approval, it unavoidably could not be a key priority. One recruiting clinician also described how they were doing their best to mention the research to as many participants as possible but that the patients who attended the clinics often felt so poorly that it was difficult to engage them in research.

These barriers led to me to note down that *"I feel disappointed with how effortful the recruitment process for the survey has been – I am spending a lot of time trying to increase recruitment, but this is still yielding low numbers of participants. I am worried that this will impact on how meaningful my results are".* I note again my use of the word 'meaningful' within my journal at this point, a prevalent idea for me. As my research progressed, I began to re-frame the difficulties in recruiting and lower than hoped for numbers as a result and point of interest within themselves.

Furthermore, of the participants who took part in the study, many offered to be contacted regarding the semi-structured qualitative interview, leading me to reflect that *“the recruitment process for the interviews has been much more straightforward than for the survey which is not what I expected! I am delighted that so many people are willing to speak about their experiences with me. This makes me feel like we are researching something which does impact on people’s lives and also the lower than wished for numbers in the survey stage will be mitigated by the numbers recruited for interview”.*

5.4 Interview Process

The interview process was a steep learning curve for me as someone who had never previously conducted qualitative research and I found research and peer supervision to be of critical importance in conducting my research in a reliable and high-quality manner. Although I was delighted to be able to conduct so many interviews and hear the views of a large number of participants, being new to qualitative research meant that at times the process felt overwhelming. Furthermore, the content of the interviews was even more emotive than I had anticipated, leading me to note down that “*I am finding it really sad to hear how disrupted many participants have found their sexuality to be following HNC. I noticed today in an interview that even when a participant expressed peace with some of the changes to his sexual relationship, I continued to dwell on how sad it was, suggesting that my own values and thoughts are appearing in relation to the topic area*”. Research supervision at this time provided valuable support and clarity around what were my feelings and what were the participant’s and how I could notice this and be more aware so that I felt less emotionally drained by the content of the interviews. This was beneficial in later interviews which held similarly emotional content. While several participants did share painful experiences and reflections, many commented on how they felt pleased to be able to contribute to research and some even commented that they had found it helpful to discuss the topic.

I noticed in earlier interviews that two participants had referred to my young age in the context of comments such as “this is disgusting, you won’t want to hear about an old person doing this” and “when I was your age, I didn’t think old people like me still did this”. This topic came up in research supervision and my supervisor and I decided that I should begin the interview with a disclaimer where I said that I felt comfortable with the discussion of topics that we typically would not discuss with people we did not know. Although it was a minor change, I noticed fewer references to my age or self-inhibiting remarks within later interviews.

After the first 14 interviews, I began to notice that I was finding the interviews extremely draining and I can reflect that this may have been related to the context of conducting the majority of the interviews over video calls due to the Covid-19 pandemic and the related restrictions around meeting participants to interview in person. I was wary in case this had any impact on the quality of the interviews or my adherence to the semi-structured interview schedule. In light of this, despite the urge I noticed to schedule in the final four participants as quickly as possible in order to have conducted all my interviews, I spaced out the final four participants over a two week period to ensure that I had enough cognitive resources to carry out responsive and thoughtful interviews. This also allowed me to conclude the data collection phase in a paced manner after what had been a hectic time, exacerbated by collecting interview data for a separate small-scale research project.

5.5 Reflection on Analysis Process

I noticed some feelings of trepidation when I began the process of analysis for my research: while demanding and resource-intensive, the data collection phase had been more circumscribed in terms of what to do at which times (e.g. conduct interviews, send out recruitment emails) and so the analysis process felt comparatively unstructured. The quantitative analysis felt challenging at times due to the large amount of data which had been collected: this resultantly meant that preparing the data appropriately for the datafile was often an unwieldy and iterative process which felt difficult as I had several thoughts around wanting to get the quantitative analysis “done” and this was not a straightforward task.

The qualitative analysis process was demanding in different ways: I enjoyed the process of inductively coding the interview transcripts after I had checked my first initial codes with my research supervisor but found the process of creating and applying the deductive coding framework harder. I have reflected in my reflexive journal that *“it is really difficult to make a decision about how to apply some of the deductive coding frameworks to the text. I find it really difficult to judge whether -*

considering the sexual adjustment to cancer literature - someone can be judged to be cognitively reappraising the importance of sexuality in their life and accepting of the changes or if they are avoiding/in denial about the impact of the changes! And am I in a good position to make that judgment?" My supervisor's advice was extremely helpful to me at this point, and I was advised to not overthink the use of the deductive framework and instead to view it as a tool to facilitate me looking through and seeing if any data matched with what was in the framework. This advice felt liberating and reminded me that there were multiple ways of applying a deductive coding framework and that as long as I had a rationale for the decisions I had made then this was acceptable.

5.6 Reflections on Ethical Considerations

At the end of my research project, I do not feel that I have caused any harm from an ethical perspective and in fact, I feel that the ethical justice of the process was enhanced by such measures as offering every participant who expressed interest an interview and involving service-users. This is captured in my research journal: *"I am delighted that I have been able to interview so many participants. I am proud that I have been able to offer the chance to be interviewed to every participant, whether or not they took up that opportunity. This also makes me feel like I have reduced potential selection bias to some extent".* Furthermore, I feel that the project was designed in a way that was sensitive to the needs of this particular population in that the survey could be completed online at any time, and participants were able to complete the interview either over video call, telephone call, or email exchange. Although only one participant took up the opportunity to participate in the interview over email due to the impact of his treatment, I was glad to think that his view – which offered divergent data to the general themes – was represented within the research.

A moment of doubt occurred when the partner of a participant contacted me to express that they felt it was unfair that they had not been allowed to complete the study and said that he felt that as the caregiver, he should have been completing the survey too as the sexual relationship belongs to two people and they both have to get used to changes. I initially felt disappointed and frustrated to receive this email, noting down that "*this is already a big project without incorporating caregiver/partner* *opinions and surely the person for whom it has the largest impact is the patient*?!" However, after the initial strong emotions had subsided, I realised that these had been triggered by the fear that I had been perceived as unfair/exclusionary in some way which goes against views surrounding justice which I hold very strongly. On reflection, I can now view this in a more balanced way, understanding the fact that my project was necessarily specific and individually-focussed whilst recognising the validity of the partner's points and thinking that future research could usefully address such points.

5.7 Reflections on Research Implications

I have found it useful to reflect on the overall research process and conclude by considering the research implications of my project. Two key points are apparent to me following the findings from this study, and the first surrounds the ubiquity of how personally important an individual's sexuality is to them. I have elaborated on this in my reflexive journal: *"something that has struck me multiple times during the process of conducting this research is how everyone I interviewed had something to say about their sexuality, and whether or not they engaged in sexual activity, they definitely had thoughts about it! I do not want to forget this reflection, which is why I am writing it down, as I think it is definitely easy to consider particular groups in society as asexual such as those who are older or who are unwell".* This research has helped me to understand the importance of not pre-judging who might wish to receive advice or support surrounding sexuality, regardless of age, health status, or relationship status.

Secondly, I have reflected on the importance of the most useful support being available at a time when a participant is able to make use of it i.e. sexuality information/support services may not most usefully be given when a participant has just been diagnosed but possibly later in their journey when they have noticed any potential impacts upon their sexuality. This broadens out to more general reflections I have about the importance of remaining person-centred and treating each person as an individual with idiosyncratic needs rather than delivering care to people in exactly the same way. I have found the process of reflecting on my research project useful for helping me to think through the experiences I have had and the implications of this project, as well as a fitting way to conclude this aspect of the study. It has also influenced my general clinical practice as I am now sensitive to the frequently unspoken topic of sexuality and am vigilant to moments where it appears that individuals may wish to discuss it. This project has also increased my knowledge of cancer and its physical and psychological sequelae, which I will hold in mind in the future when working with individuals experiencing any long-term condition.

Research Project Portfolio Word Count (excluding reference lists, tables, figures, appendices, and statements referring to Extended Paper): 28,352 words

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Appendices

Appendix C: Author Guidelines

Author Guidelines for Sexual and Relationship Therapy. Relevant guidelines are provided, please see the below website link for further details: https://www.tandfonline.com/action/authorSubmission?show=instructions&journalCode=csmt20

About the Journal

Sexual and Relationship Therapy is an international, peer-reviewed journal publishing high-quality, original research.

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Structure

Your paper should be compiled in the following order: title page; abstract; keywords; lay summary; main text introduction; materials and methods; results; discussion; acknowledgements; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figures; figure captions (as a list).

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Authors may submit their paper in any scholarly format or layout. Manuscripts may be supplied as single or multiple files. These can be Word, rich text format (rtf), open document format (odt), or PDF files. Figures and tables can be placed within the text or submitted as separate documents. Figures should be of sufficient resolution to enable refereeing.

- There are no strict formatting requirements, but all manuscripts must contain the essential elements needed to evaluate a manuscript: abstract, author affiliation, figures, tables, funder information, and references. Further details may be requested upon acceptance.

- References can be in any style or format, so long as a consistent scholarly citation format is applied. Author name(s), journal or book title, article or chapter title, year of publication, volume and issue (where appropriate) and page numbers are essential. All bibliographic entries must contain a corresponding in-text citation. The addition of DOI (Digital Object Identifier) numbers is recommended but not essential.
- The journal reference style will be applied to the paper post-acceptance by Taylor & Francis.
- Spelling can be US or UK English so long as usage is consistent.

Note that, regardless of the file format of the original submission, an editable version of the article must be supplied at the revision stage.

Checklist: What to Include

1. **Author details.** All authors of a manuscript should include their full name and affiliation on the cover page of the manuscript. Where available, please also include ORCiDs and social media handles (Facebook, Twitter or LinkedIn). One author will need to be identified as the corresponding author, with their email address normally displayed in the article PDF (depending on the journal) and the online article. Authors' affiliations are the affiliations where the research was conducted. If any of the named co-authors moves affiliation during the peer-review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after your paper is accepted. Read more on authorship.
2. Should contain an unstructured abstract of 200 words.
3. **Lay summaries.** Manuscripts should also include a 50-word lay summary. Lay summaries should be included after the abstract and key words. Insert a line space after the abstract, and then include a heading (Lay Summary:) and then the lay summary text. (A lay summary is a short account of a paper written in clear, non-scientific language. It can be used to explain research findings and why they matter, and can help you reach a wider audience with your research.)
4. You can opt to include a **video abstract** with your article. Find out how these can help your work reach a wider audience, and what to think about when filming.
5. Between 3 and 6 **keywords**. Read making your article more discoverable, including information on choosing a title and search engine optimization.
6. **Funding details.** Please supply all details required by your funding and grant-awarding bodies as follows:
   For single agency grants
   This work was supported by the [Funding Agency] under Grant [number xxxx].
   For multiple agency grants
   This work was supported by the [Funding Agency #1] under Grant [number xxxx]; [Funding Agency #2] under Grant [number xxxx]; and [Funding Agency #3] under Grant [number xxxx].
7. **Disclosure statement.** This is to acknowledge any financial interest or benefit that has arisen from the direct applications of your research. Further guidance on what is a conflict of interest and how to disclose it.

8. **Biographical note.** Please supply a short biographical note for each author. This could be adapted from your departmental website or academic networking profile and should be relatively brief (e.g. no more than 200 words).
9. **Data availability statement.** If there is a data set associated with the paper, please provide information about where the data supporting the results or analyses presented in the paper can be found. Where applicable, this should include the hyperlink, DOI or other persistent identifier associated with the data set(s). Templates are also available to support authors.
10. **Data deposition.** If you choose to share or make the data underlying the study open, please deposit your data in a recognized data repository prior to or at the time of submission. You will be asked to provide the DOI, pre-reserved DOI, or other persistent identifier for the data set.
11. **Geolocation information.** Submitting a geolocation information section, as a separate paragraph before your acknowledgements, means we can index your paper's study area accurately in JournalMap's geographic literature database and make your article more discoverable to others. More information.
12. **Supplemental online material.** Supplemental material can be a video, dataset, fileset, sound file or anything which supports (and is pertinent to) your paper. We publish supplemental material online via Figshare. Find out more about supplemental material and how to submit it with your article.
13. **Figures.** Figures should be high quality (1200 dpi for line art, 600 dpi for grayscale and 300 dpi for colour, at the correct size). Figures should be supplied in one of our preferred file formats: EPS, PS, JPEG, TIFF, or Microsoft Word (DOC or DOCX) files are acceptable for figures that have been drawn in Word. For information relating to other file types, please consult our Submission of electronic artwork document.
14. **Tables.** Tables should present new information rather than duplicating what is in the text. Readers should be able to interpret the table without reference to the text. Please supply editable files.
15. **Equations.** If you are submitting your manuscript as a Word document, please ensure that equations are editable. More information about mathematical symbols and equations.
16. **Units.** Please use SI units (non-italicized).

Appendix D: University of Nottingham Sponsorship Statement

Research and Innovation
University of Nottingham
East Atrium, Jubilee Conference Centre
Triumph Road
Nottingham
NG8 1DH

Our reference: R&I: 20061
IRAS Project ID: 288364

0115 8467906
sponsor@nottingham.ac.uk

Health Research Authority
Research Ethics Committee

Dr Thomas Schröder
Professor of Clinical Psychology and
Psychological Therapies
University of Nottingham
Division of Psychiatry & Applied Psychology
YANG Fujia Building, B Floor
Jubilee Campus, Wollaton Road
Nottingham
NG8 1BB

12th October 2020

Dear Sir or Madam,

Sponsorship Statement
Re: How does Head and Neck Cancer affect sexuality?

I can confirm that this research proposal has been discussed with the Chief Investigator and agreement to sponsor the research is in place.

An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.*

Any necessary indemnity or insurance arrangements will be in place before this research starts. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.

Wording has been included in the participant information sheets to address the requirements of GDPR for transparency information and has been drafted by the sponsor to ensure consistency and compliance with the University's privacy notice, HRA guidance and the expectations of other organisations, therefore the HRA template wording has not been used verbatim.

Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.

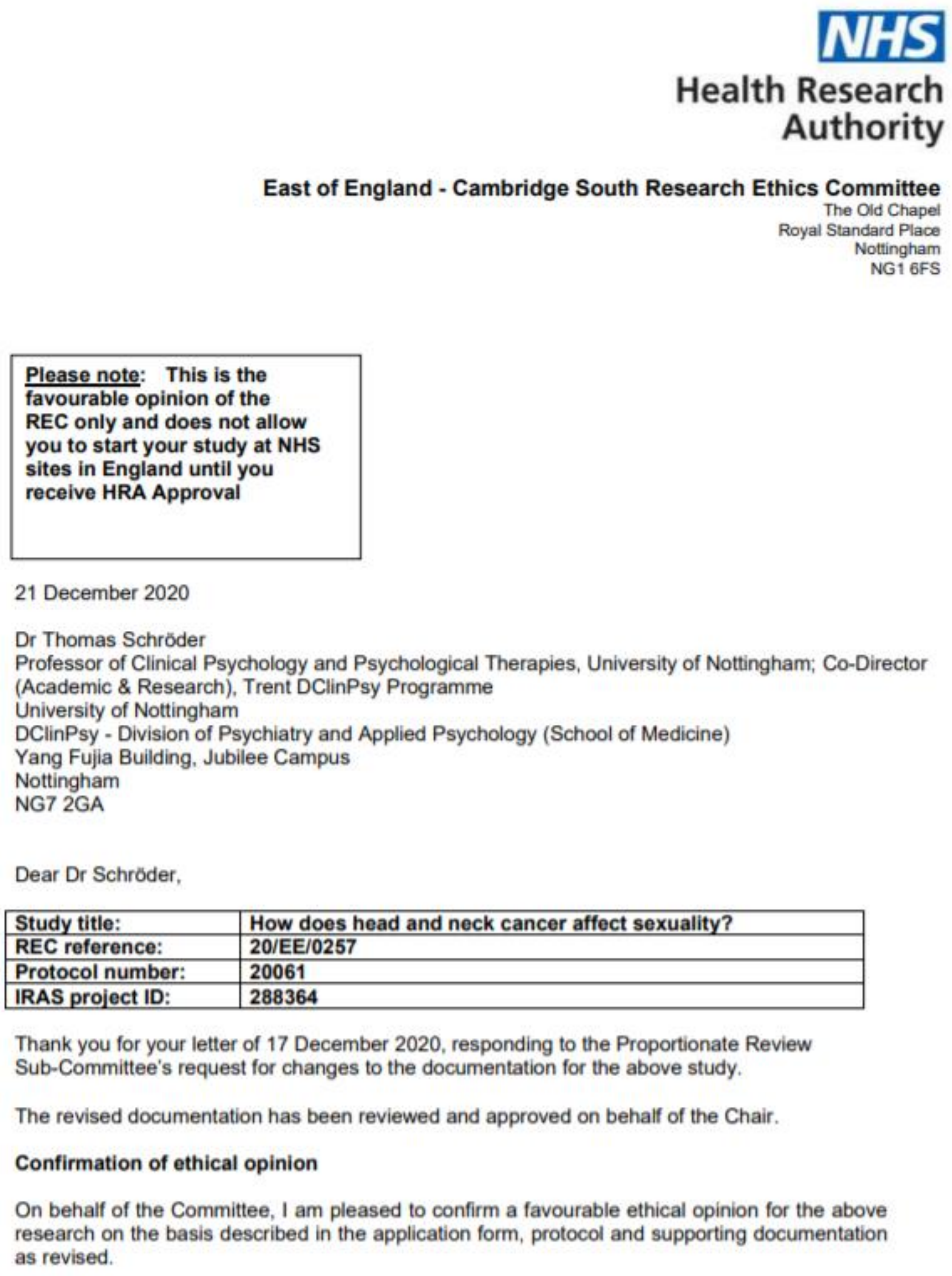
The duties of sponsors set out in the UK Policy Framework for Health and Social Care Research will be undertaken in relation to this research.**

* Not applicable to student research (except doctoral research).
** Not applicable to research outside the scope of the Research Governance Framework.

Yours faithfully

Angela Shone
Head of Research Governance
University of Nottingham

Appendix E: NHS Research Ethics Committee Approval Letter



NHS
Health Research
Authority

East of England - Cambridge South Research Ethics Committee
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

21 December 2020

Dr Thomas Schröder
Professor of Clinical Psychology and Psychological Therapies, University of Nottingham; Co-Director (Academic & Research), Trent DClinPsy Programme
University of Nottingham
DClinPsy - Division of Psychiatry and Applied Psychology (School of Medicine)
Yang Fujia Building, Jubilee Campus
Nottingham
NG7 2GA

Dear Dr Schröder,

Study title:	**How does head and neck cancer affect sexuality?**
REC reference:	**20/EE/0257**
Protocol number:	**20061**
IRAS project ID:	**288364**

Thank you for your letter of 17 December 2020, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved on behalf of the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database. For this purpose, 'clinical trials' are defined as the first four project categories in IRAS project filter question 2. Registration is a legal requirement for clinical trials of investigational medicinal products (CTIMPs), except for phase I trials in healthy volunteers (these must still register as a condition of the REC favourable opinion).

Registration should take place as early as possible and within six weeks of recruiting the first research participant at the latest. Failure to register is a breach of these approval conditions, unless a deferral has been agreed by or on behalf of the Research Ethics Committee (see here for more information on requesting a deferral: https://www.hra.nhs.uk/planning-and-improving-research/research-planning/research-registration-research-project-identifiers/

As set out in the UK Policy Framework, research sponsors are responsible for making information about research publicly available before it starts e.g. by registering the research project on a publicly accessible register. Further guidance on registration is available at: https://www.hra.nhs.uk/planning-and-improving-research/research-planning/transparency-responsibilities/

You should notify the REC of the registration details. We routinely audit applications for compliance with these conditions.

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter.

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit: https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/

N.B. If your study is related to COVID-19 we will aim to publish your research summary within 3 days rather than three months.

During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you haven't already done so, please register your study on a public registry as soon as possible and provide the HRA with the registration detail, which will be posted alongside other information relating to your project. We are also asking sponsors not to request deferral of publication of research summary for any projects relating to COVID-19. In addition, to facilitate finding and extracting studies related to COVID-19 from public databases, please enter the WHO official acronym for the coronavirus disease (COVID-19) in the full title of your study. Approved COVID-19 studies can be found at: https://www.hra.nhs.uk/covid-19-research/approved-covid-19-research/

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report

The latest guidance on these topics can be found at https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/.

Ethical review of research sites

The favourable opinion applies to all NHS/HSC sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" above).

Approved documents

The documents reviewed and approved by the Committee are:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Study Poster_How does HNC affect sexuality_Final version 1.0_12th October 2020]	Final 1.0	12 October 2020

Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Professional Indemnity evidence of Cover 2020-21_How does HNC affect sexuality_Final Version 1.0_12th October 2020]	Final 1.0	12 October 2020
Interview schedules or topic guides for participants [Interview Schedule_How does HNC affect sexuality_Final Version 1.0_12th October 2020]	Final 1.0	12 October 2020
IRAS Application Form [IRAS_Form_19102020]		19 October 2020
Letter from sponsor [Sponsor Letter_How does HNC affect sexuality_Final Version 1.0_12th October 2020]	Final 1.0	12 October 2020
Letters of invitation to participant [Covering Email to Invite Individuals to Participate_How does HNC affect sexuality_Final Version 2.0_11th December 2020]	Final 2.0	11 December 2020
Non-validated questionnaire [Additions to SexFS Questionnaires_How does HNC affect sexuality_Final Version 1.0_12th October 2020]	Final 1.0	12 October 2020
Other [Participation Identification Centre Agreement_How does HNC affect Sexuality_ Final Version 1.0_12th October 2020]	Final 1.0	12 October 2020
Other [Social Media Advert Text_How does HNC affect sexuality_Final Version 1.0_12th October 2020]	Final 1.0	12 October 2020
Other [Response Letter_How does HNC affect sexuality_Final Version 1.0_11th December 2020]	Final 1.0	11 December 2020
Participant consent form [Phase One Participant Consent Form_How does HNC affect sexuality_Final Version 2.0_11th December 2020]	Final 2.0	11 December 2020
Participant consent form [Phase Two Participant Consent Form_How does HNC affect sexuality_Final Version 1.0_12th October 2020]	Final 2.0	11 December 2020
Participant information sheet (PIS) [Phase One Participant Information Sheet_How does HNC affect sexuality_Final Version 2.0_11th December 2020]	Final 2.0	11 December 2020
Participant information sheet (PIS) [Phase Two Participant Information Sheet_How does HNC affect sexuality_Final Version 2.0_11th December 2020]	Final 2.0	11 December 2020
Referee's report or other scientific critique report [Scientific Critique Report_How does HNC affect sexuality_Final Version 1.0_12th October 2020]	Final 1.0	12 October 2020
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Summary CV for Chief Investigator (CI) [Staff - CV Thomas Schroder_How does HNC affect sexuality_Final Version 1.0_12th October 2020]	Final 1.0	12 October 2020
Summary CV for student [Student CV Linda McCabe_How does HNC affect sexuality_Final Version 1.0_12th October 2020]	Final 1.0	12 October 2020
Summary CV for supervisor (student research) [CV Nima Golijani Moghaddam Academic Supervisor_How does HNC affect sexuality_Final Version 1.0_12th October 2020]	Final 1.0	12 October 2020
Summary CV for supervisor (student research) [CV Anna Tickle Academic Supervisor_How does HNC affect sexuality_Final Version 1.0_12th October 2020]	Final 1.0	12 October 2020
Validated questionnaire [PROMIS Sex FS Questionnaire_How does HNC affect sexuality_Final Version 1.0_12th October 2020]	Final 1.0	12 October 2020
Validated questionnaire [CompACT Questionnaire_How does HNC affect sexuality_Final Version 1.0_12th October 2020]	Final 1.0	12 October 2020
Validated questionnaire [FACT H & N Questionnaire_How does HNC affect sexuality_Final Version 1.0_12th October 2020]	Final 1.0	12 October 2020

Validated questionnaire [Brief IPQ Measure_How does HNC affect sexuality_Final Version 1.0_12th October 2020]	Final 1.0	12 October 2020
Validated questionnaire [BriefCopeScale_How does HNC affect sexuality_Final Version 1.0_12th October 2020]	Final 1.0	12 October 2020

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

IRAS project ID: 288364	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely,

pp

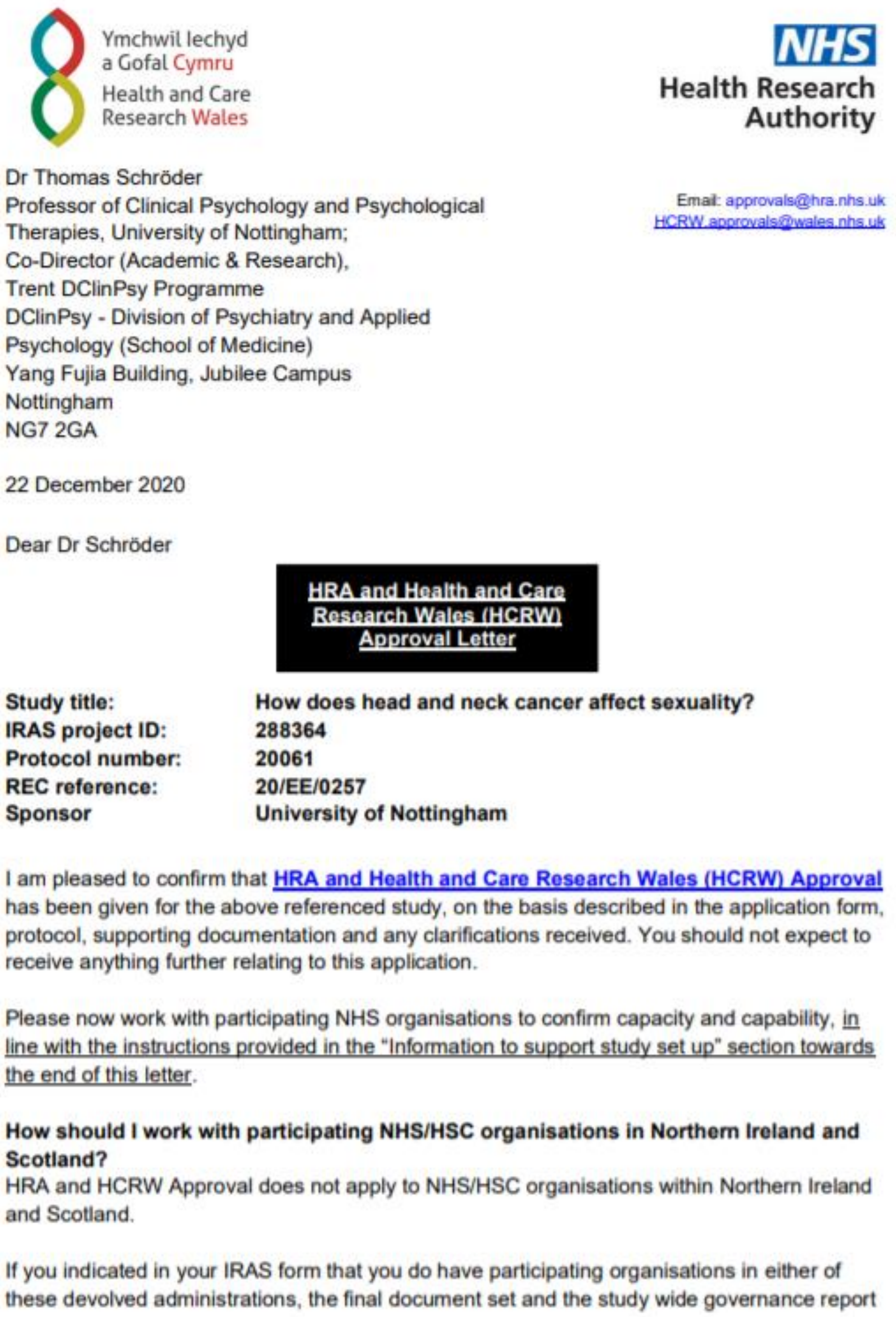
Dr Leslie Gelling
Chair

Email: cambridgesouth.rec@hra.nhs.uk

Enclosures: "After ethical review – guidance for researchers"

