# Survivorship Concerns in Head and Neck Cancer Patients Following Definitive Radiation

A DNP project written by:

Bridgett Harr, MSN, APRN-CNP, AOCNP

B.S.N., Kent State University 2007

M.S.N., Kent State University 2012

D.N.P., Kent State University 2022

Approved by:

Lisa Onesko, DNP, APRN-BC, Doctoral Project Committee Chair

Eldora Lazaroff, DNP, Doctoral Project Committee Member

Denise Pacholski, DNP, Doctoral Project Committee Member

Accepted by:

Lisa Onesko, DNP, APRN-BC, Director of the DNP program

Versie Johnson-Mallard, PhD, RN, APRN, FAANP, FAAN

## Table of Contents

# Abstract

A cancer diagnosis and its treatment can have long-lasting effects on quality of life. The Institute of Medicine identified evaluation and management of these late and long-term effects as a gap in current oncology care. These effects vary based on cancer diagnoses and/or treatment creating the need for disease-specific resources. Utilizing a provider-written set of questions, patients will be assessed for frequency of unmet survivorship concerns. Head and neck cancer-specific survivorship concerns identified in the literature being assessed include: body image, eating, speaking, intimacy, social health, and financial health. This project included head and neck patients who were 18 years or older, had no evidence of disease, and were greater than 4 months from treatment. Patients were identified from the DNP student's follow up schedule and the survey was done during routine, standard of care follow up. The DNP student queried patients for presence of specific concerns. A provider-written dot phrase was utilized to document patient-reported concerns within the progress note. Data analysis focused on descriptive statistics, specifically analyzing frequency and measures of central tendency. Frequency of survivorship concerns were examined in order to update patient education and direct resources to meet the overall project and Institute of Medicine's goal of providing meaningful survivorship care.

***Keywords:*** Head and neck cancer, survivorship, late and long-term effects

# Survivorship Concerns in Head and Neck Cancer Patients Following Definitive Radiation

## Introduction

A cancer diagnosis and its subsequent treatment can have life changing effects lasting long after treatment completion. With advancements in cancer treatments, cancer survivors are living longer and, subsequently, experiencing greater consequences from late and long-term effects. Late effects are survivorship concerns appearing months to years following a cancer diagnosis and/or treatment. Long-term effects, in contrast, are survivorship concerns that begin at diagnosis or during treatment and persist for months to years following a cancer diagnosis and/or treatment (NCI, 2021). The term survivorship concerns will encompass both late and long-term effects from here forward. Specific survivorship concerns depend largely on the cancer diagnosis and treatment(s) utilized; examples of potential concerns include altered nutrition, depression and/or anxiety, and coping with body image changes.

### Background

Recognizing a need to provide care for this unique group, the National Comprehensive Cancer Network (NCCN) issued clinical practice guidelines for survivorship care; within these guidelines, 11 key survivorship concerns were identified as important to assess in all survivors: cardiac health, anxiety and depression, cognitive function, fatigue, lymphedema, hormone-related symptoms, pain, sexual function, sleep disorder, healthy lifestyle, and immunizations and infections (NCCN, 2019). The Cleveland Clinic Survivorship Steering Committee adopted a general survey as a standard component within survivorship visits; the goal of this survey was to identify and address potential survivorship concerns across all disease-sites and treatment types.

### Problem Statement

Head and neck cancer (HNC) comes with its own set of patient challenges and survivorship concerns specific to both the diagnosis and treatment received. It was therefore hypothesized the generic survey did little to assess HNC-specific concerns. Two assessments of the utility of the Cleveland Clinic Survivorship Survey (Harr et al., 2018) were completed by the HNC survivorship program. First, a retrospective chart review was completed to identify HNC-specific responses approximately one year following the survey's implementation. Of the 63 patients reviewed, a majority of patients noted 2 or fewer survivorship concerns out of a possible 31 concerns. Frequently, documentation reflected patients had further concerns not identified by the survey.

Second, a formal IRB-approved study utilizing the Confidence in Survivorship Information Questionnaire sought to assess patient's knowledge in certain aspects of their cancer care (Palmer, Jacobs, Mao, & Stricker, 2012). It was found 31% of patients lacked knowledge regarding physical survivorship concerns and 41% of patients lacked knowledge of mental health survivorship concerns (Harr et al, 2019). This DNP project sought to identify specific survivorship concerns as well as quantify the frequency of these concerns within patients with a diagnosis of HNC diagnosis.