Copy to: Ms Angela Shone

Appendix F: Health Research Authority Approval Letter



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Dr Thomas Schröder
Professor of Clinical Psychology and Psychological
Therapies, University of Nottingham;
Co-Director (Academic & Research),
Trent DClinPsy Programme
DClinPsy - Division of Psychiatry and Applied
Psychology (School of Medicine)
Yang Fujia Building, Jubilee Campus
Nottingham
NG7 2GA

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

22 December 2020

Dear Dr Schröder

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**How does head and neck cancer affect sexuality?**
IRAS project ID:	**288364**
Protocol number:	**20061**
REC reference:	**20/EE/0257**
Sponsor	**University of Nottingham**

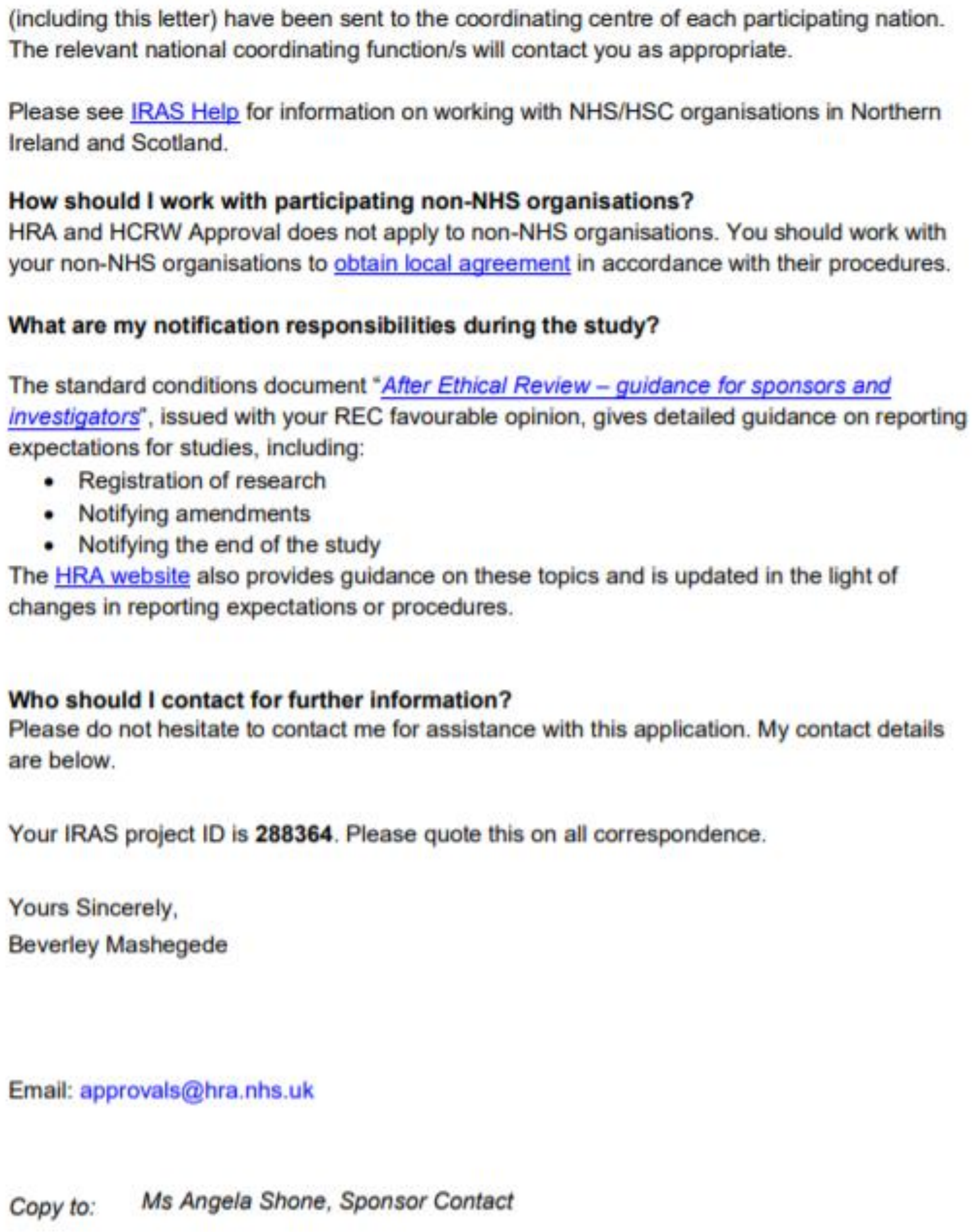
I am pleased to confirm that HRA and Health and Care Research Wales (HCRW) Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report



(including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **288364**. Please quote this on all correspondence.

Yours Sincerely,
Beverley Mashegede

Email: approvals@hra.nhs.uk

Copy to: *Ms Angela Shone, Sponsor Contact*

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Study Poster_How does HNC affect sexuality_Final version 1.0_12th October 2020]	Final 1.0	12 October 2020
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Professional Indemnity evidence of Cover 2020-21_How does HNC affect sexuality_Final Version 1.0_12th October 2020]	Final 1.0	12 October 2020
Interview schedules or topic guides for participants [Interview Schedule_How does HNC affect sexuality_Final Version 1.0_12th October 2020]	Final 1.0	12 October 2020
IRAS Application Form [IRAS_Form_19102020]		19 October 2020
IRAS Application Form XML file [IRAS_Form_19102020]		19 October 2020
IRAS Checklist XML [Checklist_17122020]		17 December 2020
Letter from sponsor [Sponsor Letter_How does HNC affect sexuality_Final Version 1.0_12th October 2020]	Final 1.0	12 October 2020
Letters of invitation to participant [Covering Email to Invite Individuals to Participate_How does HNC affect sexuality_Final Version 2.0_11th December 2020]	Final 2.0	11 December 2020
Non-validated questionnaire [Additions to SexFS Questionnaires_How does HNC affect sexuality_Final Version 1.0_12th October 2020]	Final 1.0	12 October 2020
Other [Participation Identification Centre Agreement_How does HNC affect Sexuality_ Final Version 1.0_12th October 2020]	Final 1.0	12 October 2020
Other [Social Media Advert Text_How does HNC affect sexuality_Final Version 1.0_12th October 2020]	Final 1.0	12 October 2020
Other [Response Letter_How does HNC affect sexuality_Final Version 1.0_11th December 2020]	Final 1.0	11 December 2020
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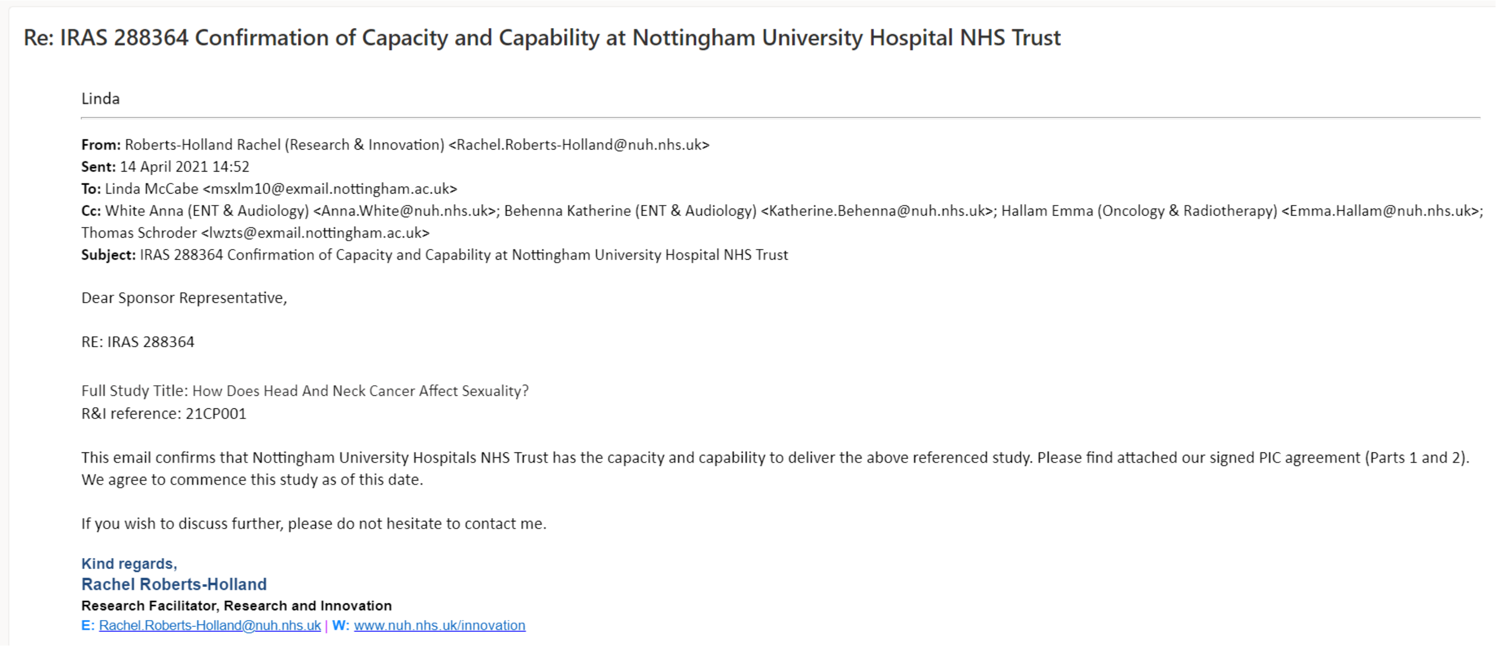
Summary CV for student [Student CV Linda McCabe_How does HNC affect sexuality_Final Version 1.0_12th October 2020]	Final 1.0	12 October 2020
Summary CV for supervisor (student research) [CV Nima Golijani Moghaddam Academic Supervisor_How does HNC affect sexuality_Final Version 1.0_12th October 2020]	Final 1.0	12 October 2020

Appendix H: Nottingham University Hospitals NHS Trust – Research and Innovation Capacity and Capability Approval



Re: IRAS 288364 Confirmation of Capacity and Capability at Nottingham University Hospital NHS Trust

Linda

From: Roberts-Holland Rachel (Research & Innovation) <Rachel.Roberts-Holland@nuh.nhs.uk>
Sent: 14 April 2021 14:52
To: Linda McCabe <msxlm10@exmail.nottingham.ac.uk>
Cc: White Anna (ENT & Audiology) <Anna.White@nuh.nhs.uk>; Behenna Katherine (ENT & Audiology) <Katherine.Behenna@nuh.nhs.uk>; Hallam Emma (Oncology & Radiotherapy) <Emma.Hallam@nuh.nhs.uk>; Thomas Schroder <lwzts@exmail.nottingham.ac.uk>
Subject: IRAS 288364 Confirmation of Capacity and Capability at Nottingham University Hospital NHS Trust

Dear Sponsor Representative,

RE: IRAS 288364

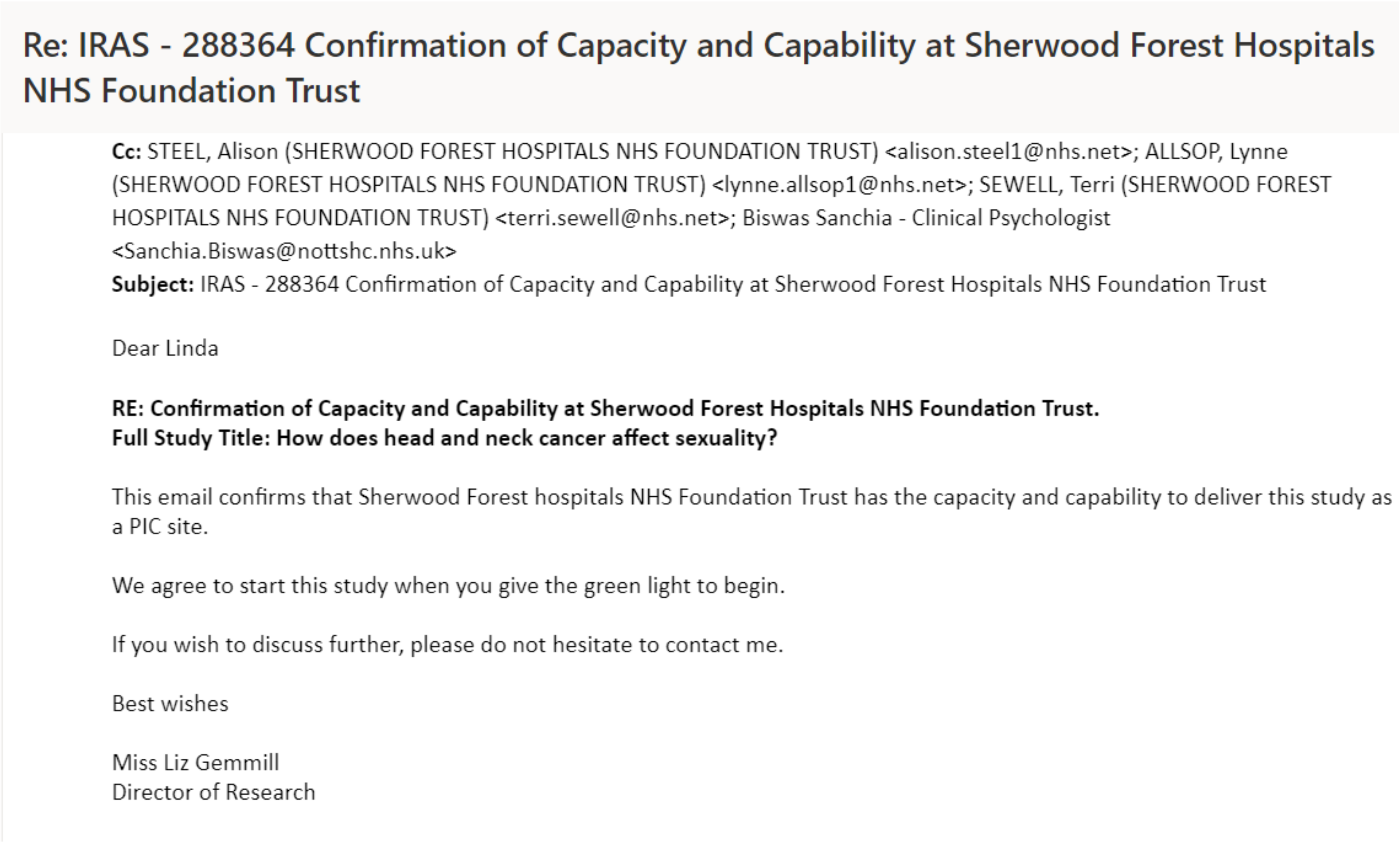
Full Study Title: How Does Head And Neck Cancer Affect Sexuality?
R&I reference: 21CP001

This email confirms that Nottingham University Hospitals NHS Trust has the capacity and capability to deliver the above referenced study. Please find attached our signed PIC agreement (Parts 1 and 2). We agree to commence this study as of this date.

If you wish to discuss further, please do not hesitate to contact me.

Kind regards,
Rachel Roberts-Holland
Research Facilitator, Research and Innovation
E: Rachel.Roberts-Holland@nuh.nhs.uk | **W:** www.nuh.nhs.uk/innovation

Appendix I: Sherwood Forest Hospitals NHS Foundation Trust – Research and Development Capacity and Capability Approval



Re: IRAS - 288364 Confirmation of Capacity and Capability at Sherwood Forest Hospitals NHS Foundation Trust

Cc: STEEL, Alison (SHERWOOD FOREST HOSPITALS NHS FOUNDATION TRUST) <alison.steel1@nhs.net>; ALLSOP, Lynne (SHERWOOD FOREST HOSPITALS NHS FOUNDATION TRUST) <lynne.allsop1@nhs.net>; SEWELL, Terri (SHERWOOD FOREST HOSPITALS NHS FOUNDATION TRUST) <terri.sewell@nhs.net>; Biswas Sanchia - Clinical Psychologist <Sanchia.Biswas@nottshc.nhs.uk>
Subject: IRAS - 288364 Confirmation of Capacity and Capability at Sherwood Forest Hospitals NHS Foundation Trust

Dear Linda

RE: Confirmation of Capacity and Capability at Sherwood Forest Hospitals NHS Foundation Trust.
Full Study Title: How does head and neck cancer affect sexuality?

This email confirms that Sherwood Forest hospitals NHS Foundation Trust has the capacity and capability to deliver this study as a PIC site.

We agree to start this study when you give the green light to begin.

If you wish to discuss further, please do not hesitate to contact me.

Best wishes

Miss Liz Gemmill
Director of Research

Appendix J: Participant Information Sheet Online Survey Phase

Phase One Participant Information Sheet

Participant Information Sheet

IRAS Project ID: 288364

Title of Study: How does Head and Neck Cancer affect Sexuality?

Name of Chief Investigator: Thomas Schroder
Local Researcher(s): Linda McCabe

We would like to invite you to take part in our research study. Before you decide, we would like you to understand why the research is being done and what it would involve for you. We would ask you to read this information sheet before deciding whether to provide your consent to participate in this study. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

What is the purpose of the study?

This study aims to explore how Head and Neck Cancer (HNC) affects sexuality. Following the diagnosis of and treatment for cancer, many survivors experience an impact on their sexuality. This study will be using the World Health Organisation definition of sexuality, namely that sexuality is 'a central aspect of being human throughout life [which] encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships.' This study aims to ask HNC survivors about their experience as well as understanding whether particular ways of coping and responding influence how much an individual's sexuality is likely to be impacted by the challenges associated with HNC.

The results from this study will be used to achieve a greater understanding of the impact on sexuality for those who have experienced HNC and may additionally go on to help identify what the clinical need is for supporting those who experience sexuality difficulties following diagnosis and treatment, so that they are receiving holistic and effective care. This study is also being undertaken towards the Doctorate in Clinical Psychology qualification.

Why have I been invited?

You are being invited to take part because you have experienced Head and Neck Cancer, whether currently or in the past. We are inviting 96 participants like you to take part in the online questionnaire stage.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to complete a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. This would not affect your legal rights.

What will happen to me if I take part?

Once you have given your consent to take part in the study, you will be asked to fill in some demographic information about yourself. If the information you provide shows that you are eligible to take part in the study, you will be able to access the online questionnaire which will take between 40 minutes to 1 hour. However, the length of time the questionnaire will take may vary, depending on the individual. If the information you fill in shows that you are not eligible to take part in the study, you will be thanked for your time but will be withdrawn from the study. This online questionnaire can be filled in anywhere that is convenient and does not require a researcher to be present. Following the completion of the online questionnaire, you will be offered the opportunity to fill in your details if you are willing to be contacted regarding the possibility of taking part in the second part of the study. This second part will involve one interview with a researcher to gather more information regarding the topics explored in the questionnaire.

If you do not want to be contacted regarding the interview stage of the study, then your involvement with this study is finished when you have completed the online questionnaire. However, if you are willing to be contacted regarding the interview stage of the study, and are asked to take part, then your involvement with the study will be finished once you have completed the interview.

What are the possible disadvantages and risks of taking part?

By taking part in the online questionnaire phase of the study, you will be required to use your free time.

Furthermore, the questions in the online questionnaire could cause distress due to both the personal nature of the questions and the fact that the questions will be asking you to reflect on potentially distressing aspects of your experience with Head and Neck Cancer, and the impact it has on your life currently. You are not obliged to share any information if it feels too uncomfortable. Additionally, information about services and charities who can provide you with support will be included on the 'Debriefing Form' at the end of the study if you find that you feel distressed following your participation. However, some participants may not experience any distress as a result of taking part in this study.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from this study may help to develop a greater understanding of how Head and Neck Cancer can affect sexuality which could help to provide more sensitive and holistic patient care.

What happens when the research study stops?

After the recruitment for the study has stopped, your data and the data of other participants will be used to see whether survivors of Head and Neck Cancer do experience an impact on their sexuality and quality of life. The study will also analyse whether the coping and response styles of participants relate to the extent of the impact someone may experience.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers' contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting the Patient Advice and Liaison Service (PALS) on 0800 183 0204 or by emailing PALS@nuh.nhs.uk.

In the event that something does go wrong, and you are harmed during the research, and this is due to someone's negligence then you may have grounds for a legal action for compensation against the University of Nottingham, but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

Will my taking part in the study be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence.

If you join the study, we will use information collected from you during the course of the research. This information will be kept **strictly confidential** and stored in a secure and locked office and on a password protected database at the University of Nottingham. Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security), Qualtrics is the data processor (processing your data on behalf of the University) and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as we need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights we will use the minimum of personally identifiable information possible. The Qualtrics questionnaire software used to administer the online questionnaires will back up all respondent data for disaster recovery purposes only. When a data deletion request is sent to Qualtrics, all backups of this data will be deleted within 90 days.

You can find out more about how we use your information and to read our privacy notice at:

https://www.nottingham.ac.uk/utilities/privacy.aspx.

The data collected for the study will be looked at and stored by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people from regulatory organisations to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

If you choose to enter the prize draw or express your interest in the interview your contact information will be kept by the University of Nottingham for one year after the end of the study so that we are able to contact you about the findings of the study and possible follow-up studies (unless you advise us that you do not wish to be contacted). This information will be kept separately from the research data collected and only those who need to will have access to it. All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team given permission by the data custodian will have access to your personal data. The chief researcher will individually control access to the personal data on the Qualtrics server – no-one else will have access to these data. Once the study is closed, the researcher will erase all study data from the Qualtrics servers.

In accordance with the University of Nottingham's, the Government's, and our funders' policies we may share our research data with researchers in other Universities and organisations, including those in other countries, for research in health and social care. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. Data sharing in this way is usually anonymised (so that you could not be identified) but if we need to share identifiable information we will seek your consent for this and ensure it is secure. You will be made aware then if the data is to be shared with countries whose data protection laws differ to those of the UK and how we will protect your confidentiality.

Although what you say to us is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons.

What will happen if I don't want to carry on with the study?

Your participation is voluntary, and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw we will no longer collect any information about you or from you, but we will keep the information about you that we have already obtained as we are not allowed to tamper with study records and this information may have already been used in some analyses and may still be used in the final study analyses. To safeguard your rights, we will use the minimum of personally identifiable information possible.

Payments

You will not be paid to take part in this study. However, if you give your consent and provide some contact details on the consent form, you will be entered into a prize draw which consists of either a £100 or £50 Amazon voucher.

What will happen to the results of the research study?

The results of this study will be written up for a doctoral thesis. The thesis will be submitted to journals with the aim of publication. You will not be identified in any presentation or publication of the data. You can request a copy of the results of the study from the researcher. The contact details for the researcher are supplied at the end of this information sheet.

Who is organising and funding the research?

This research is being organised by the University of Nottingham and is being funded by the University of Nottingham.

Who has reviewed the study?

All research in healthcare is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Cambridge South Research Ethics Committee.

Further information and contact details

Linda McCabe (linda.mccabe@nottingham.ac.uk)

Supervised by:

Anna Tickle (anna.tickle@nottingham.ac.uk)

Nima Moghaddam (nmoghaddam@lincoln.ac.uk)

Appendix K: Participant Information Sheet Interview Phase

Phase Two Participant Information Sheet

Participant Information Sheet

IRAS Project ID: 288364

Title of Study: How does Head and Neck Cancer affect Sexuality?

Name of Chief Investigator: Thomas Schroder
Local Researcher(s): Linda McCabe

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have: depending on how the interview is taking place, this may be over a video call/the phone or in person in a socially distanced way. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

What is the purpose of the study?

This study aims to explore how Head and Neck Cancer (HNC) affects sexuality. Following the diagnosis of and treatment for cancer, many survivors experience an impact on their sexuality. This study will be using the World Health Organisation definition of sexuality, namely that sexuality is 'a central aspect of being human throughout life [which] encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships.' This study aims to ask HNC survivors about their experience as well as understanding whether particular ways of coping and responding influence how much an individual's sexuality is likely to be impacted by the challenges associated with HNC.

The results from this study will be used to achieve a greater understanding of the impact on sexuality for those who have experienced HNC and may additionally go on to help identify what the clinical need is for supporting those who experience sexuality difficulties following diagnosis and treatment, so that they are receiving holistic and effective care. This study is also being undertaken as part of the researcher's Doctorate in Clinical Psychology training.

Why have I been invited?

You are being invited to take part because you have experienced Head and Neck Cancer, whether currently or in the past. You have taken part in the questionnaire phase of this study and have expressed an interest in taking part in the interviews. We are inviting participants like you to take part in the interview stage.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form, if the interview is taking place face-to-face. If the interview is taking place over the phone/using video technology, a consent form will be emailed over to you ahead of the interview which you will be asked to return over email ahead of the interview. If you decide to take part, you are still free to withdraw at any time and without giving a reason. This would not affect your legal rights.

What will happen to me if I take part?

Once you have given your consent to take part in the interview phase, you will be asked to some questions regarding demographic information about yourself before participating in one interview with a researcher to gather more information regarding the topic of sexuality, quality of life and coping and response styles. The interview will be recorded and transcribed. The interview will either be transcribed by the interviewer or a third-party transcriber who will be asked to sign a confidentiality agreement. This interview will last between 1 hour and 2 hours and will be carried out at a place that is convenient for you, whether this is a face-to-face interview, or an interview conducted over the phone/using video technology.

If you are willing to participate in the interview stage of the study, and are asked to take part, then your involvement with the study will be finished once you have completed the interview.

What are the possible disadvantages and risks of taking part?

By taking part in the interview phase of the study, you will be required to use your free time.

Furthermore, the questions in the interview could cause distress due to both the personal nature of the questions and the fact that the questions will be asking you to reflect on potentially distressing aspects of your experience with Head and Neck Cancer, and the impact it has on your life currently. You are not obliged to share any information if it feels too uncomfortable. Additionally, information about services and charities who can provide you with support will be included on the ‘Debriefing Form’ at the end of the study if you find that you feel distressed following your participation. However, some participants may not experience any distress as a result of taking part in this study.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from this study may help to develop a greater understanding of how Head and Neck Cancer can affect sexuality and may indicate what the clinical need is for those who do experience a negative impact on their sexuality following Head and Neck Cancer, which could help to provide more sensitive and holistic patient care.

What happens when the research study stops?

After the recruitment for the study has stopped, your data and the data of other participants will be used to see whether survivors of Head and Neck Cancer do experience an impact on their sexuality and quality of life. The study will also analyse whether the coping and response styles of participants relate to the extent of the impact someone may experience.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers' contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting the Patient Advice and Liaison Service (PALS) on 0800 183 0204 or by emailing PALS@nuh.nhs.uk.

In the event that something does go wrong, and you are harmed during the research, and this is due to someone's negligence then you may have grounds for a legal action for compensation against the University of Nottingham, but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

Will my taking part in the study be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence.

If you join the study, we will use information collected from you during the course of the research. This information will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database at the University of Nottingham. Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as we need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights, we will use the minimum personally – identifiable information possible.

You can find out more about how we use your information and to read our privacy notice at:

https://www.nottingham.ac.uk/utilities/privacy.aspx.

The data collected for the study will be looked at and stored by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people from regulatory organisations to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

Your contact information will be kept by the University of Nottingham for one year after the end of the study so that we are able to contact you about the findings of the study and possible follow-up studies (unless you advise us that you do not wish to be contacted). This information will be kept separately from the research data collected and only those who need to will have access to it. The recordings from the interviews will be destroyed, by being expunged from the encrypted recording device as soon as they have been transcribed. All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team given permission by the data custodian will have access to your personal data.

In accordance with the University of Nottingham's, the Government's, and our funders' policies we may share our research data with researchers in other Universities and organisations, including those in other countries, for research in health and social care. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. Data sharing in this way is usually anonymised (so that you could not be identified) but if we need to share identifiable information, we will seek your consent for this and ensure it is secure. You will be made aware then if the data is to be shared with countries whose data protection laws differ to those of the UK and how we will protect your confidentiality.

Although what you say to us is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons.

What will happen if I don't want to carry on with the study?

Your participation is voluntary, and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you wish to withdraw from the study, please contact us within a week from the day of the interview to ask us to destroy the data we have recorded from your interview. If you withdraw from the study more than a week after the interview, we will not be able to destroy the data from the interview and it may be used in the final analysis. To safeguard your rights, we will use the minimum of personally identifiable information possible.

What will happen to the results of the research study?

The results of this study will be written up for a doctoral thesis. The thesis will be submitted to journals with the aim of publication. You will not be identified in any presentation or publication of the data. You can request a copy of the results of the study from the researcher. The contact details for the researcher are supplied at the end of this information sheet.

Who is organising and funding the research?

This research is being organised by the University of Nottingham and is being funded by the University of Nottingham.

Who has reviewed the study?

All research in healthcare is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Cambridge South Research Ethics Committee.

Further information and contact details

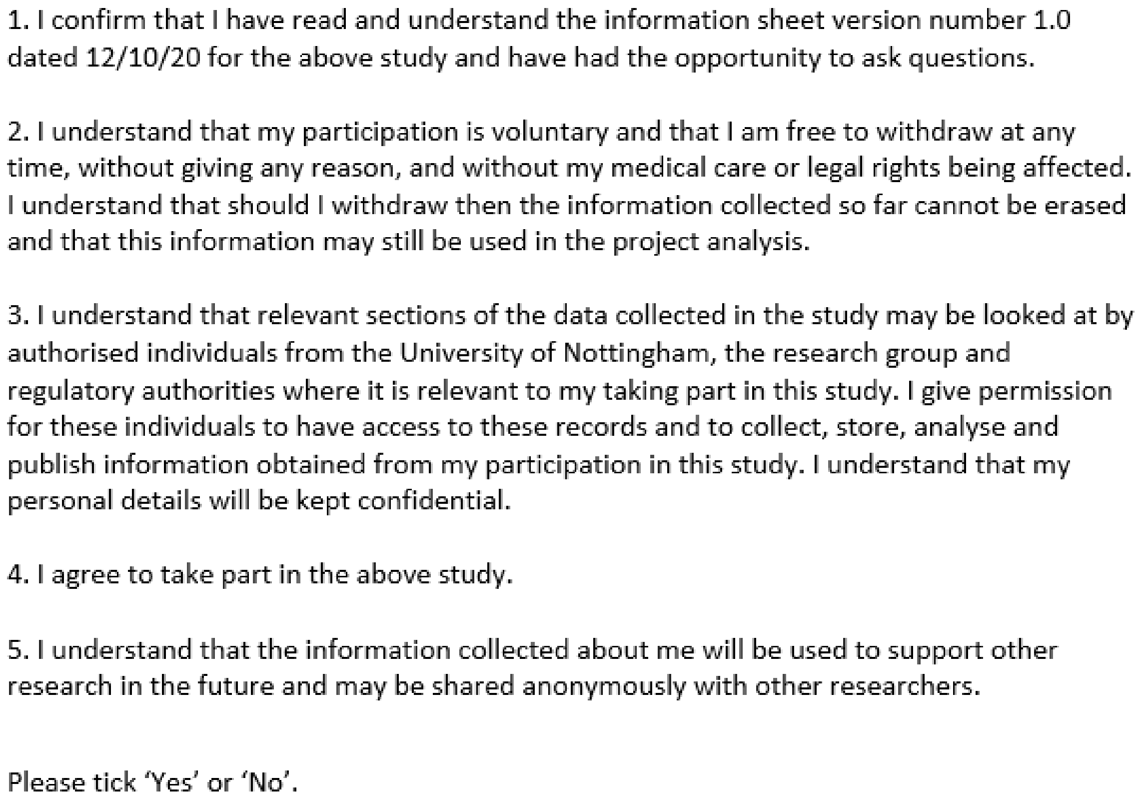
Linda McCabe (linda.mccabe@nottingham.ac.uk)

Supervised by:

Anna Tickle (anna.tickle@nottingham.ac.uk)

Nima Moghaddam (nmoghaddam@lincoln.ac.uk)

Appendix L: Consent Form Online Survey Phase



1. I confirm that I have read and understand the information sheet version number 1.0 dated 12/10/20 for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my medical care or legal rights being affected. I understand that should I withdraw then the information collected so far cannot be erased and that this information may still be used in the project analysis.

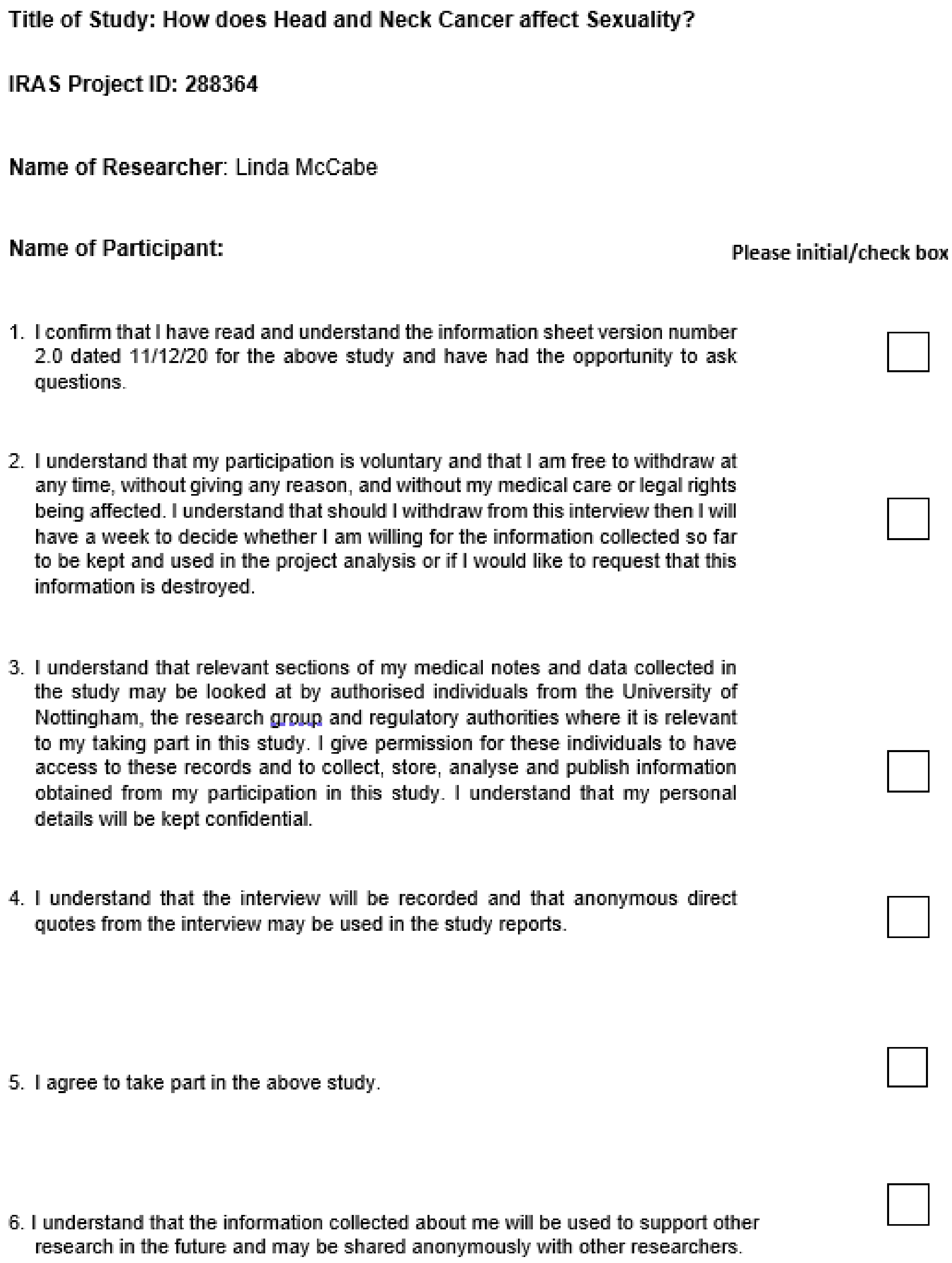
3. I understand that relevant sections of the data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential.

4. I agree to take part in the above study.

5. I understand that the information collected about me will be used to support other research in the future and may be shared anonymously with other researchers.

Please tick ‘Yes’ or ‘No’.

Appendix M: Consent Form Interview Phase



Title of Study: How does Head and Neck Cancer affect Sexuality?

IRAS Project ID: 288364

Name of Researcher: Linda McCabe

Name of Participant:

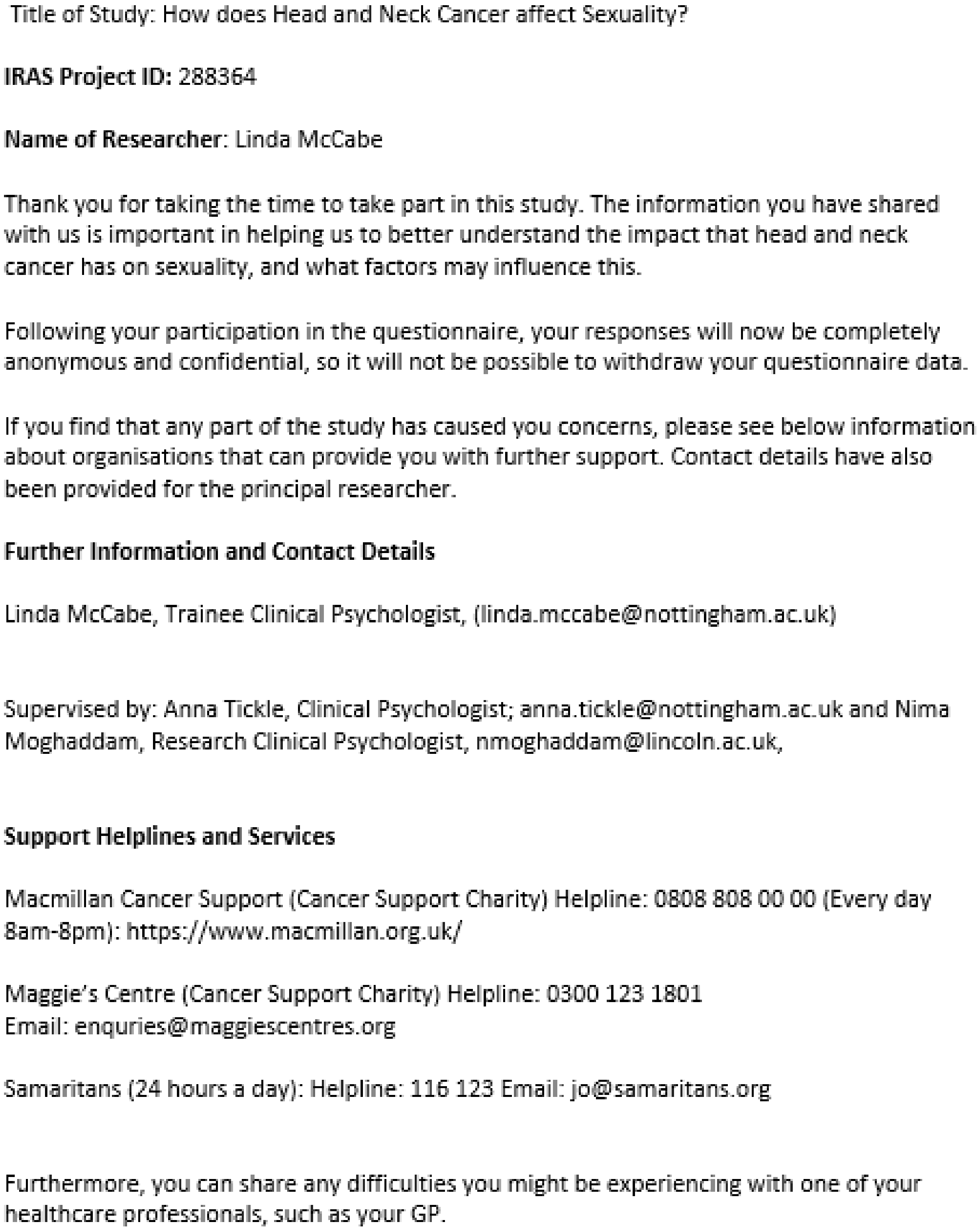
Please initial/check box

1. I confirm that I have read and understand the information sheet version number 2.0 dated 11/12/20 for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my medical care or legal rights being affected. I understand that should I withdraw from this interview then I will have a week to decide whether I am willing for the information collected so far to be kept and used in the project analysis or if I would like to request that this information is destroyed. ☐
3. I understand that relevant sections of my medical notes and data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐
4. I understand that the interview will be recorded and that anonymous direct quotes from the interview may be used in the study reports. ☐
5. I agree to take part in the above study. ☐
6. I understand that the information collected about me will be used to support other research in the future and may be shared anonymously with other researchers. ☐

Name of Participant	Date	Signature/Digital signature
Name of Person taking consent	Date	Signature/Digital signature

2 copies: 1 for participant, 1 for the project notes

Appendix N: Debriefing Form Online Survey Phase



Title of Study: How does Head and Neck Cancer affect Sexuality?

IRAS Project ID: 288364

Name of Researcher: Linda McCabe

Thank you for taking the time to take part in this study. The information you have shared with us is important in helping us to better understand the impact that head and neck cancer has on sexuality, and what factors may influence this.

Following your participation in the questionnaire, your responses will now be completely anonymous and confidential, so it will not be possible to withdraw your questionnaire data.

If you find that any part of the study has caused you concerns, please see below information about organisations that can provide you with further support. Contact details have also been provided for the principal researcher.

Further Information and Contact Details

Linda McCabe, Trainee Clinical Psychologist, (linda.mccabe@nottingham.ac.uk)

Supervised by: Anna Tickle, Clinical Psychologist; anna.tickle@nottingham.ac.uk and Nima Moghaddam, Research Clinical Psychologist, nmoghaddam@lincoln.ac.uk,

Support Helplines and Services

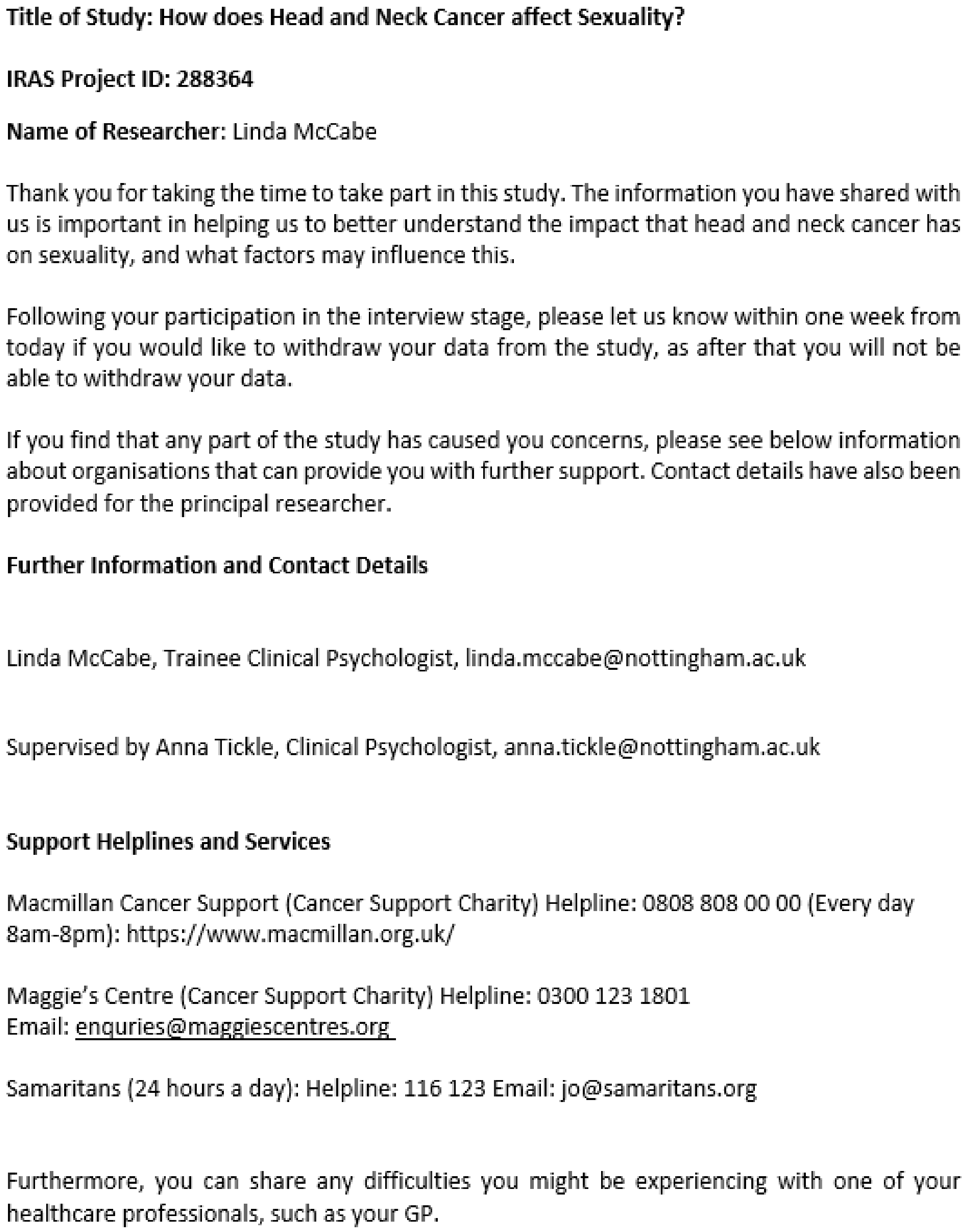
Macmillan Cancer Support (Cancer Support Charity) Helpline: 0808 808 00 00 (Every day 8am-8pm): https://www.macmillan.org.uk/

Maggie's Centre (Cancer Support Charity) Helpline: 0300 123 1801
Email: enquries@maggiescentres.org

Samaritans (24 hours a day): Helpline: 116 123 Email: jo@samaritans.org

Furthermore, you can share any difficulties you might be experiencing with one of your healthcare professionals, such as your GP.

Appendix O: Debriefing Form Interview Phase



Title of Study: How does Head and Neck Cancer affect Sexuality?

IRAS Project ID: 288364

Name of Researcher: Linda McCabe

Thank you for taking the time to take part in this study. The information you have shared with us is important in helping us to better understand the impact that head and neck cancer has on sexuality, and what factors may influence this.

Following your participation in the interview stage, please let us know within one week from today if you would like to withdraw your data from the study, as after that you will not be able to withdraw your data.

If you find that any part of the study has caused you concerns, please see below information about organisations that can provide you with further support. Contact details have also been provided for the principal researcher.

Further Information and Contact Details

Linda McCabe, Trainee Clinical Psychologist, linda.mccabe@nottingham.ac.uk

Supervised by Anna Tickle, Clinical Psychologist, anna.tickle@nottingham.ac.uk

Support Helplines and Services

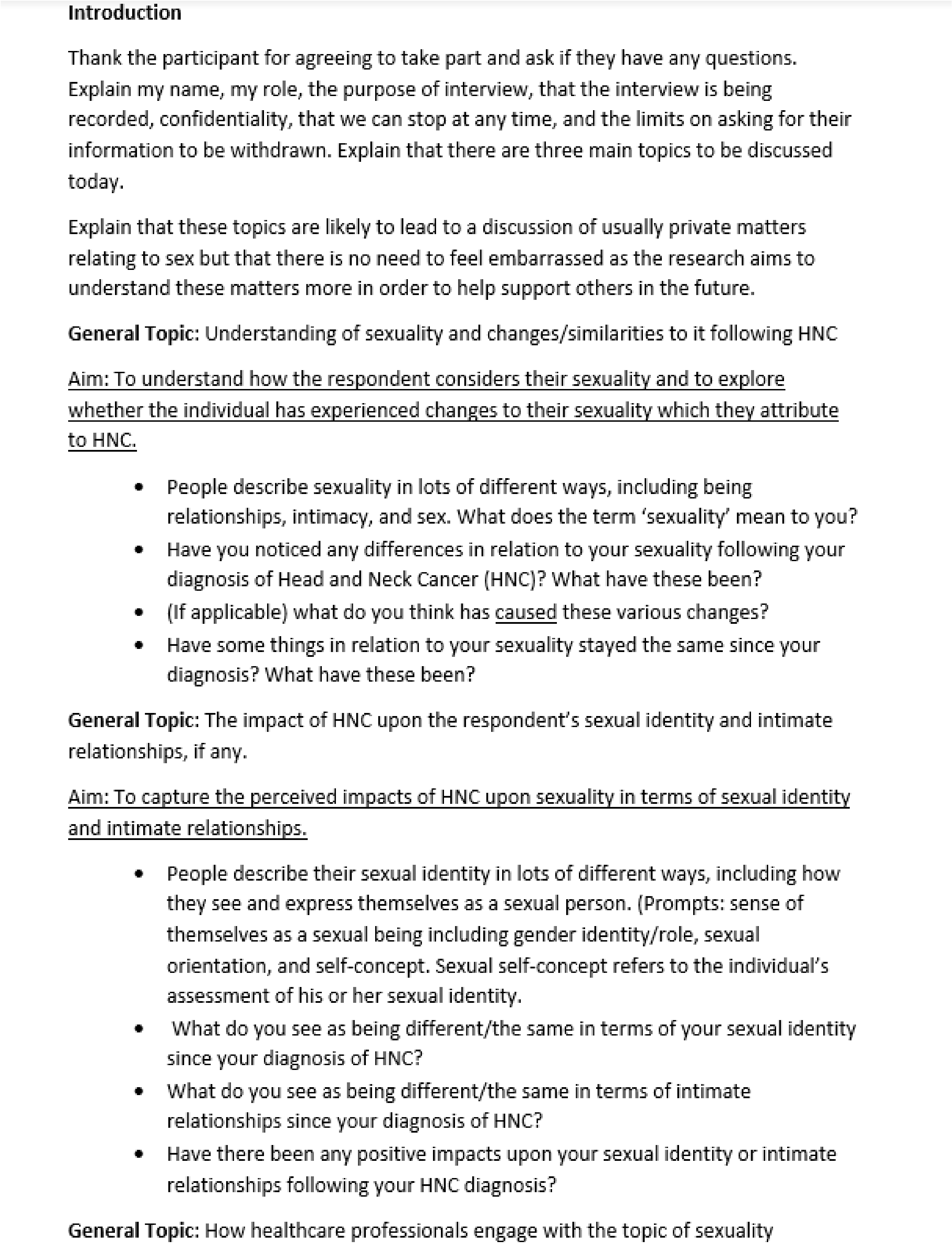
Macmillan Cancer Support (Cancer Support Charity) Helpline: 0808 808 00 00 (Every day 8am-8pm): https://www.macmillan.org.uk/

Maggie's Centre (Cancer Support Charity) Helpline: 0300 123 1801
Email: enquries@maggiescentres.org

Samaritans (24 hours a day): Helpline: 116 123 Email: jo@samaritans.org

Furthermore, you can share any difficulties you might be experiencing with one of your healthcare professionals, such as your GP.