## Project Questions & Local Problem

To quantify the presence and frequency of survivorship concerns among patients with HNC, the following concerns were asked of patients during routine follow-up visits: Do you have concerns or questions surrounding:

(1) Appearance

(2) Dentition?

(3) Chewing, eating, or swallowing

(4) Eating in a social setting

(5) Being understood when speaking

(6) Relationship changes

(7) Human papilloma virus

(8) Resumption of family and social roles

(9) Finances

(10) Returning to work.

Specifically, this project sought to answer the question: Among patients with HNC, what is the type and frequency of unmet survivorship concerns of patients seen in routine follow up within a 3 month period? Objectives for this project were to (1) determine what common survivorship concerns exist within patients with HNC and (2) describe frequency of these concerns within the overall project population, with regard to time from treatment, and by human papilloma virus (HPV)-disease status. This project sought to determine the presence and frequency of survivorship concerns of patients with HNC; these concerns will be utilized to direct future education and resources to address these unmet concerns.

## Review of Literature

Patients with HNC have primary tumor sites located in the nasopharynx, oral cavity, oropharynx, pharynx, and larynx (Giuliani et al., 2016). HNC patients are at particular risk for significant LLE; many key anatomy structures (i.e. nose, mouth, vocal cords) and processes (i.e. speaking, chewing, and breathing) can potentially be affected. Potential LLE from a HNC diagnosis and treatment include difficulty with tasks essential to daily living such as speaking, swallowing, and breathing in addition to risk of psychosocial challenges including changes in social roles (Badr et al., 2016; Fang & Heckman, 2016; Ghazali, Roe, Lowe, & Rogers, 2015; Giuliani et al., 2016; Gold, 2012; Jabbour et al., 2017; Moore, Ford, & Farah, 2014). If left unaddressed, these LLE can cause significantly diminish quality of life.

A literature review was conducted to identify the potential unmet LLE needs within the HNC patient population. The following terms were used to identify potential articles using Pubmed and CINAHL: HNC, survivorship, quality of life, and unmet needs. Both qualitative and quantitative studies were identified to provide valuable information. All types of articles including expert opinion were considered for inclusion; systematic reviews, case-controlled, cohort, and review articles were identified. For inclusion, articles must be HNC-focused, address post-treatment unmet needs, be from 2007 or later, and in English. Articles were excluded if their main focus was on caregivers' unmet needs or addressed unmet needs prior to or during treatment only. An initial search identified 68 potential articles of which only 19 were applicable for inclusion after title and abstract review. Potential bias in this search included articles not translated into English.

A total of 19 articles provided insight into the unmet LLE needs of HNC patients. No randomized control trials were identified that met the inclusion criteria. Two systematic reviews of qualitative studies were identified with the following additional types: three controlled trials without randomization (Ghazali et al., 2015; Giuliani et al., 2016; Wells et al., 2015), five case-control or cohort studies, four descriptive studies, and five expert reviews. Unmet needs were found to be high in this population with 68% (Henry et al., 2013) to 96% (Giuliani et al., 2016) having at least 1 unmet need. These identified needs can be categorized into 6 distinct themes: body image, eating, speaking, intimacy, social health, and financial health. Additional unmet needs concerning emotional health, fatigue and sleep, healthy lifestyle and general survivorship topics are adequately assessed using the current CC survivorship survey and will not be discussed in this project (Harr et al., 2018). Each of the additional 6 themes are further defined and expanded upon below.

## Body image

For this project, body image will be inclusive of both physical and perceived appearance, inclusive of dental health. Eleven studies cite evidence of body image unmet needs. Approximately 75% of HNC patients reported feeling embarrassed by body changes associated with their cancer (Fang & Heckman, 2016); many studies identify the need to reconcile an altered, scarred or disfigured appearance on a highly visible part of the body while also overcoming negative connotations of medical equipment (i.e. feeding tube or tracheostomy) on appearance (Fang & Heckman, 2016; Ghazali et al., 2015; Gold, 2012; Jabbour et al., 2017; Ringash, 2015; Wells et al., 2015). During this adaptation period, HNC patients required specialized information and support to acclimate to body image changes (Fang & Heckman, 2016; Gold, 2012; Henry et al., 2013; Jabbour et al., 2017).