Appendix P: Semi-Structured Interview Schedule



Introduction

Thank the participant for agreeing to take part and ask if they have any questions. Explain my name, my role, the purpose of interview, that the interview is being recorded, confidentiality, that we can stop at any time, and the limits on asking for their information to be withdrawn. Explain that there are three main topics to be discussed today.

Explain that these topics are likely to lead to a discussion of usually private matters relating to sex but that there is no need to feel embarrassed as the research aims to understand these matters more in order to help support others in the future.

General Topic: Understanding of sexuality and changes/similarities to it following HNC

Aim: To understand how the respondent considers their sexuality and to explore whether the individual has experienced changes to their sexuality which they attribute to HNC.

- People describe sexuality in lots of different ways, including being relationships, intimacy, and sex. What does the term 'sexuality' mean to you?
- Have you noticed any differences in relation to your sexuality following your diagnosis of Head and Neck Cancer (HNC)? What have these been?
- (If applicable) what do you think has caused these various changes?
- Have some things in relation to your sexuality stayed the same since your diagnosis? What have these been?

General Topic: The impact of HNC upon the respondent's sexual identity and intimate relationships, if any.

Aim: To capture the perceived impacts of HNC upon sexuality in terms of sexual identity and intimate relationships.

- People describe their sexual identity in lots of different ways, including how they see and express themselves as a sexual person. (Prompts: sense of themselves as a sexual being including gender identity/role, sexual orientation, and self-concept. Sexual self-concept refers to the individual's assessment of his or her sexual identity.
- What do you see as being different/the same in terms of your sexual identity since your diagnosis of HNC?
- What do you see as being different/the same in terms of intimate relationships since your diagnosis of HNC?
- Have there been any positive impacts upon your sexual identity or intimate relationships following your HNC diagnosis?

General Topic: How healthcare professionals engage with the topic of sexuality

Aim: To explore the respondent's experiences of discussing their sexuality with healthcare professionals for those with HNC with a view to identifying the clinical need for this population and any perceived barriers.

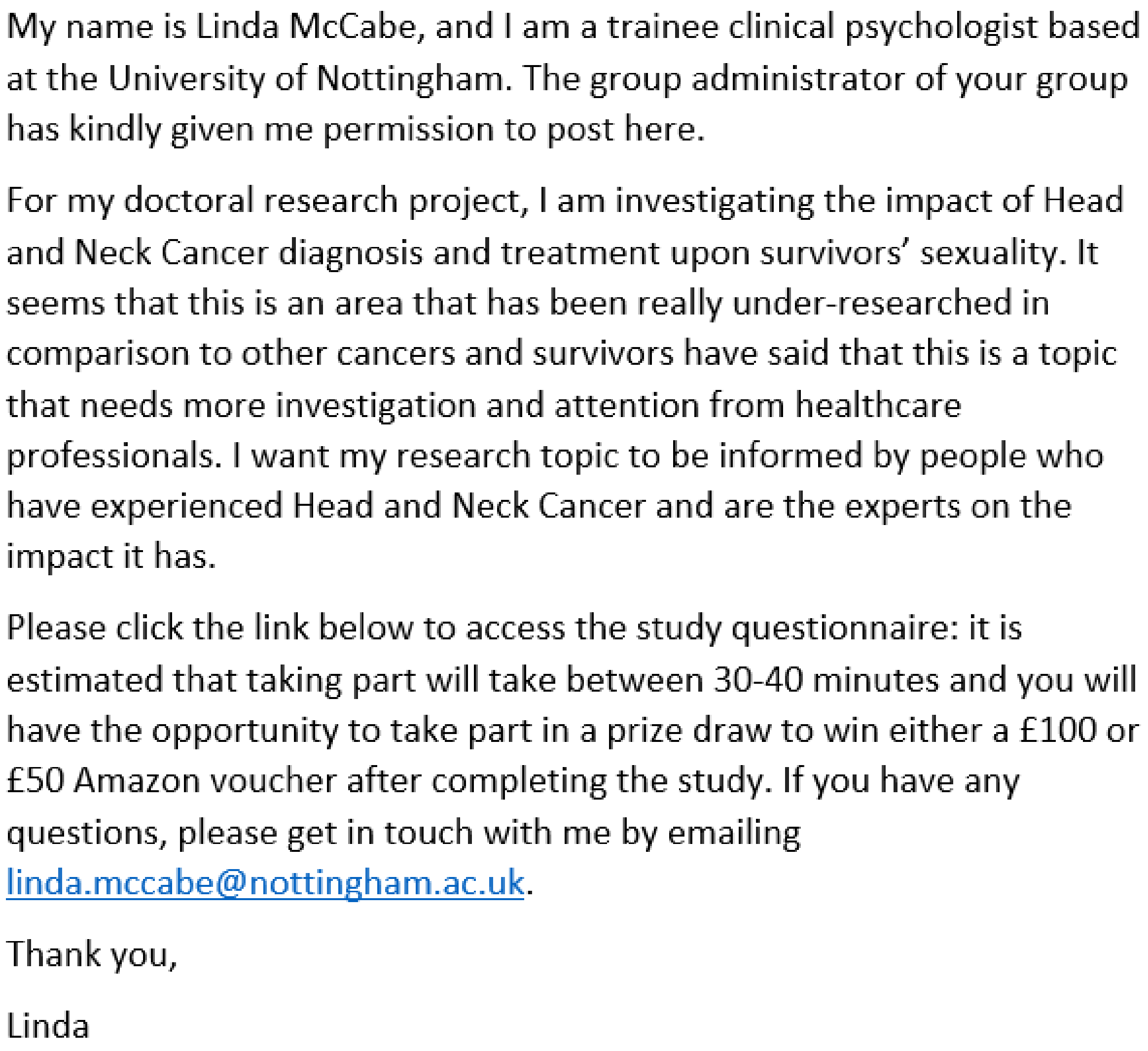
- Were you able to discuss your sexuality with healthcare professionals following your diagnosis of HNC?
- (If applicable) what was it like to have these discussions?
- How much information and support, if any, did you receive from healthcare professionals around sexuality following your diagnosis of HNC?
- What barriers, if any, did you experience in discussing issues relating to sexuality with healthcare professionals?
- Is there any information/support that it would it have been helpful to receive surrounding sexuality, following your diagnosis of HNC? Can you provide examples?
- (If applicable) what would you want in a pamphlet?

Prompts: Minimal encouragers (e.g. mm, mmhmm, OK). Can you give an example of that? Are you able to say more about that? How have you made sense of that? Anything else? Can you provide any more details about that?

Ending

Thank participant for taking part, explain that debriefing form will be emailed over to them, ask them if they have any further questions for me.

Appendix Q: Social Media Advert Text



My name is Linda McCabe, and I am a trainee clinical psychologist based at the University of Nottingham. The group administrator of your group has kindly given me permission to post here.

For my doctoral research project, I am investigating the impact of Head and Neck Cancer diagnosis and treatment upon survivors' sexuality. It seems that this is an area that has been really under-researched in comparison to other cancers and survivors have said that this is a topic that needs more investigation and attention from healthcare professionals. I want my research topic to be informed by people who have experienced Head and Neck Cancer and are the experts on the impact it has.

Please click the link below to access the study questionnaire: it is estimated that taking part will take between 30-40 minutes and you will have the opportunity to take part in a prize draw to win either a £100 or £50 Amazon voucher after completing the study. If you have any questions, please get in touch with me by emailing linda.mccabe@nottingham.ac.uk.

Thank you,

Linda

Appendix R: Study Recruitment Poster

Do you want to help develop understanding of the impact of Head and Neck Cancer upon Sexuality?

Chance to win £100 amazon Voucher

We're recruiting:

People with a diagnosis of Head and Neck Cancer

for a research study into the impact of Head and Cancer upon sexuality and intimacy, and ways of coping.

Part I: Anonymous Online Survey

Part II: Interviews

Most participants will only be required to complete the survey section.

For more information please follow the link to the survey https://unioflincoln.eu.qualtrics.com/jfe/form/SV_40VE7v6pb2anSC1 or contact the lead researcher:

Linda McCabe (linda.mccabe@nottingham.ac.uk)

University of Nottingham
UK | CHINA | MALAYSIA

UNIVERSITY OF LINCOLN

Appendix S: Qualitative Interview Data Initial Coding Example

R: Okay.

P: Yes, it is very, you know, I don't know, it like I say, it could be my age, but it just seems, you know, I was 37 when I was diagnosed. You know, that's still quite, that's still very young very, you know, to still be sexually active and then yeah it just goes. It just stops and you go, why? You know, I know at the time it was like I wanted to have sex with him, but I couldn't have sex with him because he wouldn't find me attractive. I don't find myself attractive, so how could he find me attractive? Alright, I remember going to my GP to get some cream to put on my neck to help with the scarring on my arm. And, and they’d taken skin off my stomach to replace on my arm sort of thing and I’d mentioned to him about having you know a

Sexual changes: age-related but unlikely
Diagnosed at age expect to be sexually active.

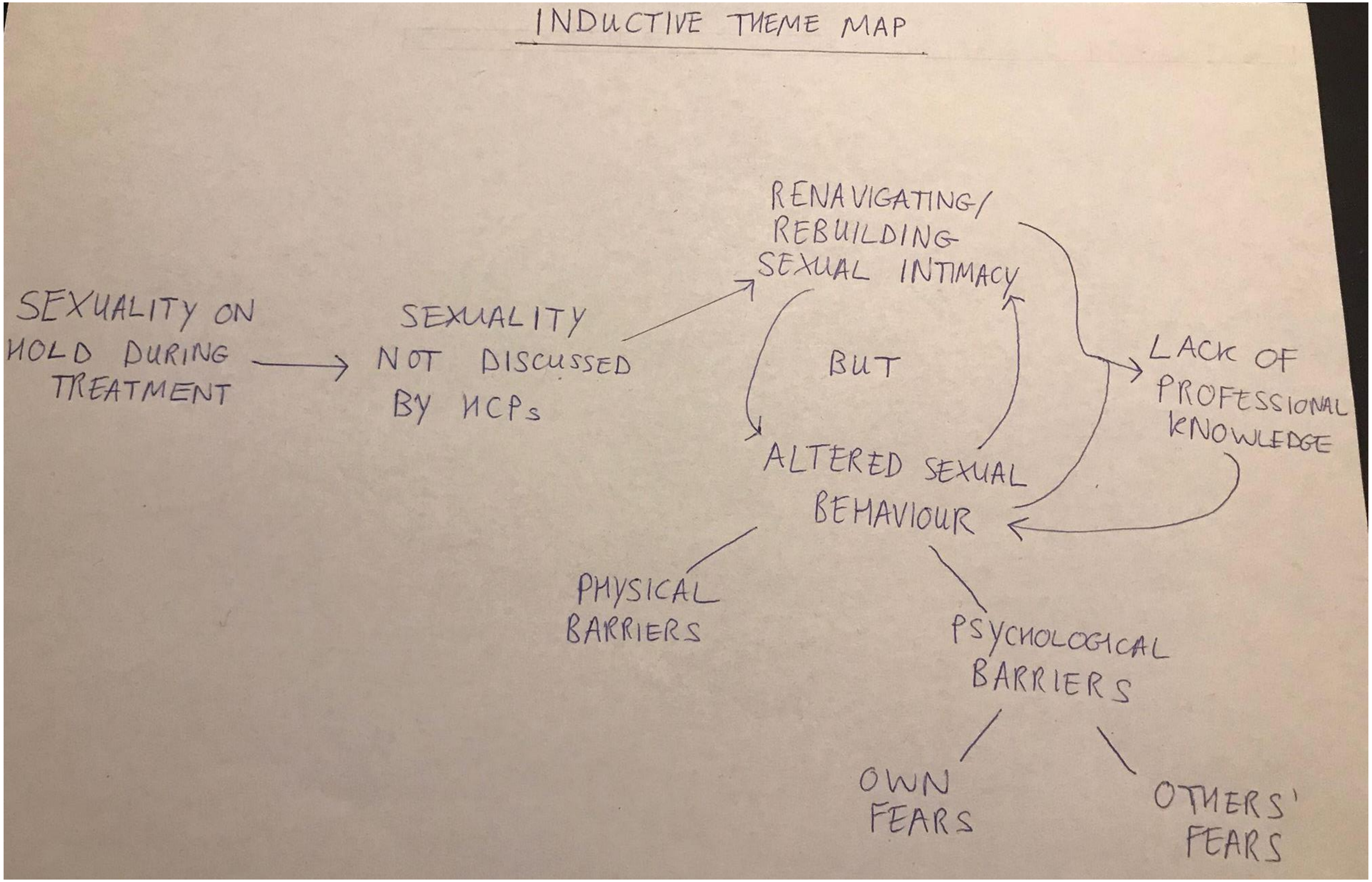
Sex life stopping: unsure why
Want to have sex but cannot
Sexual desire: still there
Believed partner would not be attracted.
Do not find self attractive

tummy tuck is, or maybe I would be so, and he went, you know what	
[partner’s name] loves you just the way you are. But I didn't feel that.	Reassurance of partner’s love ineffective.
How could he? You know I've got this thing in my mouth. I got this	Did not feel loveable
huge scar on my neck. I got this big scar on my arm and now my,	Surgical consequences: multiple physical changes
my tummy is being cut across and it yeah it's not a pretty sight.	Body image: not pretty sight
R: And you still feel that way, you still feel that it's not a pretty sight?	
P: Yeah, yeah.	
R: Okay, so yeah, no –	
P: The thing is I had, I mean we've got five children. They were all	
born by caesarean. So you know you've got those scars. And then	Previous scars: from caesarean births
after number 4 was born, I ended up having a hernia. So I've got	
another scar going down my tummy. And then I got this big scar	Perceived body image: not attractive
across where they took the skin from, so yeah, it's not so attractive.	Not all body image issues relate to cancer
R: So you've been through a lot, medically, haven't you? And that's	
left a lot of scars, leaving you feeling that you're not attractive, you	

don't see yourself as attractive and you don't see how your husband could see you as attractive too.	
P: Exactly, exactly.	
R: Also, what you said [participant’s name] about how kind of you don't masturbate anymore and I wondered what felt like maybe the barrier to doing that? Is it just a lack of desire like you said?	
P: Yeah, probably.	Barrier to masturbation: lack of desire
R: So just not having the urge or the instinct to?	
P: Yeah, it's just like give me Kindle, I’ll read my Kindle instead.	Would rather read than masturbate
R: Yeah, you’d just rather do something else.	
P: Yeah, yeah.	
R: And again, that sounds like a difference from before the cancer.	
P: Yeah, you see, we’re quite happy, [partner’s name] and I, we’re very happy with, with anything and you know, but yeah, it's, it is strange, it is very strange that it can just go completely.	Perception of relationship: happy Sex drive diminishing: strange Sex drive: completely gone

R: And would you say for you that that sex drive has gone	
completely?	
P: Yes and no because I know, I think yeah, I, you know, I build	Sex drive: Not completely gone
myself up to think, right, yeah we, we can have, you know we've got	
a couple of hours now and then it's just, I don't look in the mirror	Sex: Possible without looking in mirror
anymore at myself. So I don't see what I look like and then if I just	
catch a glimpse, it’s like, no, that's not happening then. You know, or	Sex: won’t happen if sees herself
if we were to be intimate, it would be a case of it's gonna be dark,	Sexual intimacy: needs lights off
you know, lights off. This, I don’t really want him to see, you know,	Partner seeing her: not wanted
how my, you know, how I look, and I know, I guess, that's in my	Fears around partner’s opinion: in own head
head because [partner’s name] is forever saying, you know, you	
look beautiful or you, you know I love you and you’re beautiful, but in	Partner: offers frequent affirmation
my head, well, he's only just saying that, but I know he's not. It's, it's	Partner’s affirmation: fears not true
very, it's very strange.	

Appendix T: Initial Inductive Map



Appendix U: Inductive theme development and application of Deductive Coding Framework

Relevant Transcript Excerpt	Initial Code	Deductive Coding Framework
Um, it just, it just didn't form part of my natural mind to go, right, today I'll do some nice things with my make-up, I'll do hair, I'll put some underwear on, I'll go and seduce my husband, we'll have a nice sex… that sort of stuff, it, it just didn't cross my mind. My mind just became focussed on, I have a thing in my mouth, I don't want it there, let's focus on getting as strong as I can to get through surgery, to get through treatment, to get to the next stage and everything became about rest and one day at a time rather than what I can do with my husband.	Being sexual: didn't cross mind Mind focussed on having thing in mouth Focus: get through this as strong as possible to surgery What can I do with husband: not considered	5 7 5
The main treatment I had was radiotherapy. And although very precisely targeted, I'm learning a lot more about this, it still does disrupt the soft tissue around the site which meant that really from the end of the first week, I was having terrible sore throats, literally burning, like sunburn on both the outside		

and the inside, and the inside of my cheeks, all that. This leads to a huge drop-off in the volume of saliva that's produced, which again, is quite important in a sex life.	Drop-off in saliva volume: important in a sex life	3
Um, and that leads to thrush and other really nasty mouth conditions. There's one which is called black fur – you can probably guess what that's like. And that coats your tongue, it coats your tongue. And it pulls off in strips – it really is quite a nasty thing.	Treatment sequelae: Thrush in mouth	3
And all this coming together, I don't think we were intimate, to use the euphemism, for the whole of my treatment which was six weeks, um,	Sex during treatment: did not happen	10
and probably not from diagnosis to way beyond the end of the treatment so that would be a time of probably 4 months?	Sexual intimacy: did not happen for 4 months	
I mean the only real disruption [to sex life] would have been for the 10 days or so after the surgery where I was not in a fun place and lots of painkillers.	Disruption to sex life: immediately post-surgery	
So therefore that leads into, that has led into problems within sex and within what I am physically capable of doing. I think particularly through my treatment, I mean, it is not a sexy treatment so there is no desire whatsoever	Treatment: not sexy Treatment: no desire there	1 10

there, and I found it very difficult when I was having my treatment that my partner, I find it very difficult that she would still find me attractive because to be blunt, she cleaned up my shit, and I think that's probably too blunt. How, you know, how can you do, how do you do that? She was, essentially became my carer, and found that very difficult during that. And then I think particularly after as I was recovering from the treatment, then I found it very difficult. I also had a feeding tube, a stomach feeding tube and that when you – it was fine, but it's not attractive is it, that's not sexy, this big, massive tube sticking out and, and then I think, I struggled confidence wise with that.	During treatment: did not believe partner could find me attractive Partner: she became my carer Partner being carer: very difficult Feeding tube: not attractive/sexy Feeding tube: struggled confidence-wise	1 1 1 1 1
I mean obviously immediately after the operation, I mean, you're not going to want to do it anyway and you've got, you know, you've still got stitches in and dressings and whatever, and it's a little bit, that's off-putting, um, but that's immediately after your operation, you know, after you come out of hospital. But after a while, it's fine.	Sex immediately post-treatment: wouldn't want to Having stitches and dressings: bit off-putting Sex a while after surgery: fine	

I could communicate but not in the same way, no. I was, I was covered in pipes and, and you know drains and stuff in various bits of me which I would prefer not to have been, you know, but that was the way it was. The idea of having sex was in my head because it's never out of my head but it was not a priority. My priority was to get walking, get thinking, getting talking.	During treatment: covered in pipes and drains Idea of having sex: in head but not priority Priority: walking, thinking, talking	10
It's a lot to take in really and if they start telling you things that it's going to affect your sexuality as well. I mean, most people, particularly if they've had it diagnosed late just want to stay alive. And I don't think that is at the top of their minds really because they don't know how they're going to feel afterwards.	Receiving sexuality information: just want to live Sexuality: not at top of their minds Sexuality: don't know how you'll feel afterwards	7
The saliva was horrible and made me feel unattractive. I would drink from like a pint glass or something, I would leave like a splodge on it. There's something about having saliva that allows you to not leave like debris, and eating was part of my – and drinking – always having a water bottle with me but yeah, saliva is, boy, I realised how important it is. And, so, yeah, I was worried about my breath and early in treatment I'd had some sores in my	Saliva: made me feel unattractive Always needed water bottle with me Concerns about breath Treatment sequelae: radiation-related sores	1

mouth that were related to radiation and chemo so yeah, that made me feel like completely unattractive, and during that time I didn’t even consider having sex or anything, I just felt like, at least as a partner I felt, non-sexual.	Chemotherapy: felt completely unattractive Sex during treatment: did not even consider Sexual identity during treatment: felt non-sexual	**1** **1**
And then you know, obviously after surgery it was very much, it's not going to happen, you know, give me time. I need time, you know just to cuddle was nice.	Post-surgery: not going to happen Post-surgery: need time Post-surgery: cuddling nice	**2** **2**
I think, initially there was very little impact at first. I think the impact came later on. I think definitely during my treatment, especially when the lump got significantly larger, I spent a lot of time covering up, I was really self-conscious. I've always been self-conscious but never to that effect. I found that I wasn't particularly interested in sex drive during the treatment part, I absolutely got it, I understood why, but during my treatment, absolutely, my sex drive just dried up, wasn't interested. Actually because obviously I wanted to sleep and I wanted to recover, etc.	Impact on sexuality: very little impact at first Impact on sexuality: came during treatment Growing lump: self-conscious and covered up Sex drive during treatment: not interested	**1** **7**

	Reduced sex drive during treatment: understood My sex drive: dried up Treatment priorities: sleeping and recovering	
So, so yeah, so obviously with treatment and everything else that had a massive effect because I was too poorly to think of anything you know. Um, sex was the last thing on my mind, you know, really, and I'd also had a stomach tube to feed so, yeah, there was all them kind of things, I got down to 10 stone 4lbs. So I mean I look skinny now but I'm 12 stone now and you know, I was 10st 4lbs so from that, from an actual physical point of view, there's not a chance I could, and it was the best part of a year until we could, so it had a big, big effect	Cancer treatment: had massive effect Cancer treatment: very poorly Sex during treatment: last thing on my mind Weight loss during treatment: lost 5 stone Sex during treatment: physically unable Sex during treatment: no sex for a year Impact of treatment on sexuality: big effect	**10** **1**
You lose your libido when you have the operation because you feel different.	Post-surgical consequences: lose libido	**1, 3**
At 80 years old being given the diagnosis my first thought was not there goes my sexuality/sex life.	First diagnosed: first thought not about sex life	

Obviously I got the cancer treatment, obviously when I did first start treatment, we didn’t have sex. Obviously when we went for treatment for chemo and radiotherapy as well, then obviously that just killed everything, you know, there was no sex there. And that was fine at the beginning,

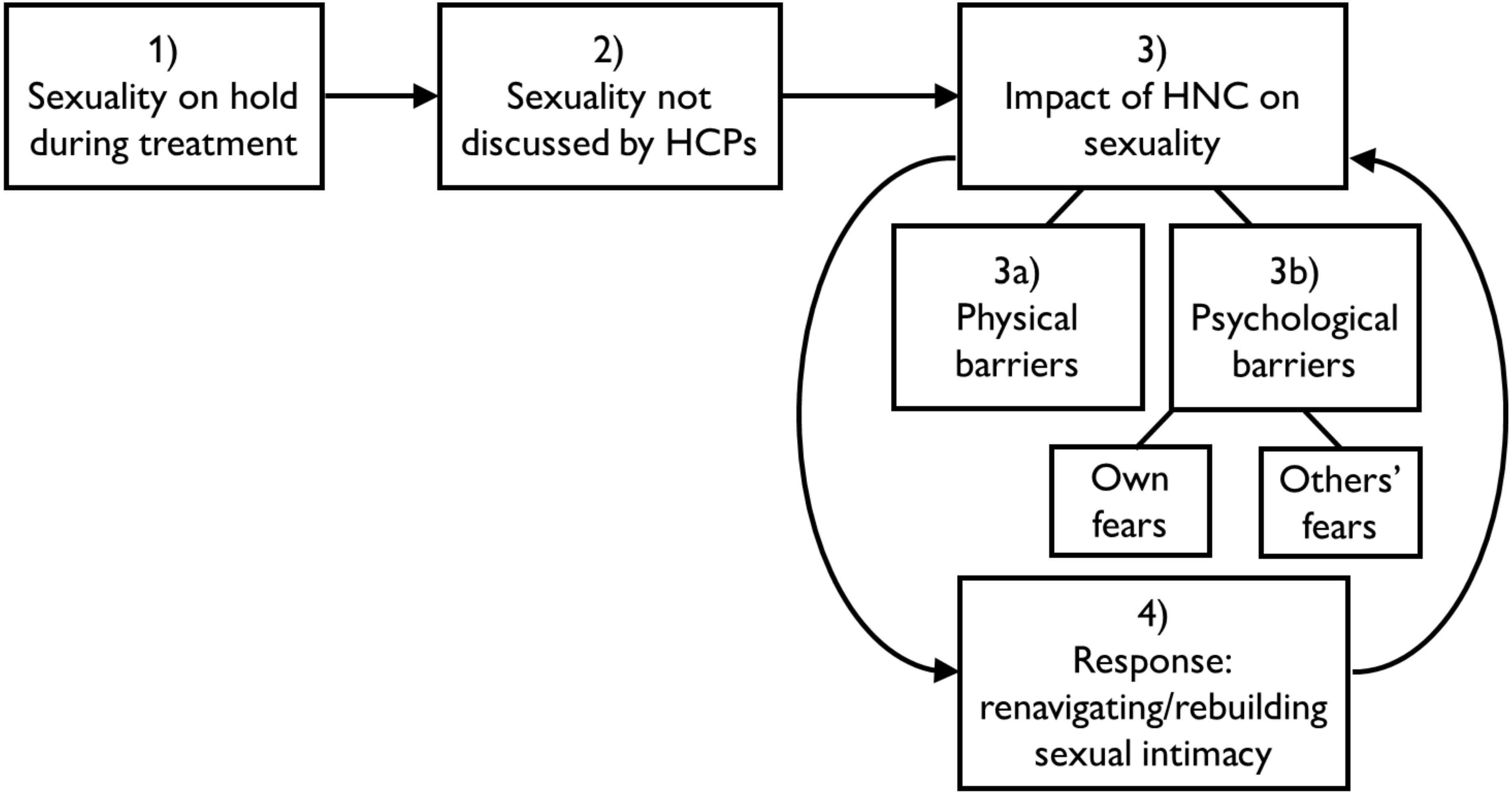
Sex during treatment: didn’t have sex
Chemo and radiotherapy: killed everything 1
Chemo and radiotherapy: no sex
No sex during treatment: fine at beginning

But in terms of the sexuality side, no, not, it probably was the last thing on my mind that was the concern at that time. It wasn't, wasn't something I gave much thought to in, in anticipation of it changing or it, it going up or down. It was all about my treatment and I weren’t in a good place, I was in a bubble and it wasn't a great place through treatment and that was the last thing on either of our minds, it was about fighting the cancer and getting through the cancer.

Sexuality during treatment: last thing on my mind
Sexuality: something I gave little thought to
During treatment: was all about my treatment 7
During treatment: wasn’t in great place
Sexuality during treatment: last thing on our minds 7
During treatment: about fighting and getting through the cancer.

Full sex with a naso-gastro tube in probably isn’t going to happen anyway, if that had been removed, I then had what they call a pack, so a pack over the right hand side of my gum that was made out of my leg and it means you were only allowed to have water, then I thought, and even now I’ve said, I don’t know how we, what we do about that because the worry is around infection and given that I’d had this horrendous infection, and that put paid to sex for a long time as well.	Full sex with naso-gastro tube: not going to happen After tube removed: had pack in gum Could only drink water Questions about oral sex to this day: worry about infection Infection during treatment: put paid to sex for long time	**1, 3**

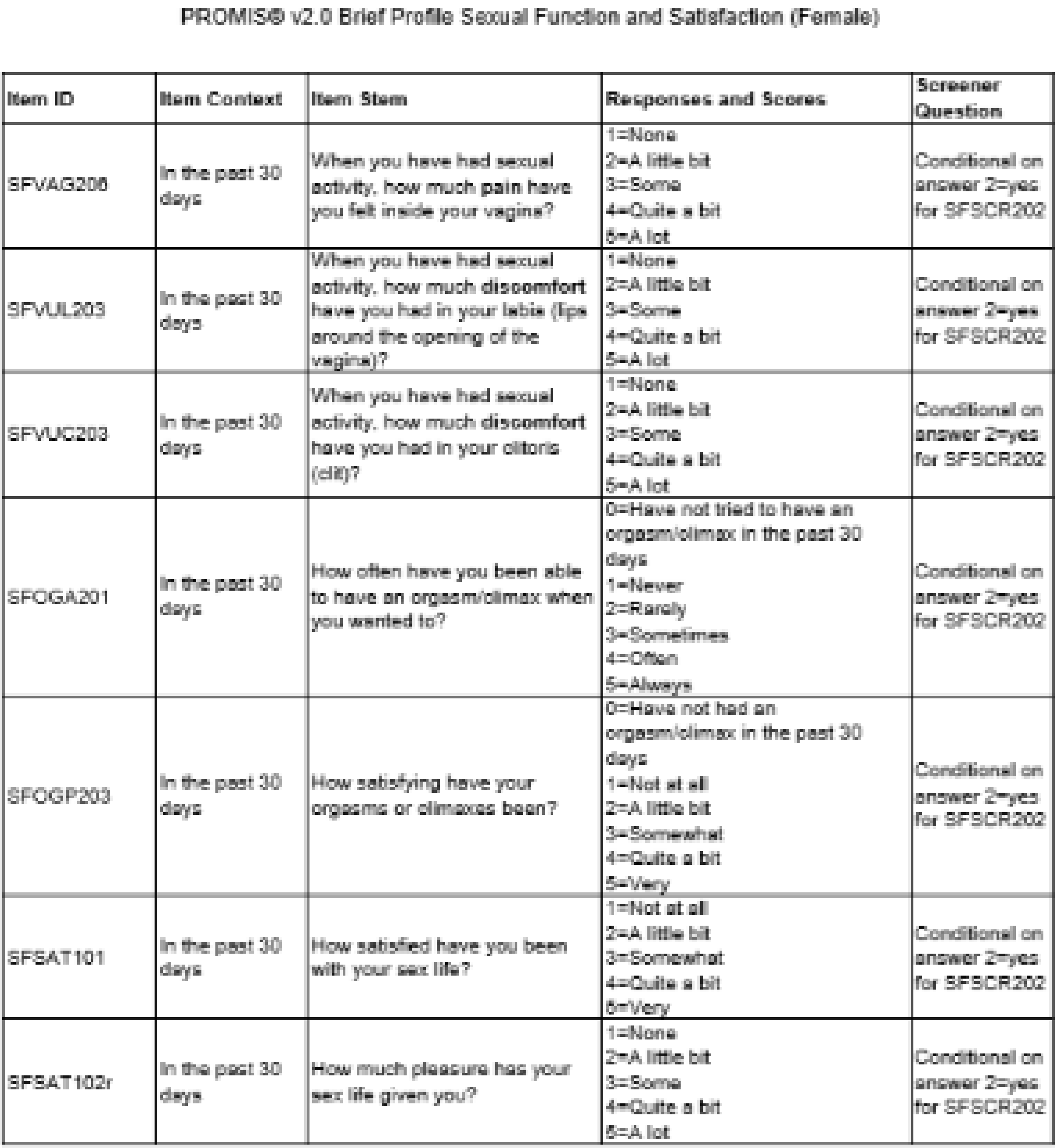
Appendix V: Revised Inductive Theme Map



Appendix W: PROMIS SexFS Questionnaire (Brief Profile)

PROMIS® v2.0 Brief Profile Sexual Function and Satisfaction (Female)

Brief Profile Sexual Function and Satisfaction (Female)				
Item ID	**Item Context**	**Item Stem**	**Responses and Scores**	**Screener Question**
SFINT101	In the past 30 days	How interested have you been in sexual activity?	1=Not at all 2=A little bit 3=Somewhat 4=Quite a bit 5=Very	
SFINT201	In the past 30 days	How often have you felt like you wanted to have sexual activity?	1=Never 2=Rarely 3=Sometimes 4=Often 5=Always	
SFSCR202	In the past 30 days	Did you have any type of sexual activity? (Examples of sexual activity are masturbation, oral sex, and sexual intercourse.)	1=No 2=Yes	
SFSCR204bpf		There are many reasons why people may not have had sexual activity during the month. What are the reasons why you did not have sexual activity in the past 30 days? Please read the list carefully and check every reason that applies to you, even if it happened only one time during the past 30 days.	1=Was not interested in having sexual activity 2=Dryness or pain in or around my vagina 3=Difficulties with orgasm/climax 4=Don't enjoy sexual activity 5=Health condition 6=No partner 7=Partner was away 8=Partner was not interested in sexual activity 9=Partner's health condition 10=Some other reason (Specify) ________	Conditional on answer 1=no for SFSCR202 - no activity
SFLUB001r	In the past 30 days	How **often** did you become lubricated ("wet") during sexual activity or intercourse?	5 = Almost always or always 4 = Most times (more than half the time) 3 = Sometimes (about half the time) 2 = A few times (less than half the time) 1 = Almost never or never	Conditional on answer 2=yes for SFSCR202
SFLUB004r	In the past 30 days	How **difficult** was it to maintain your lubrication ("wetness") until completion of sexual activity or intercourse?	1 = Extremely difficult or impossible 2 = Very difficult 3 = Difficult 4 = Slightly difficult 5 = Not difficult	Conditional on answer 2=yes for SFSCR202
SFVAG202	In the past 30 days	When you have had sexual activity, how much **discomfort** have you felt inside your vagina?	1=None 2=A little bit 3=Some 4=Quite a bit 5=A lot	Conditional on answer 2=yes for SFSCR202

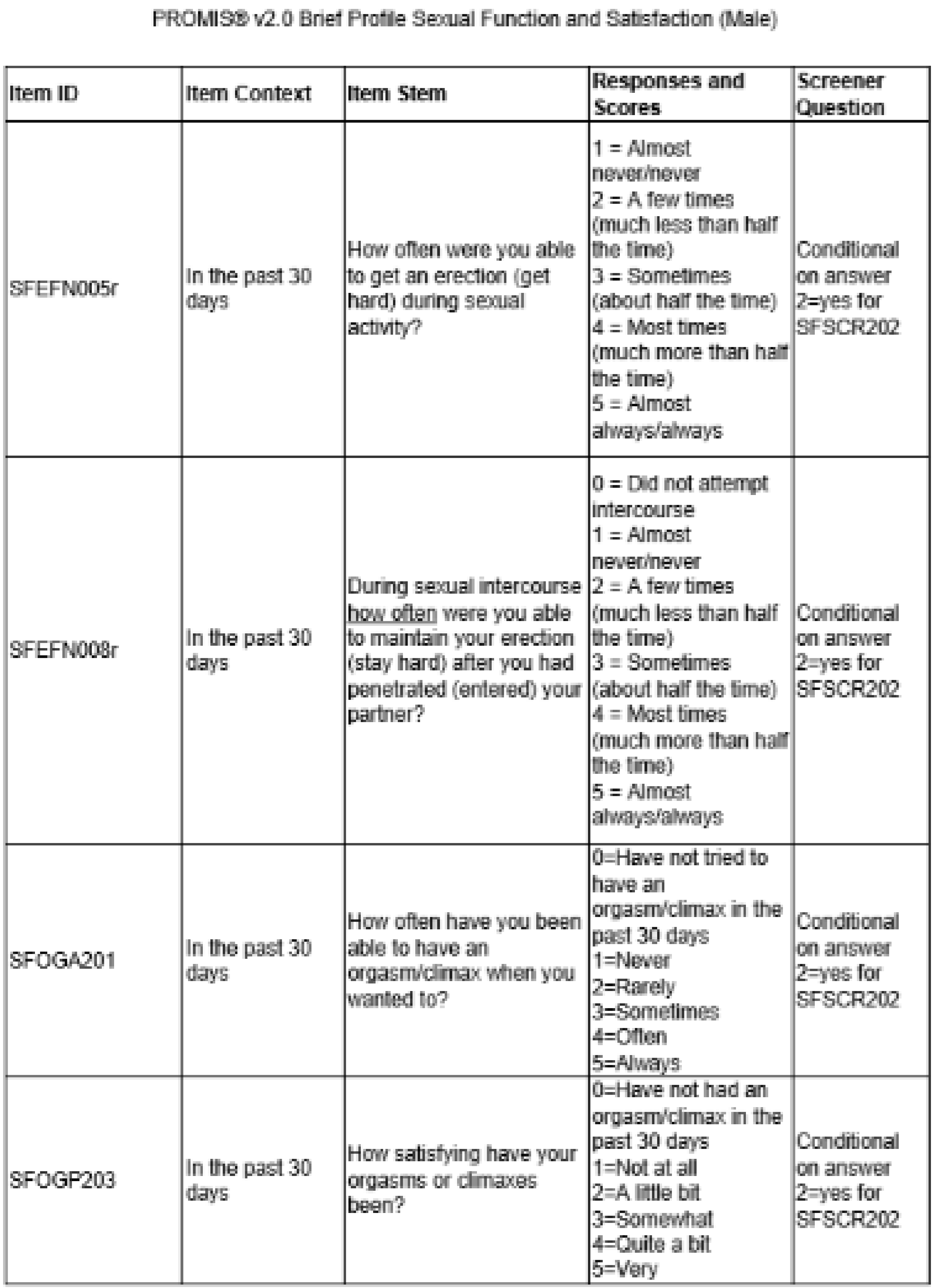


PROMIS® v2.0 Brief Profile Sexual Function and Satisfaction (Female)

Item ID	Item Context	Item Stem	Responses and Scores	Screener Question
SFVAG206	In the past 30 days	When you have had sexual activity, how much **pain** have you felt inside your vagina?	1=None 2=A little bit 3=Some 4=Quite a bit 5=A lot	Conditional on answer 2=yes for SFSCR202
SFVUL203	In the past 30 days	When you have had sexual activity, how much **discomfort** have you had in your labia (lips around the opening of the vagina)?	1=None 2=A little bit 3=Some 4=Quite a bit 5=A lot	Conditional on answer 2=yes for SFSCR202
SFVUC203	In the past 30 days	When you have had sexual activity, how much **discomfort** have you had in your clitoris (clit)?	1=None 2=A little bit 3=Some 4=Quite a bit 5=A lot	Conditional on answer 2=yes for SFSCR202
SFOGA201	In the past 30 days	How often have you been able to have an orgasm/climax when you wanted to?	0=Have not tried to have an orgasm/climax in the past 30 days 1=Never 2=Rarely 3=Sometimes 4=Often 5=Always	Conditional on answer 2=yes for SFSCR202
SFOGP203	In the past 30 days	How satisfying have your orgasms or climaxes been?	0=Have not had an orgasm/climax in the past 30 days 1=Not at all 2=A little bit 3=Somewhat 4=Quite a bit 5=Very	Conditional on answer 2=yes for SFSCR202
SFSAT101	In the past 30 days	How satisfied have you been with your sex life?	1=Not at all 2=A little bit 3=Somewhat 4=Quite a bit 5=Very	Conditional on answer 2=yes for SFSCR202
SFSAT102r	In the past 30 days	How much pleasure has your sex life given you?	1=None 2=A little bit 3=Some 4=Quite a bit 5=A lot	Conditional on answer 2=yes for SFSCR202

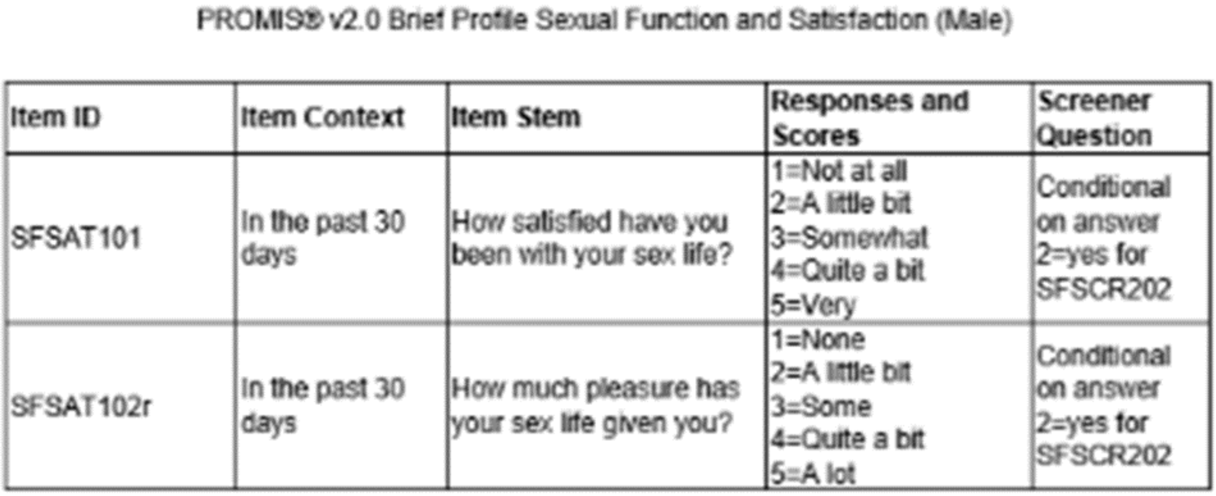
PROMIS® v2.0 Brief Profile Sexual Function and Satisfaction (Male)

Brief Profile Sexual Function and Satisfaction (Male)				
Item ID	**Item Context**	**Item Stem**	**Responses and Scores**	**Screener Question**
SFINT101	In the past 30 days	How interested have you been in sexual activity?	1=Not at all 2=A little bit 3=Somewhat 4=Quite a bit 5=Very	
SFINT201	In the past 30 days	How often have you felt like you wanted to have sexual activity?	1=Never 2=Rarely 3=Sometimes 4=Often 5=Always	
SFSCR202	In the past 30 days	Did you have any type of sexual activity? (Examples of sexual activity are masturbation, oral sex, and sexual intercourse.)	1=No 2=Yes	
SFSCR204bpm		There are many reasons why people may not have had sexual activity during the month. What are the reasons why you did not have sexual activity in the past 30 days? Please read the list carefully and check every reason that applies to you, even if it happened only one time during the past 30 days.	1=Was not interested in having sexual activity 2=Difficulties with my erections (penis not hard or is painful) 3=Difficulties with orgasm/climax 4=Don't enjoy sexual activity 5=Health condition 6=No partner 7=Partner was away 8=Partner was not interested in sexual activity 9=Partner's health condition 10=Some other reason (Specify) ________	Conditional on answer 1=no for SFSCR202 - no activity



PROMIS® v2.0 Brief Profile Sexual Function and Satisfaction (Male)

Item ID	**Item Context**	**Item Stem**	**Responses and Scores**	**Screener Question**
SFEFN005r	In the past 30 days	How often were you able to get an erection (get hard) during sexual activity?	1 = Almost never/never 2 = A few times (much less than half the time) 3 = Sometimes (about half the time) 4 = Most times (much more than half the time) 5 = Almost always/always	Conditional on answer 2=yes for SFSCR202
SFEFN008r	In the past 30 days	During sexual intercourse how often were you able to maintain your erection (stay hard) after you had penetrated (entered) your partner?	0 = Did not attempt intercourse 1 = Almost never/never 2 = A few times (much less than half the time) 3 = Sometimes (about half the time) 4 = Most times (much more than half the time) 5 = Almost always/always	Conditional on answer 2=yes for SFSCR202
SFOGA201	In the past 30 days	How often have you been able to have an orgasm/climax when you wanted to?	0=Have not tried to have an orgasm/climax in the past 30 days 1=Never 2=Rarely 3=Sometimes 4=Often 5=Always	Conditional on answer 2=yes for SFSCR202
SFOGP203	In the past 30 days	How satisfying have your orgasms or climaxes been?	0=Have not had an orgasm/climax in the past 30 days 1=Not at all 2=A little bit 3=Somewhat 4=Quite a bit 5=Very	Conditional on answer 2=yes for SFSCR202

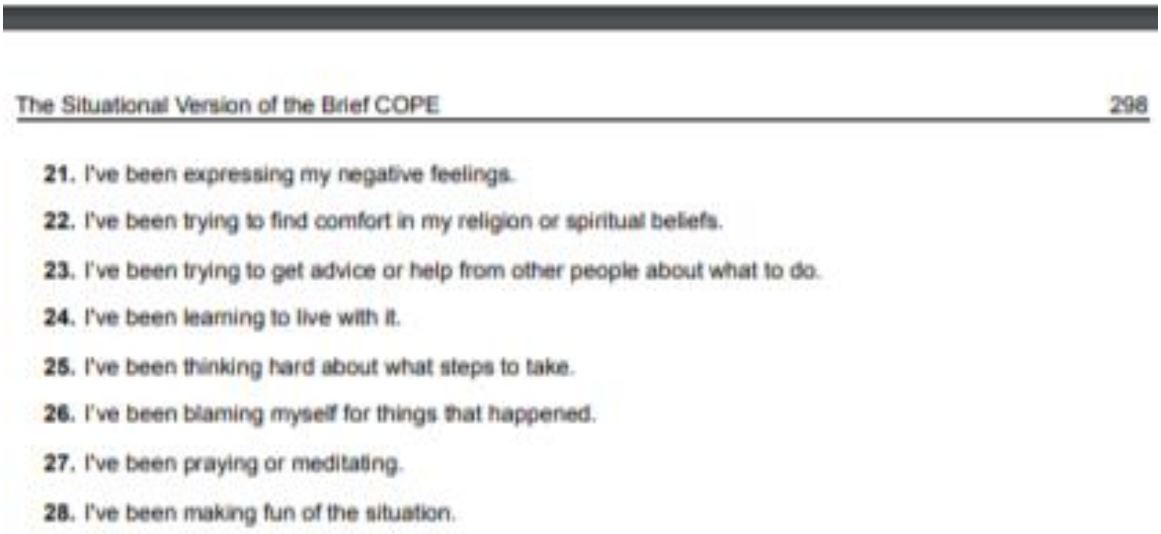


PROMIS® v2.0 Brief Profile Sexual Function and Satisfaction (Male)

Item ID	Item Context	Item Stem	Responses and Scores	Screener Question
SFSAT101	In the past 30 days	How satisfied have you been with your sex life?	1=Not at all 2=A little bit 3=Somewhat 4=Quite a bit 5=Very	Conditional on answer 2=yes for SFSCR202
SFSAT102r	In the past 30 days	How much pleasure has your sex life given you?	1=None 2=A little bit 3=Some 4=Quite a bit 5=A lot	Conditional on answer 2=yes for SFSCR202

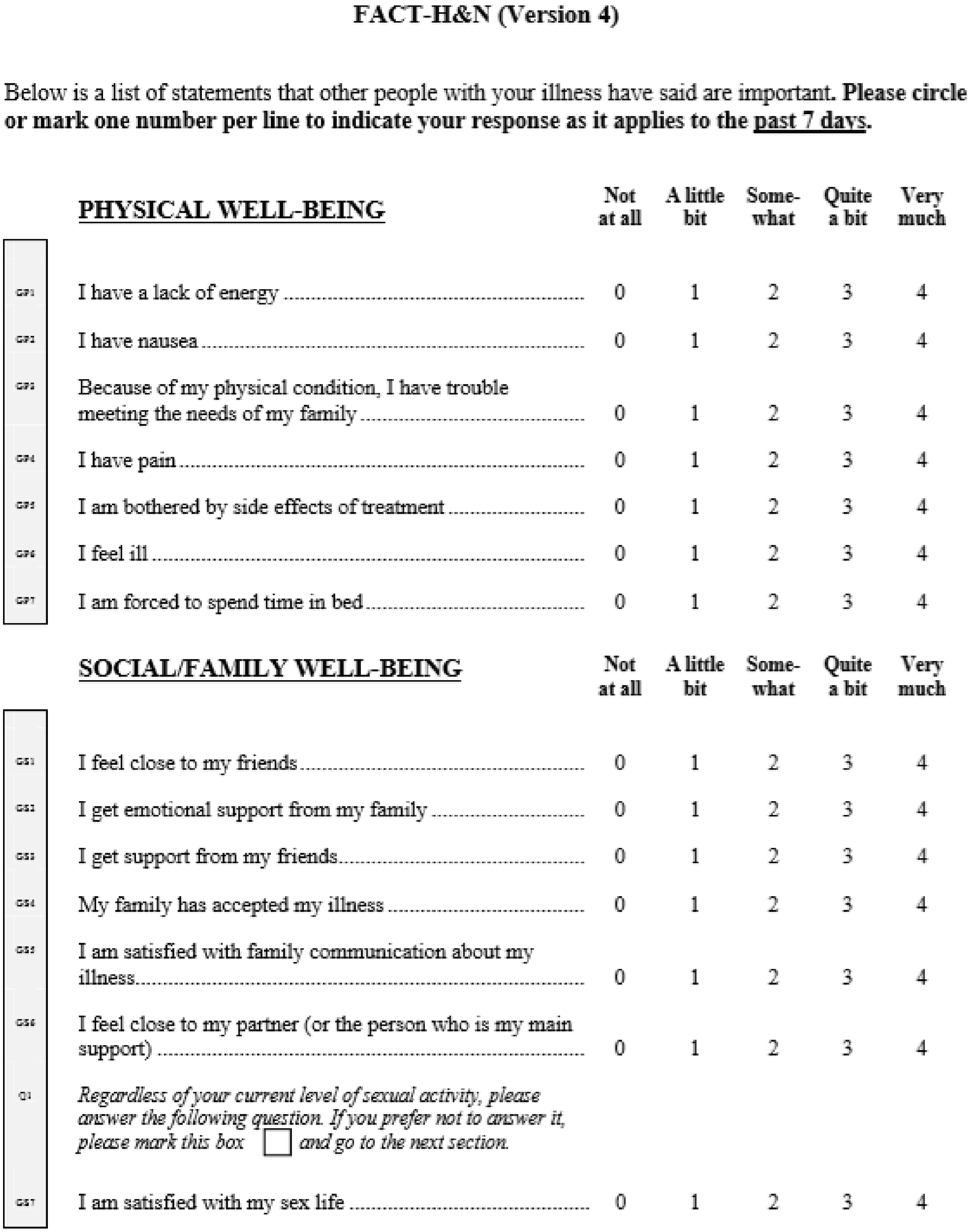
Appendix X: Brief COPE Questionnaire

1. I've been turning to work or other activities to take my mind off things.
2. I've been concentrating my efforts on doing something about the situation I'm in.
3. I've been saying to myself "this isn't real".
4. I've been using alcohol or other drugs to make myself feel better.
5. I've been getting emotional support from others.
6. I've been giving up trying to deal with it.
7. I've been taking action to try to make the situation better.
8. I've been refusing to believe that it has happened.
9. I've been saying things to let my unpleasant feelings escape.
10. I've been getting help and advice from other people.
11. I've been using alcohol or other drugs to help me get through it.
12. I've been trying to see it in a different light, to make it seem more positive.
13. I've been criticizing myself.
14. I've been trying to come up with a strategy about what to do.
15. I've been getting comfort and understanding from someone.
16. I've been giving up the attempt to cope.
17. I've been looking for something good in what is happening.
18. I've been making jokes about it.
19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.
20. I've been accepting the reality of the fact that it has happened.



21. I've been expressing my negative feelings.
22. I've been trying to find comfort in my religion or spiritual beliefs.
23. I've been trying to get advice or help from other people about what to do.
24. I've been learning to live with it.
25. I've been thinking hard about what steps to take.
26. I've been blaming myself for things that happened.
27. I've been praying or meditating.
28. I've been making fun of the situation.