Four studies cite the importance of personalized, accessible dental care in a HNC patients' long-term care (Ghazali et al., 2015; Moore, Ford, & Farah, 2014). Dental health and teeth concerns were ranked first in unmet needs with one study identifying a dental hygienist as the highest support need eight to eleven years after treatment (Ghazali et al., 2015; Moore et al., 2014). The ongoing impact of poor dental health and decay has the potential to precipitate greater LLE and negatively affect a HNC patients' quality of life indefinitely (Simcock & Simo, 2016).

## Eating

Chewing, eating, and swallowing (CES) were among the top ranked needs of HNC patients with 12 studies identifying this unmet need (Ghazali et al., 2015). Difficulty eating was found in 26.4% of HNC patients with 30.2% identifying social eating as a challenge (Jansen et al., 2018). There are many LLE from that can contribute to eating challenges ranging from general loss of appetite to complex physical changes (Fitchett, Aldus, Fitchett, & Cross, 2018; Fang & Heckman, 2016; Ghazali et al., 2015; Gold, 2012; Jansen et al., 2018; Nguyen & Ringash, 2018; Ringash, 2017; Simcock & Simo, 2016; Wells et al., 2015). HNC patients characterize these changes as feelings of harm or loss, illustrating the far-reaching consequences of these LLE (Moore et al., 2014). Physical effects can emotionally drain some HNC patients, causing a further diminished appetite (Fitchett et al., 2018).

Social eating can also be a challenge for some HNC patients. A majority of HNC patients choose to eat alone due to embarrassment over dribbling and choking; many patients choose to avoid social situations due to lack of control of food offerings and feeling self-conscious (Fitchett et al., 2018; Moore et al., 2014). Furthermore, patients may experience an increase in eating time which may far outlast any eating partner (Fitchett et al., 2018; Ringash, 2017). All of these changes can have a negative impact on emotional and social health. Specific information aimed coping with the social implications of eating is lacking (Fang & Heckman, 2016; Fitchett et al., 2018; Jabbour et al., 2017; Nguyen & Ringash, 2018).

## Speaking

Half of all HNC patients experience speech difficulties; 10 studies cite unmet needs in this category (Ringash et al., 2017). Speech impairments, while improved, are still present 1 year following treatment (Ringash, 2017). HNC patients endorse difficulty being understood and the inability to speak fluidly as a barrier to social interactions (Fitchett et al., 2018; Ghazali et al., 2015; Ringash, 2017; Wells et al., 2015). Many fear rejection due to poor or unclear speech and are unable to successfully return to pre-treatment work (Fitchett et al., 2018; Moore et al., 2014). There is a lack of discussion among all articles regarding speaking challenges specific to tracheostomies. Patients require further information regarding speech changes post-treatment as strategies to improve precision of speech (Jabbour et al., 2017; Ringash, 2017).

## Intimacy

Despite 85% of patients reporting a moderate-to-high interest in sexual relations, 51% rated the quality of their sexual functioning as poor with 58% stating they did not engage in sexual intercourse (Fang & Heckman, 2016). These statistics illustrate intimacy remains a significant unmet need in this population. Eleven studies cite intimacy as an unmet need three major themes appearing: body changes, relationship changes, and human papilloma virus (HPV)-related concerns.

As previously discussed, 75% of HNC patients felt embarrassed due to physical changes caused by their cancer diagnosis or treatment, causing distress and negative psychosocial consequences for some HNC patients (Fang & Heckman, 2016). Further insight is illustrated in the challenge one patient had overcoming the feeling a feeding tube could not be seen as desirable by his partner (Badr et al., 2016). High quality information detailing how physical changes can affect sexuality with coping strategies is needed (Badr et al., 2016; Fang & Heckman, 2016; Henry et al., 2013).

18.6-26.7% of HNC patients reported changes to their relationships; specifically, changes were found in the way leisure time was spent, a decrease in non-sexual intimacy, and communication during and after treatment (Henry et al., 2014; Jansen et al., 2017). Most couples attributed these changes to a shift in focus toward healing and recovery during cancer diagnosis and treatment. Furthermore, couples admitted cancer discussions were avoided due to inability to initiate or not wanting to vocalize a negative thought or emotion (Badr et al., 2016; Ghazali et al., 2015). Couples found it difficult to regain normalcy after treatment and identified guidance with difficult conversations and coping strategies would be useful during this period (Badr et al., 2016; Ghazali et al., 2015; Henry et al., 2013; Nguyen & Ringash, 2018; So et al., 2019).

Finally, being diagnosed with an HPV-positive HNC can cause anxiety for many HNC patients (Sandstrom et al., 2016). Emotional turmoil associated with having a sexually transmitted infection is often increased due to questions regarding HPV general knowledge, transmission, and consequences (Fang & Heckman, 2016; Gold, 2012). While questions may be asked at diagnosis, additional concerns often resurface as HNC patients face return to sexual intimacy (Gold, 2012). In addition, 20% of HNC patients with HPV-positive cancer had negative relationship consequences after previously undisclosed or accusations of infidelity surfaced (Badr et al., 2017). Additional information on relationships, sexual intimacy, and HPV infection is needed (Fang & Heckman, 2016; Henry et al., 2013; Jansen et al., 2018).

## Social health

Many HNC patients withdraw from social networks during treatment; while some rejoin their former social network(s), others may isolate themselves (Fitchett et al., 2018). Fifteen studies cite social health as an unmet need; for the purpose of this study, social health is defined as resumption of family and social roles (excluding work) following treatment. Two major themes were identified: role changes and isolation.

Return to family and social roles creates an important sense of normalcy to many HNC patients with 20 to 34.6% of HNC patients identified as not being able to do everything previously able to before diagnosis (Henry et al., 2013; Jansen et al., 2018; O'Brien et al., 2017). Post-treatment role transitions within the family may contribute to negative emotional side effects; compounding this is the shift to an increase in younger HNC patients who typically have more family responsibilities (Badr et al., 2017; Gold, 2012). Other changes to role functioning may be born out of HNC patients asking existential questions and re-evaluating priorities; some patients may choose to change or eliminate roles altogether further increasing family distress (Fitchett et al., 2018; Moore et al., 2014).

Isolation was a major theme identified in HNC patients with many citing physical LLE interfering with their ability to participate in social activities (Fang & Heckman, 2016; Fitchett et al., 2018). Often patients fear rejection due to difficulty swallowing, making noise when eating, and unclear speech; these LLE precipitate emotional drain and further withdrawal from social networks (Fitchett et al., 2018). Information regarding how treatment can impact social activities with family, friends, and other members of the public is essential for this population (Fang & Heckman, 2016; Gold, 2012; Moore et al., 2014).

## Financial health

Current research may underestimate the financial impact of cancer diagnosis and treatment on HNC patients (Fang et al., 2016); thirteen studies cite unmet financial health needs with only 18% of patients identifying this as a priority (Jabbour et al., 2017). Simcock & Simo (2016) completed a survey of HNC patients in the United Kingdom where socialized healthcare is practiced; despite low to no healthcare cost out-of-pocket, 20% of HNC patients reported an increased financial burden, citing loss of wages, change of food requirements, and increased utilization of home utilities. 25% identified the cost of gas as an additional burden. The full financial impact may not be fully appreciated in the current literature; most studies were completed at academic medical centers with patients who had access to healthcare. Information is missing for those who cannot afford or access care (Fang & Heckman, 2016). Additionally, there is a lack of discussion regarding the effect of dental costs on patient's unmet needs; only one study identifies this as a potential barrier (Moore et al., 2014). 24.6% of patients identify information on financial assistance and support as a priority unmet need (So et al., 2019).

Returning to work is another milestone for patients; however, this may be difficult or not feasible following treatment. Employment decreased from prior to treatment (75%) to following treatment (33%) (Simcock & Simo, 2016). This unexpected outcome from treatment can be distressing to patients (Moore et al., 2014). For those able to return to work, Gold (2012) found a pressure for many to return before they were physically ready due to financial or family burdens. Ringash (2015) postulated this may be due to an increase in number of HPV-positive cancers typically found in patients who have young children and more financial responsibilities. Further information and support are needed for patients and co-workers to support the patient during this transition (Nguyen et al., 2018).