Appendix Y: FACT-H&N (Version 4) Questionnaire



FACT-H&N (Version 4)

Below is a list of statements that other people with your illness have said are important. **Please circle or mark one number per line to indicate your response as it applies to the past 7 days.**

	PHYSICAL WELL-BEING	**Not at all**	**A little bit**	**Somewhat**	**Quite a bit**	**Very much**
GP1	I have a lack of energy	0	1	2	3	4
GP2	I have nausea	0	1	2	3	4
GP3	Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
GP4	I have pain	0	1	2	3	4
GP5	I am bothered by side effects of treatment	0	1	2	3	4
GP6	I feel ill	0	1	2	3	4
GP7	I am forced to spend time in bed	0	1	2	3	4

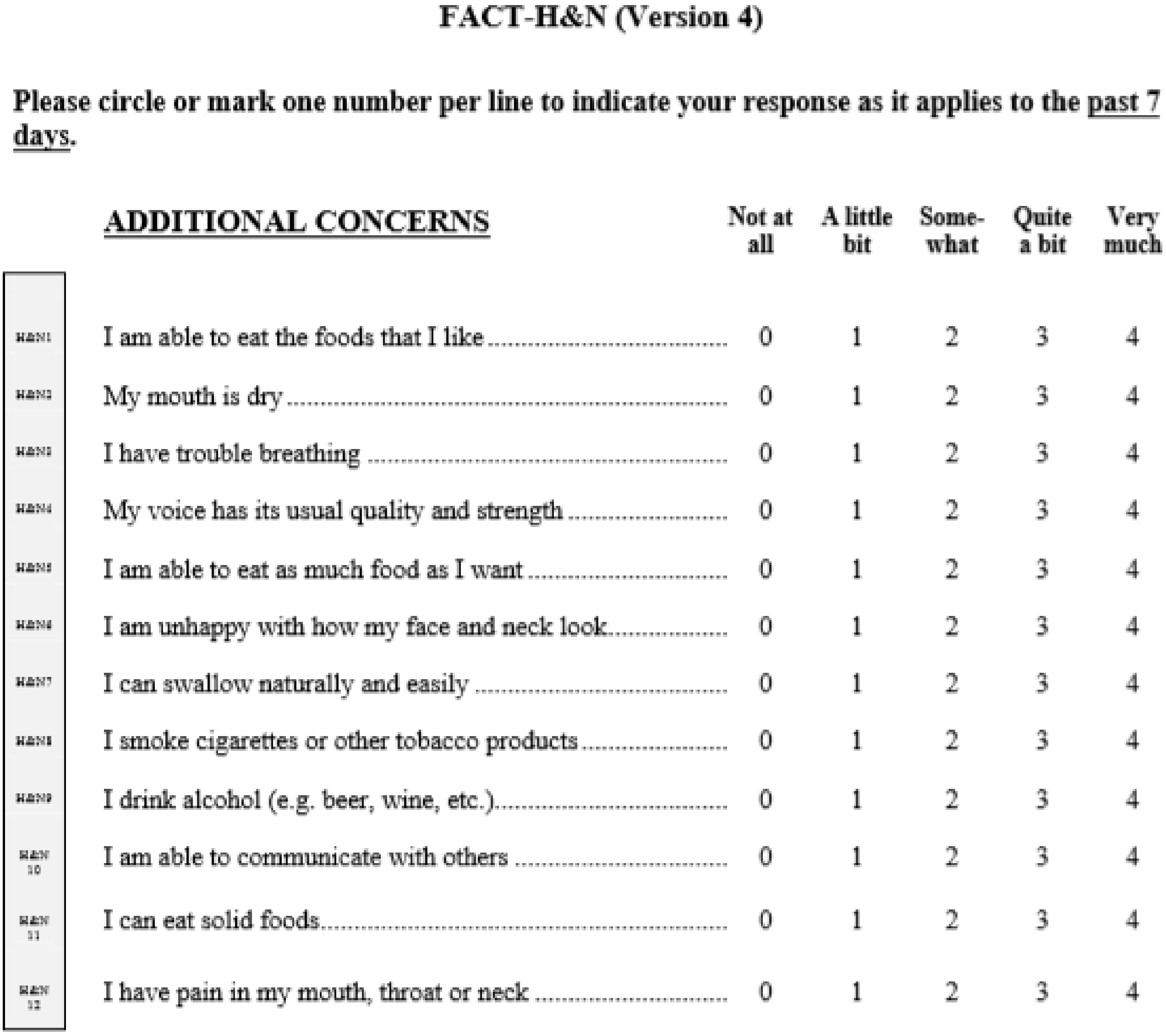
	SOCIAL/FAMILY WELL-BEING	**Not at all**	**A little bit**	**Somewhat**	**Quite a bit**	**Very much**
GS1	I feel close to my friends	0	1	2	3	4
GS2	I get emotional support from my family	0	1	2	3	4
GS3	I get support from my friends	0	1	2	3	4
GS4	My family has accepted my illness	0	1	2	3	4
GS5	I am satisfied with family communication about my illness	0	1	2	3	4
GS6	I feel close to my partner (or the person who is my main support)	0	1	2	3	4
Q1	*Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box* ☐ *and go to the next section.*					
GS7	I am satisfied with my sex life	0	1	2	3	4

FACT-H&N (Version 4)

Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

	EMOTIONAL WELL-BEING	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GE1	I feel sad	0	1	2	3	4
GE2	I am satisfied with how I am coping with my illness	0	1	2	3	4
GE3	I am losing hope in the fight against my illness	0	1	2	3	4
GE4	I feel nervous	0	1	2	3	4
GE5	I worry about dying	0	1	2	3	4
GE6	I worry that my condition will get worse	0	1	2	3	4

	FUNCTIONAL WELL-BEING	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GF1	I am able to work (include work at home)	0	1	2	3	4
GF2	My work (include work at home) is fulfilling	0	1	2	3	4
GF3	I am able to enjoy life	0	1	2	3	4
GF4	I have accepted my illness	0	1	2	3	4
GF5	I am sleeping well	0	1	2	3	4
GF6	I am enjoying the things I usually do for fun	0	1	2	3	4
GF7	I am content with the quality of my life right now	0	1	2	3	4

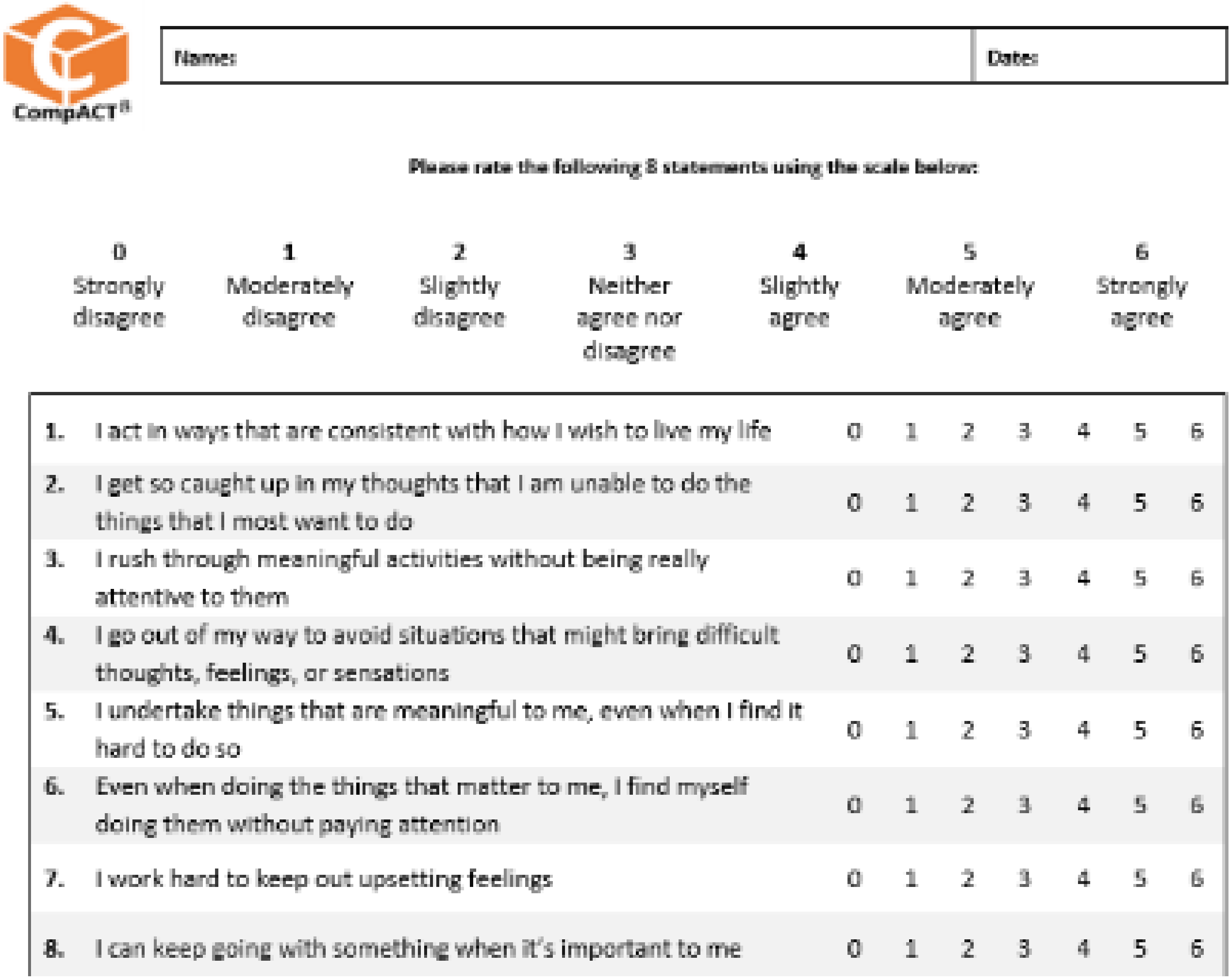


FACT-H&N (Version 4)

Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

	ADDITIONAL CONCERNS	Not at all	A little bit	Some-what	Quite a bit	Very much
H&N1	I am able to eat the foods that I like	0	1	2	3	4
H&N2	My mouth is dry	0	1	2	3	4
H&N3	I have trouble breathing	0	1	2	3	4
H&N4	My voice has its usual quality and strength	0	1	2	3	4
H&N5	I am able to eat as much food as I want	0	1	2	3	4
H&N6	I am unhappy with how my face and neck look	0	1	2	3	4
H&N7	I can swallow naturally and easily	0	1	2	3	4
H&N8	I smoke cigarettes or other tobacco products	0	1	2	3	4
H&N9	I drink alcohol (e.g. beer, wine, etc.)	0	1	2	3	4
H&N 10	I am able to communicate with others	0	1	2	3	4
H&N 11	I can eat solid foods	0	1	2	3	4
H&N 12	I have pain in my mouth, throat or neck	0	1	2	3	4

Appendix Z: CompACT-8 Questionnaire



CompACT^{8}

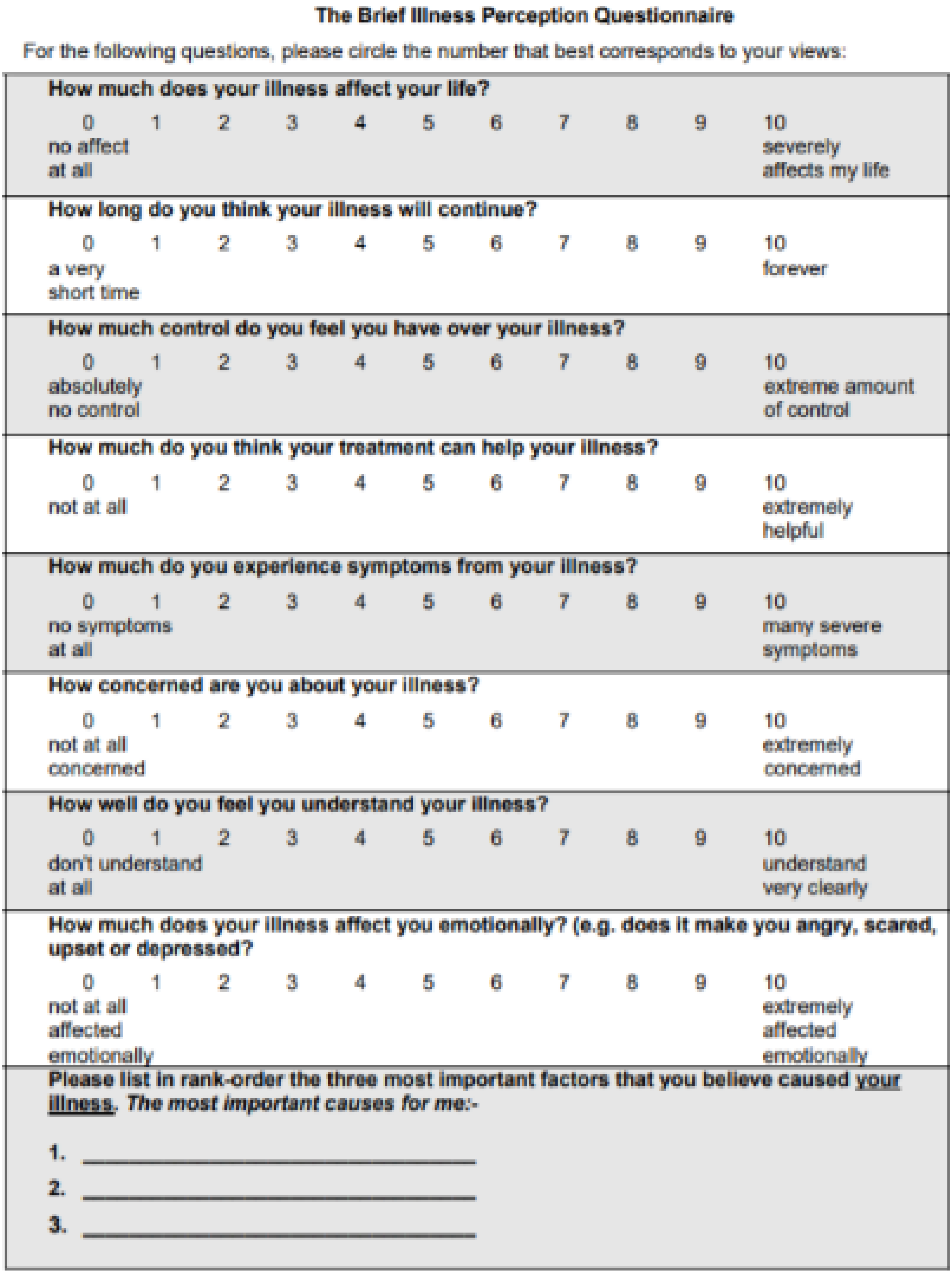
Name:	Date:

Please rate the following 8 statements using the scale below:

0	1	2	3	4	5	6
Strongly disagree	Moderately disagree	Slightly disagree	Neither agree nor disagree	Slightly agree	Moderately agree	Strongly agree

1.	I act in ways that are consistent with how I wish to live my life	0	1	2	3	4	5	6
2.	I get so caught up in my thoughts that I am unable to do the things that I most want to do	0	1	2	3	4	5	6
3.	I rush through meaningful activities without being really attentive to them	0	1	2	3	4	5	6
4.	I go out of my way to avoid situations that might bring difficult thoughts, feelings, or sensations	0	1	2	3	4	5	6
5.	I undertake things that are meaningful to me, even when I find it hard to do so	0	1	2	3	4	5	6
6.	Even when doing the things that matter to me, I find myself doing them without paying attention	0	1	2	3	4	5	6
7.	I work hard to keep out upsetting feelings	0	1	2	3	4	5	6
8.	I can keep going with something when it's important to me	0	1	2	3	4	5	6

Appendix AA: Brief IPQ Measure



The Brief Illness Perception Questionnaire

For the following questions, please circle the number that best corresponds to your views:

How much does your illness affect your life?

0	1	2	3	4	5	6	7	8	9	10
no affect at all										severely affects my life

How long do you think your illness will continue?

0	1	2	3	4	5	6	7	8	9	10
a very short time										forever

How much control do you feel you have over your illness?

0	1	2	3	4	5	6	7	8	9	10
absolutely no control										extreme amount of control

How much do you think your treatment can help your illness?

0	1	2	3	4	5	6	7	8	9	10
not at all										extremely helpful

How much do you experience symptoms from your illness?

0	1	2	3	4	5	6	7	8	9	10
no symptoms at all										many severe symptoms

How concerned are you about your illness?

0	1	2	3	4	5	6	7	8	9	10
not at all concerned										extremely concerned

How well do you feel you understand your illness?

0	1	2	3	4	5	6	7	8	9	10
don't understand at all										understand very clearly

How much does your illness affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?

0	1	2	3	4	5	6	7	8	9	10
not at all affected emotionally										extremely affected emotionally

Please list in rank-order the three most important factors that you believe caused <u>your illness</u>. ***The most important causes for me:-***

1. ______________________________

2. ______________________________

3. ______________________________

Appendix AB: MMAT Tabulated Checklist – Completed by lead researcher

Category of Study Design	Methodological Quality Criteria	Responses			
		Yes	No	Can't tell	Comments
Screening questions	S1. Are there clear research questions?	X			Aims and research questions are highlighted and explained in both the journal paper and the extended paper.
	S2. Do the collected data allow to address the research question?	X			The researcher explains which research questions are being answered by which collected data to clarify how the research questions are being answered.
1. Qualitative	1.1. Is the qualitative approach appropriate to answer the research question?	X			The qualitative approach is appropriate to answer aims one and three – which it is used to address – as aspects of aim one and the whole of aim three are concerned with exploration of subjective participant experiences.
	1.2. Are the qualitative data collection methods adequate to address the research question?	X			They are adequate as evidenced by the number of participants recruited and the amount of data generated from these interviews. The ways in which data was collected is also transparently outlined.
	1.3. Are the findings adequately derived from the data?	X			The data analysis approached used allowed for findings to be derived which addressed the research questions. The hybrid inductive-deductive approach to coding supported the

					study aim of gaining novel insights whilst still connecting with extant literature.
	1.5. Is there coherence between qualitative data sources, collection, analysis, and interpretation?	X			The links between the data sources (the interviews), collection (the process through which the researcher collected the information), analysis (how the analysis was carried out with a hybrid inductive-deductive coding approach within a wider thematic analysis) and interpretation of results (with clear links in appendices and through verbatim quotes) are clearly explained within the project.
4. Quantitative Descriptive	4.1. Is the sampling strategy relevant to address the research question?	X			The recruitment and sampling strategy is clearly explained. The sample frame is justified by the researcher.
	4.2. Is the sample representative of the target population?	X			Eligibility criteria was clearly outlined in the paper and the study respondents matched with the target population. Some insight is provided into why eligible individuals did not participate e.g. post-treatment fatigue and illness as well as the researcher’s extensive efforts to recruit a representative sample.

4.3. Are the measurements appropriate?	X			Measurements are appropriate as the variables are clearly defined (as demonstrated in theoretically informed measurement framework.) Measurements are justified within this table, as the rationale for collecting each measurement is explained e.g. is it assessing response style, background information, or psychological outcomes. Psychometric properties of the questionnaires used are provided and critically considered.
4.4. Is the risk of non-response bias low?			X	The researcher was not able to directly gather data to assess whether respondents and non-respondents were different on variables of interest – however, indirect feedback from recruiting clinicians suggested that eligible individuals who declined to participate were often debilitated by being extremely unwell following treatment. Whilst the topic area is sensitive, participants endorsing a range of attitudes to sexuality participated, suggesting that the study did not recruit an untypically

					sexually open-minded sample.
	4.5. Is the statistical analysis appropriate to answer the research question?	X			The chosen statistical analysis is appropriate to answer aims one and two (where quantitative analysis is applied). Crucial factors e.g., power and sample size are described and considered to ensure that the analyses run are appropriate.
5. Mixed Methods	5.1. Is there an adequate rationale for using a mixed methods design to address the research question?	X			The researcher explains that the use of a mixed methods design is appropriate due to the aims of the individual research questions which could be answered by both quantitative and qualitative data. Further rationale is provided in the extended paper.
	5.2. Are the different components of the study effectively integrated to answer the research question?	X			The researcher highlights that it is aim one where quantitative and qualitative data will be integrated within the discussion phase. It is clarified that aim two will be solely addressed by quantitative data and aim three will be solely addressed by qualitative data.
	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	X			The outputs of the integration are interpreted within the discussion section to aid the reader’s understanding of the concepts. This is where the meta-inference

				occurs and where the value of the triangulation of methods is displayed.
5.4. Are divergences and inconsistencies between qualitative and quantitative results adequately addressed?	X			Yes – there does not appear to be a divergence of results.
5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?	X			The researcher consistently considered the requirements for producing high quality quantitative and qualitative research and this is evidenced in the rigorous quality assurance procedures employed, including this same checklist being completed by a researcher independent of the study.

Appendix AC: MMAT Tabulated Checklist – Completed by independent party

Category of Study Design	**Methodological Quality Criteria**	**Responses**			
		Yes	No	Can't tell	Comments
Screening questions	S1. Are there clear research questions?	X			Clear aims and research questions are provided in the journal paper alongside a strong rationale. This is expanded upon in the extended paper.
	S2. Do the collected data allow to address the research question?	X			Yes – a clear and compelling rationale is given for the use of a mixed methods study. With a clear outline of which questions were addressed by which methodology.
1. Qualitative	1.1. Is the qualitative approach appropriate to answer the research question?	X			Very much so. The qualitative approach chosen allows for further, in-depth exploration of a sensitive topic. Use of a semi-structured interview allowed for flexibility; however, it is clear the approach was rigorous and well-structured.
	1.2. Are the qualitative data collection methods adequate to address the research question?	X			Yes. The collection methods are clearly outlined. Given the size of the population being studied, the researcher recruited a good number of participants for the qual interviews.

	1.3. Are the findings adequately derived from the data?	X			Yes. The researcher offers verbatim quotes from participants, and a thorough outline of the data analysis process. The researcher also offers a compelling reflective interpretation of the data, accounting for the strengths and limitations of the study.
	1.5. Is there coherence between qualitative data sources, collection, analysis, and interpretation?	X			Yes. It is clear as the reader how the study was conceptualised, the process of recruitment and analysis are outlined in detail, and the results and interpretation are considered both critically, and in reference to previous literature and theory. The qualitative aspects of the study read as very coherent and offer a unique insight into the experience of this population.
4. Quantitative Descriptive	4.1. Is the sampling strategy relevant to address the research question?	X			The researcher offers a clear outline of recruitment and sampling. The researcher acknowledges openly when difference contextual influences have input into recruitment and sampling.

4.2. Is the sample representative of the target population?	X			Clear description of target population which participants represent.
4.3. Are the measurements appropriate?	X			The measurements appear to be highly appropriate to answer the research question. The researcher also offers detail on how they amended one measure in aid of ensuring the research question was appropriately met.
4.4. Is the risk of non-response bias low?			X	The researcher states that it is possible that the more highly functioning were recruited due to the impact of the treatment but that steps were taken to ensure representativeness.
4.5. Is the statistical analysis appropriate to answer the research question?	X			Yes. The researcher considers the sample size, statistical power, and other key factors in ensuring statistical analyses are appropriate. Furthermore, the researcher is clear as to which research questions the quantitative data is answering, avoiding possible confusion between the different methodological approaches.
5.1. Is there an adequate rationale	X			Absolutely. The researcher offers a

5. Mixed Methods	for using a mixed methods design to address the research question?				strong and convincing rationale for the use of a mixed methods study. Not only does it feel appropriate, but it offers a unique and much-needed piece of research exploring sexuality and HNC.
	5.2. Are the different components of the study effectively integrated to answer the research question?	X			Yes. The researcher is clear throughout in regard to the integration of methodologies. This allows the reader to see clearly how the research questions are answered and by which aspects of the study.
	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	X			Although the two methodologies are presented separately in the results section (understandably, as it makes it clearer to the reader), the researcher ensures to integrate the results and subsequent interpretations in the discussion.
	5.4. Are divergences and inconsistencies between qualitative and quantitative results adequately addressed?	X			Yes, this is referenced by the researcher.
	5.5. Do the different components of the study adhere to the quality criteria of	X			Both methodologies were completed to a high standard. Given that the researcher effectively integrates these, the utility of a

each tradition of the methods involved?	mixed-methods approach is clear throughout the study.

POSTER

The University of Nottingham

“THIS ONE IS A BIT OF A TABOO SUBJECT":

A Mixed Methods Investigation into the Impact of Head and Neck Cancer upon Sexuality

Linda McCabe, Dr Anna Tickle, Dr Nima Moghaddam, Dr Sanchia Biswas
Trent Doctorate in Clinical Psychology

INTRODUCTION

Head and Neck Cancer (HNC) patients are vulnerable to experiencing a negatively impacted sexuality following diagnosis and treatment.[1]

Unattended sexuality difficulties can lead to reduced quality of life.[2]

Individual differences in coping/response style may account for much variability in experiences of living with cancer/illness.[3]

Professionals struggle to discuss sexuality with patients – patients may not have enough information.[4]

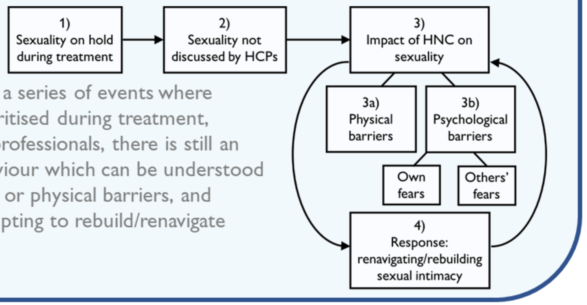
RESULTS

Online Survey Findings

- The most clinical impairment was shown in the ‘interest in sex’ domain: 44.8% (*n* = 26) were classified as clinically impaired.
- This was reported to be a post-HNC deterioration for 92.3% (*n* = 24).
- Findings relating to sexual function and response styles were not clear within the data.

Interview Findings

Themes developed illustrated a series of events where sexuality is necessarily deprioritised during treatment, sexuality is not discussed by professionals, there is still an impact of altered sexual behaviour which can be understood as due to either psychological or physical barriers, and participants respond by attempting to rebuild/renavigate their sexuality.



1) Sexuality on hold during treatment

2) Sexuality not discussed by HCPs

3) Impact of HNC on sexuality

3a) Physical barriers

3b) Psychological barriers

Own fears

Others’ fears

4) Response: renavigating/rebuilding sexual intimacy

METHODS

A mixed method convergent parallel design.