## Theoretical Framework

After completing exhaustive treatments, cancer survivors need to navigate a "new normal" that includes managing survivorship concerns. These concerns cause many obstacles for HNC patients depending on their cancer location; HNC patients may need to learn new ways to swallow or relearn how to speak, for example. It is hard for a non-HNC patients to fully appreciate how the full effect of an LLE on the HNC patients; this is where Callista Roy's Adaptation Model can provide insight.

Callista Roy visualizes the patient as interacting with an ever-changing environment which includes 3 types of stimuli: focal, contextual, and residual stimuli. Focal stimuli are defined by Roy as the internal and external environment experiences the patient confronts on a daily basis. Contextual stimuli are the stimuli that then act on the focal stimuli to further influence the patient's environment. Residual stimuli are the patient's personal beliefs, behaviors and personal experiences. Each stimuli affects how a patient may perceive and process to certain situations (Masters, 2014a; Masters, 2014b; Ursavas et al., 2014).

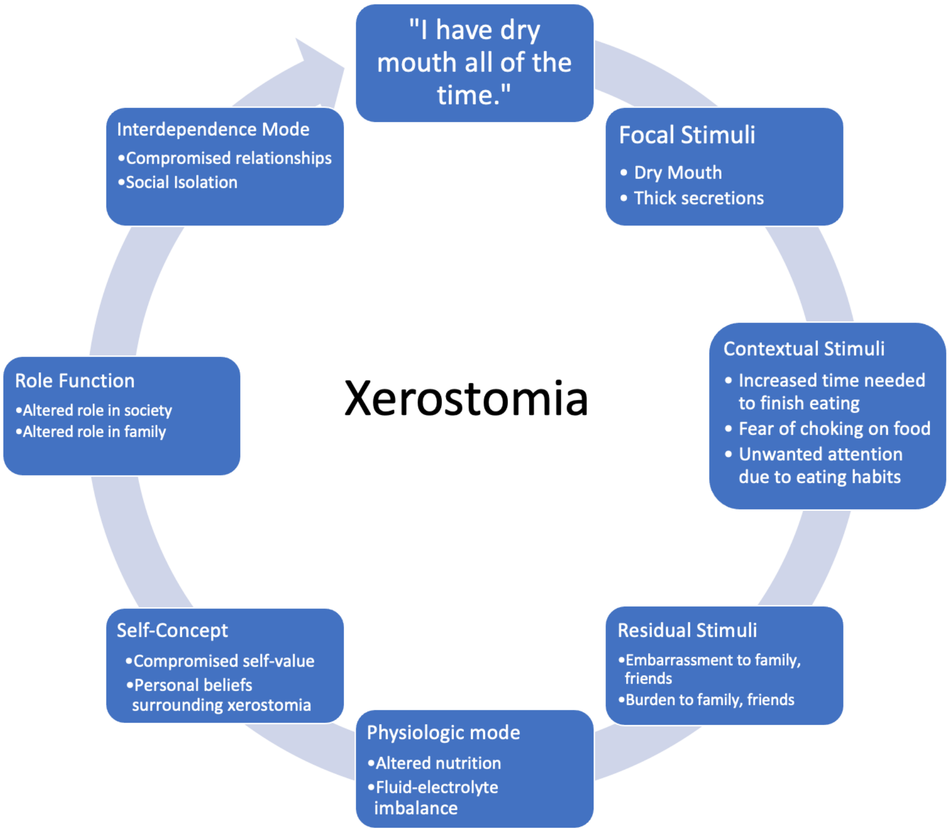
Roy further theorizes the role of nursing lies in assisting the patient to achieve balance within 4 different modes of adaptation. In each of these 4 modes, nurses have the ability to assess and intervene on behaviors and potential needs that directly affect the patient's adaptation to their altered environment. Physiologic, the first mode, addresses the patient's 9 main requirements (oxygenation, nutrition, elimination, activity and rest, protection, senses, fluid-electrolyte and acid-base balance, neurologic function, and endocrine function) that a patient requires for health and wellness. In the second mode, the self-concept mode, nursing's role is to assist the patient to find balance between his/her own beliefs and feelings regarding the stimuli. Topics potentially addressed within this mode include body image, body sense, and personal identity. Role function, the third mode, states that patients need to reconcile their social integrity in response to a stimuli specific to 3 main roles: gender, secondary roles such as mother or teacher, and tertiary roles such as the president of an organization. Reconciling these roles again the antagonist stimuli can serve assist the patient to reclaim or refine their identities. Finally, the interdependence mode addresses the importance of meaningful relationships. It is important for the nurse to assess the patient's relationships and support systems and help the patient reconcile how these will fit along with their new experience (Masters, 2014a; Masters, 2014b; Ursavas et al., 2014).

Roy's theory can best be utilized when studying survivorship concerns following treatment. Concerns that are seen following cancer treatment can be viewed as one-dimensional by an outside observer. Roy's model, however, break a singular toxic experience down into stimuli, thoughts, and behaviors to allow patients, families and providers a more comprehensive view its impact. For instance, many HNC patients have xerostomia. To a novice provider, this may be seen as simply a dry mouth or thick secretions (focal stimuli) and assume xerostomia does not have a large impact on a patient's quality-of-life following treatment. Utilizing Roy's adaptation model, however, this focal stimulus becomes multidimensional. For instance, the potential contextual stimuli experienced by a patient in a social situation with xerostomia could include increased time required to eat, fear of choking on food, having unwanted attention brought upon him/her, and the need to avoid previously enjoyed foods. A patient may even believe they are an embarrassment or burden to their family due to this (residual stimuli).

Further impact of xerostomia is seen when one examines the toxicity in the context of Roy's behavioral or adaptive modes. All four modes are affected by this toxicity: nutrition and fluid-electrolyte balance in the physiologic-physical, altered self-concept and identify as seen in his/her role in society, and the potential for compromised relationships and self-value in the interdependence mode. By applying Roy's adaptive model, xerostomia goes from a one-dimensional toxicity to having a multi-dimensional impact, allowing the provider to fully comprehend the true breadth of the toxicity's impact and better assist the patient to adapt (Masters, 2014a; Masters, 2014b; Ursavas et al., 2014). This experience is visually shown in Figure 1.

**Figure 1**

*Roy's Adaptation Model*



This DNP project sought to quantify patient-reported survivorship concerns which are affecting the HNC patients' quality of life. As seen in the above scenario, provider-graded assessments may not capture the full extent of concerns experienced by these patients. Roy's adaptation model will be used to assist identifying stimuli, behaviors/modes, and thoughts to best determine assessment techniques and intervention recommendations. In order to best meet HNC patient's needs, providers must take into consideration all relevant areas affected by the concerns. The Roy Adaptation Model will be of upmost importance to allow for this multi-dimensional view of survivorship concerns.

## Purpose

Unmet survivorship concerns can lead to decreased quality of life and distress in patients with cancer. Survivorship concerns vary by disease site and treatment causing generic assessments to have less specificity for certain cancer sites, including HNC. Identifying presence and frequency of survivorship concerns in patients with HNC will allow providers to direct resources to areas where further education and resources are needed.

## Planning and Stakeholders

Staff required for this project was intentionally limited to the DNP student who is also a provider in this practice. Past projects within this area were difficult due to staffing and patient identification challenges. As a result, the DNP student was responsible for identifying patients eligible, creating QI questions, and asking and recording these questions utilizing the corresponding dot phrase during the patient encounter. Information will be disseminated to all of the HNC team following completion of this project. The team, inclusive of physicians, advance practice providers, and nurses from the departments of medical oncology, radiation oncology, and ear, nose and throat, will meet to discuss findings and make decisions on future interventions. See Appendix A for letter of endorsement.

## Methods

### Design

This evidence-based project utilized current, up-to-date evidence that was translated into practice. IRB exemption was obtained from both Kent State University and the Cleveland Clinic. See Appendix B for IRB exemption documentation. A student-written survey based on the literature review was used to identify survivorship concerns among patients with HNC. The survey was given verbally by the DNP student during routine, standard of care follow up and documented within the EMR. Presence and frequency of concerns will be utilized to inform updates to patient education and resources following this project.

## Setting

The project was conducted at the Taussig Cancer Institute at the Cleveland Clinic from October 11, 2021, through and including December 10, 2021.