Participants

60 individuals with HNC completed the online survey. A further 18 participated in interviews.

Procedure

Participants were recruited through clinicians, social media, and HNC charities.

Analysis

Survey data were analysed using descriptive statistics and correlation analyses.. Interview data were analysed using a dual inductive-deductive thematic analysis.[5]

AIMS

1. What is the impact of HNC upon sexuality?
2. Are PF and other coping responses associated with sexuality and QoL outcomes in the context of HNC?
3. What is the clinical need for people with HNC in terms of psychological support/care provision around sexuality?

DISCUSSION

- Integrated findings support previous literature [6], showing that for many, sexuality is negatively impacted by HNC [7] and requires adjustment.[8]
- For those classified as clinically impaired in relation to sexuality, impairment represented a post-HNC deterioration that was not attributable to other measured variables (e.g., age).
- HNC patients highlight a clear unmet support need around sexuality.

Clinical Implications

Staff discussion of this topic should be sensitive and well-timed as well as raised with all patients regardless of age or health status.

Limitations

Lower sample size in the survey phase and ethnic homogeneity.

Future Research

Guidelines for clinical staff for approaching the topic of sexuality with HNC patients are needed.

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Acknowledgements: Thanks to patients, clinicians, and organisations who supported with recruitment including The Swallows and Heads2gether.

SMALL SCALE RESEARCH PROJECT

Clinical Psychologists' Engagement in Research Activities: Insights from graduates of a UK-based training programme

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Supervisors:

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Dr David Dawson

Dr Roshan Das Nair

Abstract

Background. Despite being highly trained in research skills through doctoral-level training, clinical psychologists (CPs) have historically struggled to apply their advanced research skills in qualified roles. However, the oft-quoted figure that the modal number of publications is zero insufficiently captures whether qualified CPs are working as scientist-practitioners.

Design. We applied a cross-sectional survey design to investigate research activity (and influencing factors) amongst graduates from a United Kingdom (UK) clinical psychology doctoral training programme. Specifically, we examined research publication rate, barriers, and facilitators to engaging in research, and how graduates fulfilled the qualities of scientist-practitioners.

Methods. All graduates from a UK-based training course were invited to participate in an online questionnaire regarding these features, which was developed by the research team of trainee and qualified CPs.

Results. Twenty-five graduates completed the survey (response rate: 21.37%). The modal publication rate of zero was consistent with the national picture and the historical publication rate for CPs. Participants highlighted time limitations, prioritisation of clinical work over research, and reduced research confidence as key barriers whereas having protected time, working with colleagues, and research support were facilitators to research activity. Participants embodied some aspects of the Scientist-Practitioner Model (SPM) regarding being research consumers, but they did not generally fulfil the qualities relating to generating new research.

Conclusions. Graduates from the training course continue to have low publication levels. Barriers to conducting research could be mitigated by providing protected research time within working hours, encouraging employers to prioritise research Continuing Professional Development, assisting CPs to obtain research funding and use it to buy out their time and research resources, and supporting training CPs to prepare for conducting research when qualified. With these changes, qualified CPs could likely better fulfil the qualities of the SPM in relation to producing research.

Practitioner Points

- Rather than engaging in evidence generation, CPs engage more frequently in applying research skills, such as critical thinking, into clinical practice. This indicates that qualified CPs are typically not fulfilling the qualities of the SPM.

- Qualified CPs from the training programme highly value research and would like to conduct more research, but there are individual and systemic barriers which prevent this.

- Results suggest a greater emphasis on preparing for research activity in qualified roles during training would be helpful although it is recognised that there are many systemic barriers such as a lack of protected research time which hinder research activity.

Keywords: Clinical Psychologist, United Kingdom, Clinical Psychology Training, Research Activity, Research Engagement, Research Barriers, Research Facilitators, Research Attitudes.

1. Introduction

The scientist-practitioner model (SPM) – sometimes referred to as the Boulder model (Frank, 1984) – is typically used throughout the United Kingdom (UK) and the Western world more widely as the pedagogical underpinning for clinical psychology doctoral programmes. The SPM is a model of Clinical Psychology training which emphasises the importance of training clinicians – such as Clinical Psychologists

(CPs) – in a style that supports them to apply empirical research to their clinical practice and allow their experiences in clinical practice to guide future research they conduct (Kowalski et al., 2017). The SPM proposes that research and practice should mutually inform each other and that applied psychologists should be both psychological practitioners and researchers (Belar & Perry, 1992; Rodolfa et al., 2005). The use of the SPM in clinical psychology training programmes has generated criticism (O'Gorman, 2001), despite being an approach endorsed by both training programmes and qualified CPs (Fish et al., 2017). It has been argued that its implementation has been poorly executed, as evidenced by the low amount of research activity engaged in by CPs (Gelso, 2006; Newman & Mckenzie, 2012). However, despite this criticism, in the UK, the qualities of the SPM are firmly embedded within clinical psychology training courses as trainees must generate a significant piece of original and clinically-oriented research during their training (Smith & Thew, 2017).

The British Psychological Society (BPS) endorses this emphasis on research, stating that research conducted by CPs is crucial for the advancement and promotion of the clinical psychology profession. However, it notes that very few qualified CPs conduct research despite the emphasis placed on research during training. This is supported by research which found that despite a self-reported mean number of 3.6 publications per clinical psychologist, the modal average of lifetime publications (defined as being inclusive of pre-, intra-, and post-training publications) was zero (Eke et al., 2012). Low research output has remained unchanged since the 1980s (Barrom et al., 1988) and despite the extensive time and resources dedicated to doctoral theses, only 24% of UK clinical psychology graduates go on to publish findings arising from their clinical psychology training (Cooper & Turpin, 2007).

Various suggestions have been offered to explain the low research output of CPs such as a lack of identification with the researcher role (Newman & Mckenzie, 2012) and negative previous experiences with research (Cooper & Graham, 2009). Furthermore, systemic issues have been identified as barriers to research output such as a lack of protected time, resources, and research ethos/culture within professional clinical psychology settings (Lampropoulos et al., 2002; Newman & Mckenzie, 2012; Smith & Thew, 2017). These systemic barriers are exemplified by one Irish survey's finding that on average 37% of research time for CPs happened outside of working hours (McHugh & Byrne, 2014). Holttum and Goble (2006) formulate this as a “three-pronged attack” on CPs’ ability to produce research, namely it not being valued, not being perceived as encompassing the typical role of a clinical psychologist, and broader, systemic issues such as a lack of time, resources, and research support (Holttum & Goble, 2006).

Although macro-systemic barriers clearly impact on CPs’ ability to engage in research, other individual barriers can also impact research activity. A UK study highlighted that research engagement has historically been perceived as more masculine and found that scores on a masculinity measure predicted research intention (Wright & Holttum, 2012). Furthermore, research self-efficacy was found to mediate the relationship between intention and masculinity (Wright & Holttum, 2012). The findings are important as a 2004 review (Cooke & Sheeran, 2004) showed that intention is significantly related to the performance of specific behaviours (Holttum & Goble, 2006), therefore suggesting that those who endorse more masculine qualities are more likely to intend to, and therefore engage in, research activity. The CP workforce is overwhelmingly composed of women; in 2019, 103 men accepted places out of 607 total applicant places and therefore only 17% of the 2019 national cohort were men (Clearing House for Postgraduate Courses in Clinical Psychology, 2019). This finding, in combination with practical barriers that are traditionally more likely to affect women, such as taking multiple periods of parental leave, could account, to some extent, for the reduced research activity of CPs.

Regarding research self-efficacy, this has been defined as an individual’s confidence in their ability to effectively carry out tasks linked with research such as analysing research data or completing literature reviews (Forester et al., 2004). Wright and Holttum (2010, 2012) highlight the significance of research self-efficacy as a factor that is strongly positively correlated with future research intention. Research training environments (RTE) have also been highlighted as a crucial factor in developing an individual’s beliefs around the importance of engaging in research as a CP, perceptions of what is a normal level of research engagement, and the feasibility of conducting research in clinical settings (Gelso, 2006; Holttum & Goble, 2006).

Local context and drivers for the present study

The training programme investigated by this study is widely considered to have a strong research ethos amongst Doctorate in Clinical Psychology (DClinPsy) programmes. This is established through trainees preparing their assignments in publication-ready format, a research test as part of selection, and trainees being advised to select their thesis topic in the first term of the course. However, it is likely that the findings for this course's graduates will have some broader transferability considering that the course is accredited in terms of BPS standards and all accredited courses in the UK are held to the same standards.

Rationale

We considered it important to characterise the research activity (and factors influencing this) for graduates from this programme (as a focal case) and then consider this in relation to the extant literature. We thought this would be important to investigate as we tentatively expected that this programme's particular emphasis on research would be likely to promote higher than average research activity, particularly in terms of published outputs, given the publication-based structure of research assignments on the course. Furthermore, while considerable attention has been paid to barriers, we felt it important to investigate what qualified CPs endorse as facilitators to research. While the course's training ethos follows that of the SPM, it was also important to understand whether graduates continued to embody this within their qualified roles.

Aim

To examine research activity (and influencing factors) in graduates of a local DClinPsy training programme as a focal 'case service' for understanding the national model. This will specifically address the following questions:

Questions

1. What are the post-qualification research outputs of graduates of the investigated training programme as primarily measured by research publications?

2. What are the barriers and facilitators to engagement in research for qualified CPs?

3. How do qualified CPs feel they fulfil the qualities of the scientist-practitioner model?

2. Methodology

Design

This study used a cross-sectional online survey methodology as part of a larger mixed-methods study on research engagement of qualified CPs.

Participants

We emailed all graduates with updated contact details. The study's inclusion criteria specified that all participants needed to have graduated from the training course and have access to an internet device suitable for accessing an online survey. There were no exclusion criteria for study participation.

Sample Size Calculations

We targeted a finite population of 191 graduates for study participation and aimed to achieve a sampling fraction > 10% of the target population (i.e., at least 20 participants), as sampling error reduces substantively when sampling more than 10% of a finite population – producing more accurate estimates of population responses, with narrower confidence intervals (CIs). Consistent with this focus on precision of estimates of population responses, all such estimates are reported with 95% CIs (reflecting the margin of error around each estimate, given our achieved sample size as a fraction of the target population). Please see Appendix AD for more information regarding how the confidence intervals were calculated as informed by statistical literature (Wallis, 2013).

Data Collection

Data were collected using a purpose-built questionnaire, with access through a web-link, to Qualtrics, a web-based survey tool. Data were collected over 3 months, between February and May 2021.

Measures

The questionnaire used was adapted from a previously published study (McHugh et al., 2016), which applied a survey instrument produced by the Health Service Executive (HSE) in Ireland. This HSE survey was developed and refined from a questionnaire devised by Morton et al. (2008) through expert consultation and pilot testing (with members of the HSE Health and Social Care Professionals' Education and Development Advisory Group). This survey instrument was adapted for the purposes of this study as it mapped to the focus of the current investigation, namely gathering data on the research activity of qualified practitioners. Through consultation with the authors (RdN, NM, DD) – who include CPs working in/who have worked in both clinical and academic settings – the main addition in relation to the questionnaire was to consider how qualified CPs are using their research skills to enhance their practice in line with the 'applied scientist' interpretation of the scientist-practitioner model. To this end, the items for 'other applications of research competence' were mostly derived from Shapiro's (2002) 'core competencies' of the scientist-practitioner model.

Regarding researcher facilitators in the measure, participants endorsed changes from a pre-defined list that they felt would facilitate research activity. To capture how participants were applying their research proficiencies in practice, and therefore to better understand to what extent they were fulfilling the qualities of the scientist-practitioner model, participants used a four-point Likert scale ranging from "not at all" to "to a great extent" to describe their application of research proficiencies. To estimate how the qualified CPs embodied the qualities of the SPM, participants used a five-point Likert scale ranging from 'very weak to 'very strong' to assess their research skills. The full survey is presented in Appendix AE. Participant demographics were collected, including gender, ethnicity, age, and number of years since qualification.

Validity and Reliability

As demonstrated by use in previous studies, the items within the current questionnaire have been useful in describing the research activities of CPs (and other healthcare professionals) in other contexts and there is evidence for 'known-groups validity' in that the items help to distinguish research 'active' vs. research ‘inactive’ participants (McHugh et al, 2016). It is more difficult to gauge reliability for the survey instrument: although possible to compute internal consistency values from the data through subgrouping by domains/item sets, this may not be meaningful because the questionnaire items relate to different content-areas and are therefore not necessarily expected to be inter-correlated.

Procedure

Participants were identified through the administrative team of the training course. A list of all graduates from the training course is maintained by the team with up-to-date contact details. Contact details are collected when trainees graduate from the programme and then trainees can update the course if they move positions. The administrative team distributed the generic recruitment email containing a link to the online questionnaire (see Appendix AF) to all qualified CPs on this database who have agreed to future contact. The email containing study details and the survey link was circulated to graduates on three occasions – at two-weekly intervals – to facilitate recruitment.

Analysis Plan

We aimed to generate a range of frequencies and modes from the data using SPSS, Version 27 to determine the average research output of the course’s graduates, the facilitators to research engagement, and to assess how graduates of the training programme fulfilled the qualities of the SPM. We aimed to analyse the data generated from the open-ended, free-text question regarding barriers to research engagement using frequential content analysis, as outlined by Bauer (Bauer, 2000). If more than 10% of the data was missing from a respondent’s record, it was planned that this incomplete data would be excluded from the analysis to produce conservative results and reduce the risk of bias (Brick & Kalton, 1996; Kang, 2013).

Ethical Considerations

Ethical approval for the study was provided by the University of Nottingham, Division of Psychiatry and Applied Psychology Research Ethics Committee. Study participants were informed about the research aims, data anonymity, and the voluntary nature of their participation. Study participants were required to complete a consent form before commencing the survey. Participants were also presented with a debriefing page when they left the survey. This debrief reminded them of their rights around withdrawing the data and signposting information. Participants were also offered the opportunity to provide their email address to be entered into a prize draw for the opportunity to win a £25 shopping voucher. Finally, participants were asked to provide their email addresses if they wished to be informed about the study results.

3. Results

Participant Characteristics

There were 191 graduates of the investigated training course who commenced the course between 2005 and 2017. Updated contact details were available for 117 graduates and all of these graduates were emailed. Twenty-five participants who were graduates of the training course participated in the survey. Twenty-eight individuals accessed the survey, but a meaningful amount of data was not elicited from 3 participants. There was not enough data from these individuals to characterise them in relation to survey completers. Participants' ages ranged from 29 to 48 years, with a mean age of 36.04 (*SD* = 4.95 years). Seventy-six % (*n* = 19) of the sample were women and 24% (*n* = 6) were men. Ninety-two% (*n* = 23) of the sample described themselves as White, 4% (*n* = 1) described themselves as Asian or Asian British and 4% (*n* =1) described themselves as being of mixed or multiple ethnicity. 52% (*n* = 13) of the sample had occupied a role in research prior to commencing training. Years since qualification ranged from 1 year to 14 years, with a mean number of years since qualifying of 5.68 (*SD* = 3.66 years). 20% (*n* = 5) of the participants had not taken a career break, but 4% (*n* =1) had taken a career break for personal reasons, 16% (*n* = 4) for maternity/paternity/parental leave, 4% (*n* = 1) to pursue research, and 4% (*n* = 1) preferred not to disclose.

What are the research outputs of graduates of the clinical psychology training programme?

Overall, 76% (*n* = 19), 95% CI [57.9%, 87.9%] of the participants reported that they had been involved in research activities since qualifying as a CP. Sixty percent (*n* = 15), 95% CI [41.9%, 75.7%] of the participants had published research conducted during the DClinPsy training course. Since qualifying, 15 participants (60%), 95% CI [41.9%, 75.7%] had been involved in service evaluations/clinical audits (mode number of projects = 2, *M* number of projects = 3.24, *Mdn* = 2.00). Three participants (12%), 95% CI [4.4%, 28.5%] reported involvement in reviews article (mode number of review articles = 0, *M* number of projects = 3.24, *Mdn* = 0.00), and 12 (48%), 95% CI [31.0%, 65.4%] participants had been involved with larger research projects (mode number of research projects = 1, *M* number of projects = 5.12, *Mdn* = 1.00). A further eight (32%), 95% CI [17.9%, 50.3%] participants reported that they had co-authored research publications since qualifying as a CP. For those CPs who had co-published, the modal average number of publications was 2 (*M* = 2.42, *Mdn* = 2.00). However, of the 19 participants who answered the question regarding number of co-publications since qualifying, 44% (*n* =11), 95% CI [37.2%, 76.1%] reported that they had not co-published. Six participants (24%) did not answer this question.

What are the barriers and facilitators to engagement in research for qualified CPs?

Most participants reported that they would like to spend more of their working time engaged in research (76%, *n* = 19), 95% CI [57.9%, 87.9%]. When asked how much of their overall working time they would like to spend engaged in research, responses ranged from 5% to 80%: however, the two most common responses were 10% (*n* = 7), 95% CI [14.9%, 46.2%] and 20% (*n* = 6), 95% CI [12.1%, 42.1%] of overall working time. Furthermore, 44% (*n* = 11), 95% CI [27.6%, 61.8%] of the participants reported that it was “very important” to engage in research post-qualification with a further 40% (*n* = 10), 95% CI [24.3%, 58.1%] describing it as “important”. However, despite this attitude towards research, several barriers to engagement in research were highlighted.

From the 19 comments submitted regarding factors that prevent/discourage participants from conducting research, time was cited as a barrier to research engagement by 68% (*n* =13), 95% CI [47.1%, 84.1%]. Demands associated with a high clinical caseload and a culture where clinical work was prioritised over research were also highlighted as barriers by 47% (*n* =9), 95% CI [28.1%, 67.4%] and 16% (*n* = 4), 95% CI [8.9%, 42.2%] of participants respectively. Research confidence was a barrier for 12% (*n* = 3), 95% CI [5.8%, 36.4%] of participants and a further 12% (*n* =

3), 95% CI [5.8%, 36.4%] stated that research, and their research skills as CPs, were not valued by their employers. The analysis of this data was broadly inductive, and there is potential overlap between themes. Example statements highlighting the barrier themes are displayed in Table 15.

Table 15

Five most commonly endorsed themes identifying barriers to research engagement reported by participants (n), with example statements

Theme	***n***	**%**	**Barrier Example Statements**
Time	13	52	- ‘It isn't possible to ring fence time specific to research’ - ‘There is no protected time’
High clinical caseload	9	36	- ‘Clinical demands are very high and rising’ - ‘Clinical need is too high’
Clinical work prioritised	4	16	- ‘We would not be permitted to sacrifice clinical contacts for academic research’ - ‘When risk or safety issues occur, this would be prioritised over project activity, especially when risk is imminent’
Research confidence	3	12	- ‘Confidence - dropped due to not completing any research since training’ - ‘The type of research that I imagine would be most manageable to carry out in my current role would be case study projects. I feel less confident in writing these up’
Research/CP research skills not valued	3	12	- ‘Undervaluing or lack of understanding of the research skills that clinical psychologists have’ - ‘Lack of valuing research in the team I am in’

Table 16 displays the three most endorsed facilitators which participants felt would facilitate more research activity which were: more opportunities for collaboration with other clinical/academic researchers (80% endorsed this as greatly effective), increased protected research working time (64% endorsed this as greatly effective), and greater levels of mentorship/support when conducting research (60% endorsed this as greatly effective).

Table 16

Participant endorsement (%) for how much specific facilitators would produce an increase in their level of research activity

Facilitators	*n*	No effect (%)	Somewhat effective (%)	Greatly effective (%)
Increased protected working time for research	24	4	28	**64**
Higher levels of ongoing research training	25	12	**56**	32
Recruiters in the health service giving more value to research experience when selecting candidates for clinical positions	25	28	**48**	24
A more simplified and efficient ethics application process	25	16	40	**44**
Greater levels of mentorship and support when conducting research	25	4	36	**60**
More opportunities to advance one's research qualifications (e.g., postdoctoral fellowships)	25	0	**60**	40
More opportunities for collaboration with other clinical or academic researchers	25	0	20	**80**
More funded research posts	25	8	**48**	44

Note. Emboldened figures denote the most frequently endorsed response for each suggested facilitator.

How do qualified CPs fulfil the qualities of the scientist-practitioner model?

Eighty percent (*n* = 20), 95% CI [62.2%, 90.7%] of participants reported reading a practice-relevant research article within the past week. Sixty percent (*n* =15), 95% CI [41.9%, 75.7%] of participants reported no involvement in peer review processes at all since qualifying.

To understand ways that doctoral research skills are used in applied practice, post-qualification, participants described their application of research proficiencies. The results are depicted in Table 17. The two most frequently rated practice applications of research proficiencies were “accessing and integrating scientific findings to inform healthcare decisions” and “synthesising deductive (theory- and evidence-based) and inductive (client data-driven) information to conceptualise cases and presenting problems”. The two most infrequently rated practice applications of research proficiencies were “providing research consultation or supervision to colleagues” and “teaching research skills to colleagues”.

Table 17

Participant endorsement (%) of personal applications of research proficiencies

Practice application of research proficiencies	n	Not at all (%)	Very little (%)	Somewhat (%)	To a great extent (%)
Accessing and integrating scientific findings to inform healthcare decisions	25	0	8	32	**60**
Framing and testing hypotheses that inform healthcare decisions	25	0	16	36	**48**
Building and maintaining effective teamwork with other healthcare professions that supports the delivery of scientist-practitioner contributions	25	0	8	**52**	40
Research-based training and support to other health professions in the delivery of psychological care	25	12	**32**	**32**	24
Contributing to practice-based research and development to improve the quality and effectiveness of psychological aspects of health care	25	16	24	**48**	12
Delivering and interpreting assessment procedures in practice	25	0	16	36	**48**
Delivering and evaluating intervention procedures in practice	25	4	8	**56**	32
Synthesising deductive (theory- and evidence-based) and inductive (client data-driven) information to conceptualise cases and presenting problems	25	4	4	32	**60**
Teaching research skills to colleagues	25	40	**44**	12	4
Providing research consultation or supervision to colleagues	25	**44**	32	20	4
Assessing personal effectiveness	25	8	24	**64**	4

*Note***.** Emboldened figures denote the most frequently endorsed response for each personal application of research proficiency.

Table 18 displays participants' assessments of their research skills. The strongest endorsed research skill was "critical appraisal of research", jointly followed by "generating a research idea", "collecting data", "qualitative data analysis" and "orally presenting research". The weakest research skill reported was "applying for funding". Other research skills classified as weak by the participants - as represented by endorsement by 20% or more of participants - were "applying for ethics approval", "quantitative data analysis", and "publishing research".

Table 18

Participant assessment of their research skills (%)

Research skills	*n*	Very weak	Weak	Average	Strong	Very strong
Generating a research idea	25	0	0	**52**	36	12
Conducting a literature review	25	0	0	44	**48**	8
Applying for ethics approval	25	0	20	**44**	32	4
Applying for funding	25	32	**40**	20	8	0
Designing quantitative research	25	0	16	**56**	24	4
Designing qualitative research	25	4	8	**48**	32	8
Recruiting participants	25	4	0	40	**48**	8
Collecting data	25	0	0	36	**52**	12
Quantitative data analysis	25	4	24	**52**	12	8
Qualitative data analysis	25	4	16	32	**36**	12
Presenting results	25	0	0	36	**56**	8
Critical appraisal of research	25	0	0	20	**64**	16
Orally presenting research	25	0	8	36	**44**	12
Publishing research	25	4	20	**56**	16	4

*Note***.** Emboldened figures denote the most frequently endorsed response for each assessment of participants' research skills.

4. Discussion

This small-scale research project explored the research activities and outputs of CPs qualifying from one UK clinical psychology training programme, with consideration of both the barriers/facilitators to research engagement post-qualification and how these CPs more broadly adhered to the SPM in their clinical practice. The results show that the modal average number of post-qualification research publications for graduates of this programme is zero. This number is consistent with research that has repeatedly demonstrated the same finding over a 25 year period (Brems et al., 1996; Eke et al., 2012; Norcross et al., 2005) and suggests that findings from this training course reflect national and international findings.

In relation to the barriers and facilitators to conducting research, we found that despite participants reporting that they wished to spend more time engaging in research and the majority stating that engaging in research post-qualification was either important or very important, numerous barriers impeded translation from intention to enaction. The positive research attitude expressed indicates that the low research output of CPs is not related to reduced perception of its value within this sample. The highlighted barriers fit with previous literature and include both systemic barriers such as time (Shapiro, 2002), high clinical caseload, the prioritisation of clinical over research work (McHugh & Byrne, 2014), and the management-level undervaluing of CP research skills (Smith & Thew, 2017) together with the more individual barrier of research confidence (Wright & Holttum, 2012). The weakest research skill reported by respondents related to funding applications: arguably, if qualified CPs report lower skills in relation to skills such as grants, funding, and the publication process, it is not surprising that research activity continues to be low. Furthermore, these results suggest that barriers to CPs conducting research, despite being well-documented in the literature, are not being addressed.

This data partially supports the aforementioned “three-pronged attack on clinical psychologists’ appetite for research” (Holttum & Goble, 2006): research being under-valued, not seen as a prominent aspect of a CP’s workload, and other external control factors such as a lack of appropriate research support and time (Holttum & Goble, 2006). Our findings provide nuance to Holttum and Goble’s point, indicating that the course’s graduates value research but felt that the under-valuing of research typically occurred at service management level. This study finding also challenges perceptions (e.g. of Australian course directors in Pachana et al., 2006) that research inactivity reflects a lack of interest/motivation in those who train to be CPs. Arguably the attitudes towards the importance of research within the current study sample could reflect a success of this course’s RTE in instilling the value of research.

Regarding facilitators for research, the findings were consistent with previous literature, namely that research would be encouraged by increased protected research time (Morton et al., 2008), more research/academic collaboration opportunities (Newman & Mckenzie, 2012), and greater access to mentorship/support when conducting research.