## Sample

The total project population was 150 patients with HNC seen in routine follow up at the Taussig Cancer Institute at the main campus of the Cleveland Clinic. Patients were limited to those who received definitive radiation with or without concurrent systemic therapy to ensure similar treatment courses and outcomes. All patients 18 years and older regardless of gender were eligible to be included in this project. As the questions were asked verbally by the DNP student, patients who were illiterate and non-English speaking patients with an in-person interpreter were also eligible for inclusion. Ineligible patients were those who did not receive definitive radiation, those with surgery as the primary treatment, patients less than 4 months from treatment completion, and patients with residual or metastatic disease that is biopsy proven. A review of the medical record by the DNP student prior to scheduled visit confirmed patient eligibility.

## Outcomes & Measurements

Measurements for all outcomes was based on the student-written scale. Patients were requested to respond to each queried concern with one of the following responses:

Option 1: I have no concerns.

Option 2: I have concerns but don’t need resources.

Option 3: I have concerns and would like resources.

Option 4: These concerns are overwhelming me.

Additionally, the date of treatment completion and date of follow up visit were noted for each patient by the DNP student.

Outcome 1: Frequency of survivorship concerns of the project population. The literature identified 10 potential survivorship concerns patients with HNC could continue to experience. Patients fitting project inclusion criteria were verbally queried on routine follow up to determine incidence of each concern within this population. Patients were counted as having a concern if they answered options 2-4 on the survey.

Outcome 2: Frequency of information and resource needs for each survivorship concern. It is hypothesized that patients could have survivorship concerns but not require further information or resources; future updates to patient education and resources should be focused on only those concerns patients identify as requiring further information and/or resources. Data was collected to determine the frequency of patients with a concern who required more information and/or resources. Patients were considered to have a concern but not need information if they answered with option 2 to the survey; by contrast, patients who responded with options 3 and 4 were considered as needing additional information and/or resources.

Outcome 3: Frequency of patients with survivorship concerns responding they are “overwhelmed.” It is hypothesized that patients may be so affected by the particular concern that they may not be able to determine what is needed to assist them based on multiple literature sources (Fang & Heckman, 2016; Giuliana et al., 2016). As such, the frequency of patient responses of overwhelm (option 4) will be separately tallied and analyzed.

Outcome 4: Frequency of survivorship concerns by time from treatment completion. There is little to no information in the literature regarding how, if at all, potential survivorship concerns change over time. Patients responding with options 2-4 will be considered to have a concern. Time from treatment completion to visit date will be calculated in years.

Outcome 5: Frequency of survivorship concerns stratified by HPV status. Patients with HPV-positive and HPV-negative HNCs have different treatment experiences based on patient characteristic and treatment differences (Fang & Heckman, 2016). As such, survivorship concerns are hypothesized to differ in each sub-population. Patients responding with options 2-4 were considered to have a concern; additionally, patients with a NA response for the HPV transmission concern were considered to be HPV negative. Patients were divided into 2 groups by HPV status: (1) HPV-positive and (2) HPV-negative/NA and overall concerns were tallied.

## Data Collection

Patient survey responses were asked verbally by the DNP student during routine, standard of care visits. Responses were documented in the electronic medical record (EMR) utilizing a student-written dotphrase. After working hours, patient responses were pulled from the EMR and assigned a patient project number by the DNP student. Corresponding date of treatment completion, visit date, and survey responses were recorded in a password-protected excel spreadsheet. No patient-identifiable data was collected. See Appendix C for data collection form and EMR dotphrase.

### Data Analysis Plan

Project data for each outcome was summed utilizing descriptive statistics. Descriptive data collected were both nominal and ordinal. Analyses include *n* and percentile. The data's mean and range were calculated to further describe the data's central tendency and potential variability. Pie and bar graphs were utilized to further describe the data visually further.

## Financial Implications

There was minimal physical costs for this project. Since the project was done in the same setting where the DNP student works, strategies were in place to minimize overlap during working hours. Overlap did occur, however, when the DNP student asked the assessment questions during SOC follow up encounters; it is estimated this took 5 minutes per patient. Schedule screening pre-clinic and data compilation was done outside of work hours. Appendix D shows the actual cost-benefit analysis in more detail.