When considering the third aim regarding fulfilment of the qualities of the SPM, namely as consumers and generators of research (Shapiro, 2002), the findings were mixed. Despite participants being engaged in consuming research for clinical advancement, production of research output remains low, with our modal number of publications remaining zero. This is despite representing a range of ages and professional ranks. While the results showed that there was CP engagement in service evaluations and audits, other Allied Health Professionals who are not trained to a doctoral level - such as nurses and occupational therapists - also engage in service evaluations and audits. The more frequently endorsed applications of research by respondents were more individual and client-focussed (e.g. reading practice-relevant research). The applications that would arguably provide broader impact (upskilling colleagues and cascading skills) were the areas of least confidence for this sample’s CPs, further suggesting that the envisioned SPM is not routinely realised in practice.

The low average number of publications indicated in the current study does not automatically mean that other aspects of the SPM are not being fulfilled (Newman & Mckenzie, 2012). The findings portray a picture of more circumscribed and individualistic applications of research skills and arguably the SPM would be better fulfilled by CPs if they could have broader/outward-facing impacts in terms of application of their research skills. These results should also be considered in relation to research suggesting that many CPs view the SPM as an attitude towards clinical practice as opposed to something which they actively embody in terms of the generation of as well as the consumption of research (Kennedy & Llewelyn, 2001). However, when considering the full definition of the SPM (Shapiro, 2002), the results demonstrate that the current study's participants do not fully fulfil the qualities of the SPM.

Study Limitations

The sample size of the project was relatively small due to lower than anticipated numbers of CPs participating. Although this project was intended to be small-scale in its scope, the small sample combined with an inability to establish why particular CPs did not participate makes it difficult to confidently judge whether the sample was representative of CPs with a diversity of opinions regarding research, or only attracted research-positive CPs. The most robust method to establish population estimates would be to gain responses from the whole population. However, lacking this, we characterised the degree of imprecision/margin of error in estimates to consider whether our sampling was likely to be biased in ways that distort our understanding of post-qualification research activity (and influencing factors) for graduates of this programme.

The results of the research are largely consistent with existing literature within the subject area (Eke et al., 2012), suggesting that the low sample size did not negatively impact on the integrity of the research too greatly. In terms of whether our sampling frame was broadly representative of the target population, there was a broad representation across cohorts in terms of years since qualifying. Regarding the proportion of the sample who had published their DClinPsy work, as a reference value to measure representativeness, the number who published from their DClinPsy work in the three most recent completing cohorts (2015-2017) was 60.9%. In our sample, of the 25 participants, 15 (60%) had published their research, suggesting that the sample was highly representative of the course average. Additionally, there is an ethnicity bias in the survey as only two participants did not identify as White British: this reflects wider issues in the profession about the dominance of white female CPs.

Another limitation pertains to the participants who self-selected to participate as it is possible that those who participated were different from those who declined to participate. In the context of the current study, participants may have been especially likely to represent those who place an increased importance on research participation which could lead to the study capturing the views of those with favourable opinions of research and the results possibly being affected by non-response bias (Fricker, 2016; Sax et al., 2008). Social desirability bias may also have occurred for survey participants, as it is expected that CPs trained in the SPM will possess a high level of research knowledge and be practising as evidence-based practitioners, therefore possibly making it uncomfortable for participants to endorse items/provide opinions that did not reflect this. Finally, the dissemination of the survey invite coming from a course with a strong research ethos likely entails perceived demand characteristics that could have shaped responses (e.g. towards greater valuing of research). The survey aimed to mitigate the risk of demand characteristics/social desirability bias influencing answers by preserving anonymity, but the responses may still have been affected.

Implications/Recommendations

We offer these recommendations to support the engagement of CPs in research.

1. Individual recommendations for CPs: conducting a thorough assessment of research skills to identify relative areas of strengths and weakness, exploring available peer/colleague research support networks within the Trust, contacting their local course with research proposals that could be supported by trainees from the course.

2. Systemic recommendations: More support to be available from course after training to help CPs to secure funding to enable post-qualification research (e.g. support to buy out time), offering CPs 10% protected research time to allow them to fulfil their job description, support CPs to engage in research skills' CPD.

Acknowledgements. This study was conducted and funded as part of a Doctorate in Clinical Psychology course, undertaken by the first author. This mixed-methodology study was jointly conducted with another colleague who wrote up the qualitative data from the study. The authors wish to acknowledge the Trent DClinPsy administrative team for their assistance.

Financial support. This research received no specific grant from any funding agency, commercial or not-for-profit sectors.

Conflicts of interest. None to report.

Ethical statements. The author abided by the Ethical Principles of Psychologists and Code of Conduct as set out by the BPS. Ethical approval given by University of Nottingham Division of Psychiatry and Applied Psychology Ethics Subcommittee.

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Appendices

Appendix AD: Sample Size Confidence Interval Calculation Information

A calculator was created in Microsoft Excel which obtained a scaled confidence interval for a population based on a subsample were the sample is a credible proportion of the finite population.

It employs the Wilson score interval to compute the interval but adjusts it by employing a modified sample size *N*. Before computing the interval we calculate n = Ö(*N*-n)*/(N*-1) (where *n* is the sample size, *N* population size). We then divide *n* by n to obtain a new, increased *n'* which is substituted into the Wilson formula in place of *n*.

Appendix AE: Full Survey

Post-Qualification Research Activity

Start of Block: Introduction

Intro
Understanding qualified clinical psychologists' engagement in research activities

Researchers/Students: [names]
Supervisor/Chief Investigator: [name]
Additional Supervisors: [names] Ethics Reference Number : 1646
We would like to invite you to take part in a research study about clinical psychologists' engagement in research activities after they qualify from doctoral training. Clinical training from the [course name] Doctorate in Clinical Psychology (DClinPsy) is designed to fit the scientist-practitioner model, and involves a third of trainees' time conducting research. However, following qualification from DClinPsy training, it is uncertain to what extent [course name] graduates engage in research or make use of research skills within their clinical work. There are many things which may affect engagement in research, and we would also like to further explore these. Please click the image below to download the participant information sheet.

What is the purpose of this study? We aim to find out more about qualified Clinical Psychologists' engagement with and attitudes towards research and research skills. Currently within the UK, Clinical Psychologists are trained to a doctoral level, but little is known about how this training impacts on research engagement and attitudes following training. Through an online survey and follow up interviews with [course name] DClinPsy graduates, we aim to improve this understanding. We also aim to submit the results as part of the research component of the student researchers' current training.

Do I have to take part?
It is up to you to decide whether or not to take part. You are free to change your mind about being involved at any time.

What will I be asked to do? If you choose to take part, you will be asked to complete a 30 minute online questionnaire. It will involve questions about you, including your age, ethnicity, gender, and roles held since qualification. You will then be asked about your research experience and engagement, including your research activity, applications of research competencies, research attitudes, research skills and barriers or motivators for research engagement. Following this, you will be asked if you wish to take part in a follow up interview to further explore your views on research engagement. Participation in the online survey does not require participation in the follow up interview. If you would like to be interviewed you will receive further information about this via email before you decide to take part. You will also be asked if you would like to be entered into a prize draw to win one of two £25 high street vouchers for completing the online survey, and an additional prize draw to win one £25 high street voucher for completing the follow up interview.

Are there any possible disadvantages in taking part in the study?
We don't expect there to be any disadvantages or risks to taking part. In the unlikely event that it does give rise to any concerns for you, we advise you to approach your clinical supervisors or your General Practitioners for support.

What will happen to the information provided?
Your answers from the online survey, and the interview if you choose to take part, will be kept confidential and not shared outside of the study team. Anything you discuss that could identify you, including quotations, will be anonymised. You can find out more about how we use your information and details of privacy notice at: https://www.nottingham.ac.uk/utilities/privacy.aspx.

Further information and contact details
Student Researchers: [names and email addresses]

Please use the arrows at the bottom of the page to move through the survey

Page Break

Consent Items

Understanding qualified clinical psychologists' engagement in research activities Researchers/Students: [names]

Supervisor/Chief Investigator: [name]

Additional Supervisors: [names]

Ethics Reference Number : 1646

	Yes (1)	No (2)
Have you read and understood the Participant Information? (1)	○	○
Do you agree to participate in a questionnaire about the barriers and facilitators to conducting or engaging in research following qualification as a Clinical Psychologist? (2)	○	○
Do you know how to contact the researcher if you have questions about this study? (3)	○	○
Do you understand that you are free to withdraw from the study without giving a reason? (4)	○	○
Do you understand that for anonymous questionnaire studies, once you have completed the study and submitted your answers, the data cannot be withdrawn? (5)	○	○
Do you give permission for your data from this study to be shared with other researchers in the future provided that your anonymity is protected? (6)	○	○
Do you understand that non-identifiable data from this study including quotations might be used in academic research reports or publications? (7)	○	○
I confirm that I am 18 years old or over (8)	○	○

Email_Address **If you would like a summary of the research findings please insert your email address in this text box**

____

Consent **By ticking the button below, I indicate that I understand what the study involves, and I agree to take part.   I consent to take part in this research study. If I do not want to participate, I can close this window/press the exit button.**

○ Yes (1)

End of Block: Introduction

Start of Block: Demographics

Q35
<u>Understanding qualified clinical psychologists' engagement in research activities</u>

About You

In this section we would like to collect some information about you that helps us understand the types of people who have been involved in the study.

✱

Age **What is your age?**

____

Gender **Which one of the following best describes your gender?**

○ Male (1)

○ Female (2)

○ ⊗ Prefer not to say (3)

○ If you describe your gender with another term, please provide this here: (4)
____

Ethnicity **What is your ethnicity?**
We have included categories currently in use by the UK Census.

○ **Asian or Asian British** (Includes any Asian background, for example, Bangladeshi, Chinese, Indian, Pakistani) (1)

○ **Black, African, Black British or Caribbean** (Includes any Black background) (2)

○ **Mixed or multiple ethnic groups** (Includes any Mixed background) (3)

○ **White** (Includes any White background) (4)

○ **Another ethnic group** (Includes any other ethnic group, for example, Arab) (5)

○ **Prefer not to say** (6)

Page Break

Q42
About Your Professional Experience

Previous_research **Prior to DClinPsy training, did you occupy a role involving research?**
This could be as research assistant/associate, a PhD student, or a clinical role with a significant emphasis on research (e.g. research nurse)

○ Yes (1)

○ No (2)

Qualified years **How many years has it been since you qualified from the DClinPsy?**
(Please round to the nearest whole year)

____

Role **What roles have you held since you qualified?**

☐ NHS Clinical Role (1)

☐ Private Clinical Role (2)

☐ University Research Role (3)

☐ Other (please describe): (4)
____

☐ Private Research Role (5)

☐ Trainer (DClinPsy, Specialist Model, etc) (6)

☐ Supervisor/Manager (7)

Career_break **Have you ever taken a career break?**

○ Yes (1)

○ No (2)

Display This Question:

If Have you ever taken a career break? = Yes

Career_break_reason **If you have taken a career break, was this for:**

☐ Personal reasons (1)

☐ Maternity/Paternity/Shared Parental leave (2)

☐ To engage in research (3)

☐ To engage in other professional opportunities (4)

☐ ⊗Prefer not to say (5)

☐ Other (please specify if you wish to): (6)
____

Dclin_published **Have you had any research published that was conducted while training on the DClinPsy?**

○ Yes (1)

○ No (2)

End of Block: Demographics

Start of Block: Research Activity

Q1

Research Activity

Research activity here is defined as being involved in the design (e.g., supervisory activity) or execution of a research project. Research of relevance not only includes those projects based on the collection of new data, but also projects which involve an analysis of existing data or research literature (e.g., review articles, meta-analyses, etc.). For present purposes, research activity includes practice-based research – such as being involved in the design and conduct of service evaluations, audits, or single-case designs. Research conducted to achieve an academic degree or postdoctoral qualification is considered relevant.

Research_Involved **Since qualifying as a Clinical Psychologist have you been involved in any research activities?**

○ Yes (1)

○ No (2)

Skip To: End of Block If Since qualifying as a Clinical Psychologist have you been involved in any research activities? = No

No_Projects **Please specify, using the table below, the number of projects you have been involved with since qualifying as a CP. Please indicate with reference to the type of research. The definition of each type of research is provided in the table.**

	Number of Projects (1)
Service evaluation or clinical audit: The analysis of a service, or part of a service, for the purposes of comparison or improvement. The primary goal is to evaluate a service as it functions in its natural context. (1)	
Research: The collection and/or analysis of data for the purpose of generating new knowledge. Compared to service evaluation, there is a responsibility to generalise beyond the context of analysis. For example, research may examine the effectiveness of a therapy, while a service evaluation may examine whether this therapy is effective within the context of a service. (2)	
Review article: Project based on the analysis of existing research literature. May include meta-analyses. (3)	

Mentor **Were you provided with mentorship during any of these projects?**

○ Yes (1)

○ No (2)

Display This Question:

If Were you provided with mentorship during any of these projects? = Yes

Mentor_Further_Info **Please describe your mentorship (including any limitations or strengths of this provision):**

____

Publish_Training **Were any of these projects conducted as part of completing an academic degree or post-qualification training?**

○ Yes (1)

○ No (2)

Publish_Qualified **Have you co-authored any research publications since qualifying as a CP?** ***(Not including research undertaken during DClinPsy training)***

○ Yes (1)

○ No (2)

Display This Question:

If Have you co-authored any research publications since qualifying as a CP?(Not including research u... = Yes

Coauthor_No **How many have you co-authored?**

____

Display This Question:

If Have you co-authored any research publications since qualifying as a CP?(Not including research u... = Yes

Research_Role **In the research leading to publication(s), what was your role? *Please select all that apply.***

☐ Principal Investigator (1)

☐ Co-Investigator (2)

☐ Supervisor (3)

☐ Recruitment (4)

☐ Provision of Intervention (5)

☐ Outcome Assessor (6)

☐ Other (please specify): (7) ____

End of Block: Research Activity

Start of Block: Research Applications

Q52
Other Applications of Research Competence

Proficiency_Applicat **To what extent do you apply your research proficiencies in the following areas of practice:**

	To a great extent (1)	Somewhat (2)	Very little (3)	Not at all (4)
Accessing and integrating scientific findings to inform healthcare decisions (1)	○	○	○	○
Framing and testing hypotheses that inform healthcare decisions (2)	○	○	○	○
Building and maintaining effective teamwork with other healthcare professions that supports the delivery of scientist-practitioner contributions (3)	○	○	○	○
Research-based training and support to other health professions in the delivery of psychological care (4)	○	○	○	○
Contributing to practice-based research and development to improve the quality and effectiveness of psychological aspects of health care (5)	○	○	○	○
Delivering and interpreting assessment procedures in practice (6)	○	○	○	○
Delivering and evaluating intervention procedures in practice (7)	○	○	○	○

Synthesising deductive (theory- and evidence-based) and inductive (client data-driven) information to conceptualise cases and presenting problems (8)	○	○	○	○
Teaching research skills to colleagues (9)	○	○	○	○
Providing research consultation or supervision to colleagues (10)	○	○	○	○
Assessing personal effectiveness (11)	○	○	○	○

Reading_Articles **When was the last time you read a research article that related to your practice or Clinical Psychology more broadly?**

○ Within the last week (1)

○ Within the last month (2)

○ Within the last three months (3)

○ Within the last year (4)

○ Longer than a year ago (5)

PeerReview **Have you been involved in any peer review processes since qualifying?**

- ○ No (1)
- ○ Yes, within the last month (2)
- ○ Yes, within the last year (3)
- ○ Yes, longer than a year ago (4)

Other_Applications **Please describe any other ways that you apply your research competence in your work since qualifying:**

____

____

____

____

____

End of Block: Research Applications

Start of Block: Research Attitude

Q51
Research Attitudes

Time **Would you like to spend more of your working time conducting research?**

- ○ Yes (1)
- ○ No (2)

Display This Question:

If Would you like to spend more of your working time conducting research? = Yes

Discourage **Please indicate the factors that prevent or discourage you from doing so:**

____

____

____

____

____

Percentage **Ideally, what percentage of your overall working time would you like to spend engaged in research:**

____

Overall_Attitude **How would you describe your feelings towards engaging in research?**

○ Negative (1)

○ Neutral (2)

○ Positive (3)

Research_Imp **How important it is for CPs to engage in research post-qualification?**

- ○ Not at all important (1)
- ○ Slightly important (2)
- ○ Important (3)
- ○ Very important (4)

Publishing_Imp **How important is it to get research published?**

- ○ Not at all important (1)
- ○ Slightly important (2)
- ○ Important (3)
- ○ Very important (4)

End of Block: Research Attitude

Start of Block: Research Skills

Q50
Research Skills

Research_Skill **Evaluate your research skills using the table below:**

	Very Weak (1)	Weak (2)	Average (3)	Strong (4)	Very Strong (5)
Generating a research idea (1)	○	○	○	○	○
Conducting a literature review (2)	○	○	○	○	○
Applying for ethics approval (3)	○	○	○	○	○
Applying for funding (4)	○	○	○	○	○
Designing quantitative research (5)	○	○	○	○	○
Designing qualitative research (6)	○	○	○	○	○
Recruiting participants (7)	○	○	○	○	○
Collecting data (8)	○	○	○	○	○
Quantitative data analysis (9)	○	○	○	○	○
Qualitative data analysis (10)	○	○	○	○	○
Presenting results (11)	○	○	○	○	○
Critical appraisal of research (12)	○	○	○	○	○
Orally presenting research (13)	○	○	○	○	○
Publishing research (14)	○	○	○	○	○

Display This Question:

If Evaluate your research skills using the table below: = Very Weak

Or Evaluate your research skills using the table below: = Weak

Weak_Skill **Does your weakness in this skill discourage you from engaging in research?**

____

____

____

____

____

Training_Type_Rank **The options below represent different forms of research training for clinicians. Please rank in order of preference from 1-5, with 1 representing your highest preference & 5 representing your lowest preference.**

______ Lectures: The presentation of educational material with little audience involvement (1)
______ Practice-based workshops: In addition to presenting educational material, participants get an opportunity to discuss and work through problems. (2)
______ Online training: May include online modules, collaborative hubs etc. (3)
______ One-to-one mentorship: The provision of a high degree of support from an experienced researcher when conducting research. (4)
______ Research clusters: Conducting research within a network of supportive peer clinicians &/or academics. (5)

Research_CPD **Have you engaged in training/education opportunities to improve your research skills since qualifying as a CP?**

○ Yes (1)

○ No (2)

Competence_Change
Since qualifying as a CP, how has your overall research competence changed?

○ It has substantially declined (1)

○ It has slightly declined (2)

○ It has not changed (3)

○ It has slightly improved (4)

○ It has substantially improved (5)

Add_Support **Reflecting on your DClinPsy training now, what other forms of support and teaching would have helped you to develop your research skills?**

____

____

____

____

____

End of Block: Research Skills

Start of Block: Encouraging Research

Q49
Encouraging Research

Changes **Of the changes listed in the table below, indicate how effective you believe they would be in increasing your level of research activity:**

	Would have no effect (1)	Would be somewhat effective (2)	Would be greatly effective (3)
a) Increased protected working time for research (1)	○	○	○
b) Higher levels of ongoing research training (2)	○	○	○
c) Recruiters in the health service giving more value to research experience when selecting candidates for clinical positions (3)	○	○	○
d) A more simplified and efficient ethics application process (4)	○	○	○
e) Greater levels of mentorship and support when conducting research (5)	○	○	○
f) More opportunities to advance one's research qualifications (e.g. post-doctoral fellowships) (6)	○	○	○
g) More funded research posts (7)	○	○	○
h) More opportunities for collaboration with other clinical or academic researchers (8)	○	○	○

Add_Changes **Are there other changes not mentioned above that would encourage you to increase your engagement in research?**

____

____

____

____

____

Training_Changes **Reflecting on your DClinPsy training now, what could we have done to enable you to increase your engagement in research after qualifying?**

____

____

____

____

____

End of Block: Encouraging Research

Start of Block: Training and Practice Models

Q48

Training Models

A variety of models are currently used to train clinical psychologists.

Advanced Practitioner models train clinicians to Masters postgraduate level or equivalent. This model is typically seen in the training of nurses, pharmacists and occupational therapists. It allows for further development of skills and knowledge, enabling professionals to take on expanded roles and a wider scope of practice.

Scientist Practitioner models train clinicians to a Doctoral standard. It focuses on the development of skills in research and scientific practice, encouraging the exchange of empirical research in both informing current and developing future clinical practice.

Practitioner Scholar models train clinicians to a Doctoral standard. It focuses on the application of scholarly knowledge to clinical areas, with a strong emphasis on clinical practice.

Pref_Model **Please consider the following models of DClinPsy training and indicate (1) which model you think is most apt for training CPs and (2) which model you would have preferred for your own training:**

	1. Most apt for training (1)	2. Personal preference (2)
M Level (Advanced Practitioner) (1)	☐	☐
DClinPsy (Scientist-Practitioner) (2)	☐	☐
ClinPsyD (Practitioner-Scholar) (3)	☐	☐

Model_Qual **Could you explain your answer further?**

____

____

____

____

____

End of Block: Training and Practice Models

Start of Block: End of Questions

Q50
<u>Understanding qualified clinical psychologists' engagement in research activities</u>

You have now completed all the questions in this survey.

Thank you for your involvement in this research. You now have the opportunity to be entered into a random prize draw to win a £25 high street voucher. Your email address will be stored separately from your answers to the survey. If you are the winner we will contact you to confirm where to send your prize.

Prize draw **I wish to be entered into the £25 voucher prize draw for taking part**

○ Yes (1)

○ No (2)

Follow_Up We are also interviewing people who have taken part in this survey. This is to find out more about qualified Clinical Psychologist's engagement in and attitudes towards research. Interviews take place virtually via Microsoft Teams with a member of the research team. **If you would like to find out more about this please select 'Yes' below and enter your email address.**

○ Yes (1)

○ No (2)

Display This Question:

If I wish to be entered into the £25 voucher prize draw for taking part = Yes

Or We are also interviewing people who have taken part in this survey. This is to find out more abou... = Yes

*

Prize_Email **Please enter your email address so that we can contact you:**

____

Q56 **Please press the next arrow to submit your answers**

End of Block: End of Questions

Appendix AF: Recruitment Emails

Project: Understanding qualified clinical psychologists' engagement in research activities

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Subject: Research Opportunity – Research Engagement of Qualified Clinical Psychologists
Dear Dr [XX]
We are contacting you to take part in a [course name] -based study investigating the research engagement of qualified clinical psychologists who graduated from the [course name] programme as we would really appreciate you sharing your views.
While your clinical training at [course name] focussed on the development of research skills, little is known about how these skills are used following qualification. The average number of publications by qualified Clinical Psychologists (CPs) within the UK is estimated to be zero, therefore we would like to understand to what extent graduates of the [course name] programme differ from this figure. We would also like to know what your attitudes towards research are, and your opinions on the Scientist-Practitioner model as a whole.
This study involves an online survey and an optional follow up interview. Taking part in either stage will enter you into a prize draw to win one of two £25 high street vouchers to thank you for your time in participating.
Please take your time to read through the attached Participant Information Sheet. If you have any questions or would like more information, the researcher's contact details can be found at the bottom of the email and we would be happy to answer any queries you have. You are, however, under no obligation to take part in this study.
Please use the link below to access the anonymous survey:

[Survey Link]

This survey will remain open until **[DATE]**.
Many thanks for your time and consideration in taking part. We would really appreciate your views as ex- [course name] trainees on engagement in research post qualifying.
[Student Names]

Student Researchers/Joint Investigators: [names]; Trainee Clinical Psychologists (Trent DClinPsy)
Supervisor/Chief Investigator: [name] (University of Nottingham, Nottinghamshire Healthcare Foundation NHS Trust)

This research is being conducted in part fulfilment of the [course name]. It has received favourable ethical opinion by the Division of Psychiatry and Applied Psychology Ethics Committee
(Reference: 1646)

Reminder 1 29/3/2021
Please address any queries to the researchers at the bottom of this email and not [email address].

Dear [Course Name] Graduate
We contacted you last week to take part in a [course name]-based study investigating the research engagement of qualified clinical psychologists who graduated from the [course name] programme. We've had an **amazing response** to the survey so far and thank you to all who have taken part. **If you haven't yet had chance to take part, then the survey is still open.** We'd love to hear your views on how your [course name] developed research skills are used following qualification and what the barriers or facilitators to these might be.

This study involves an online survey and an optional follow up interview. Taking part in either stage will enter you into a prize draw to win one of two £25 high street vouchers to thank you for your time in participating. You are under no obligation to take part in this study.

Please use the link below to access the anonymous survey:
[survey link]

This survey will remain open until **Monday 19th April**.
Many thanks for your time and consideration in taking part.

[Student Names]

Student Researchers/Joint Investigators): [names and email addresses]; Trainee Clinical Psychologists (Course name)
Supervisor/Chief Investigator: [Supervisor name and email address]
This research is being conducted in part fulfilment of the [course name] Doctorate in Clinical Psychology. It has received favourable ethical opinion by the Division of Psychiatry and Applied Psychology Ethics Committee (Reference: 1646)

Reminder 1 6/4/2021
Please address any queries to the researchers at the bottom of this email and not [email address].
Dear [Course Name] Graduate

We contacted you last week to take part in a [course name]-based study investigating the research engagement of qualified clinical psychologists who graduated from the [course name] programme.

We've had a **fantastic response** to the survey so far and thank you to all who have taken part. However, we'd still love to hear more of your experiences – whether this has been positive *or* negative. **Time is running out to take part, but the survey is still open for now.**

If you've offered to take part in our follow up interviews, then we'll be in touch soon.

This study involves an online survey and an optional follow up interview. Taking part in either stage will enter you into a prize draw to win one of two £25 high street vouchers to thank you for your time in participating.

Please use the link below to access the anonymous survey:
[survey link]

This survey will remain open until **Monday 19th April**.
If you have any questions or would like more information, the researcher's contact details can be found at the bottom of the email and we would be happy to answer any queries you have. You are, however, under no obligation to take part in this study.
Many thanks for your time and consideration in taking part.

[Student Names]

Student Researchers/Joint Investigators: [names and email addresses]; Trainee Clinical Psychologists ([course name] DClinPsy)
Supervisor/Chief Investigator: [name and email address]

This research is being conducted in part fulfilment of the [Course Name] Doctorate in Clinical Psychology. It has received favourable ethical opinion by the Division of Psychiatry and Applied Psychology Ethics Committee (Reference: 1646)