## Ethics

It is important to ensure with any patient care or research opportunity the APRN has respect for the individual's autonomy. It is understood within the profession that human research has inherent risks but is essential to building our knowledge of evidence-based practice. According to code of ethics written by the American Nurses Association, APRNs have the obligation to know and abide by this code that was set forth to protect a research subject's rights to privacy, self-determination, confidentiality, fair treatment, and protection from harm due to the research (Zaccagini & White, 2011). This project abided by this code of ethics by limiting data collective to and ensuring data was non-identifiable data; furthermore, all data was stored in a password-protected excel file accessible only by the DNP student. All patients were included within this project if he/she met inclusion criteria. Finally, patients were informed of their right to skip questions if they felt uncomfortable or did not want to answer.

## Results

A total of 150 patients with head and neck cancer were included in this project. Patient selection occurred off the DNP student's follow up schedule from October 2021 through December 2021. No patient and treatment characteristics were coded to ensure patient confidentiality. There were a total of 290 concerns with an average of 1.93 concerns per patient (range: 0-9). Half of the patients surveyed had a HPV-positive HNC. Finally, 71 (47.3%) were surveyed within 2 years of treatment completion, 53 (35.4%) from 2 to 5 years post-treatment completion, and 26 (17.3%) were surveyed greater than 5 years post-treatment completion; the minimum time from treatment was 4.8 months with the maximum time from treatment was 16.5 years.

### Outcome 1

There were 290 individual concerns with 1500 total responses identified within this project; patients had a range of 0 to 9 concerns when surveyed. When looking at individual concern categories, an average of 81% patient responses indicated no concerns. In general, patients were most likely to respond they did not need additional resources (17%) if they indicated they had a concern. Of the survey concerns, more patients identified dental concerns (82, 54.7%) and to concerns with CES (96, 64%). Patients were least likely to identify knowledge regarding HPV infection as a concern (2, 1.3%). See Table 1 for all concerns identified by concern category as well as Figure 1 below for a visual description of the data.

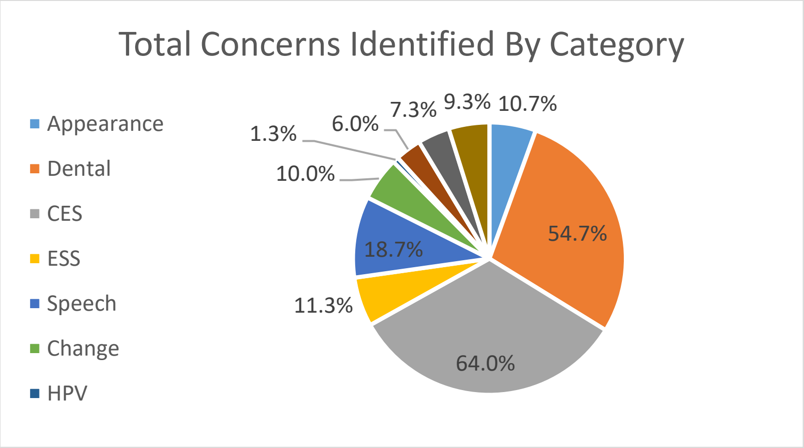
**Table 1**

*Total Concerns Identified by Category*

| | Appearance | | Dental | | CES | | ESS | | Speech | | Change | | HPV | | Family | | Finances | | Work | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Total Identified | 16 | 11% | 82 | 55% | 96 | 64% | 17 | 11% | 28 | 19% | 15 | 10% | 2 | 1% | 9 | 6% | 11 | 7% | 14 | 9% |
| No Concern/NA | 134 | 89 | 68 | 45 | 54 | 36 | 133 | 89 | 122 | 81 | 135 | 90 | 148 | 99 | 141 | 94 | 139 | 93 | 136 | 91 |
| Have Concern, No Info Needed | 13 | 9 | 76 | 51 | 84 | 56 | 12 | 8 | 23 | 15 | 14 | 9 | 1 | 0.7 | 8 | 5 | 9 | 6 | 12 | 8 |
| Have Concern, Info Needed | 3 | 2 | 6 | 4 | 11 | 7 | 5 | 3 | 4 | | 0 | 0 | 1 | 0.7 | 0 | 0 | 0 | 0 | 1 | 0.7 |
| Overwhelmed by Concern | 0 | 0 | 0 | 0 | 1 | 0.7 | 0 | 0 | 1 | 0.7 | 1 | 0.7 | 0 | 0 | 1 | 0.7 | 2 | 1 | 1 | 0.7 |

*Note:* CES=Chewing, eating and swallowing, ESS=Eating in a social situation

**Figure 1**

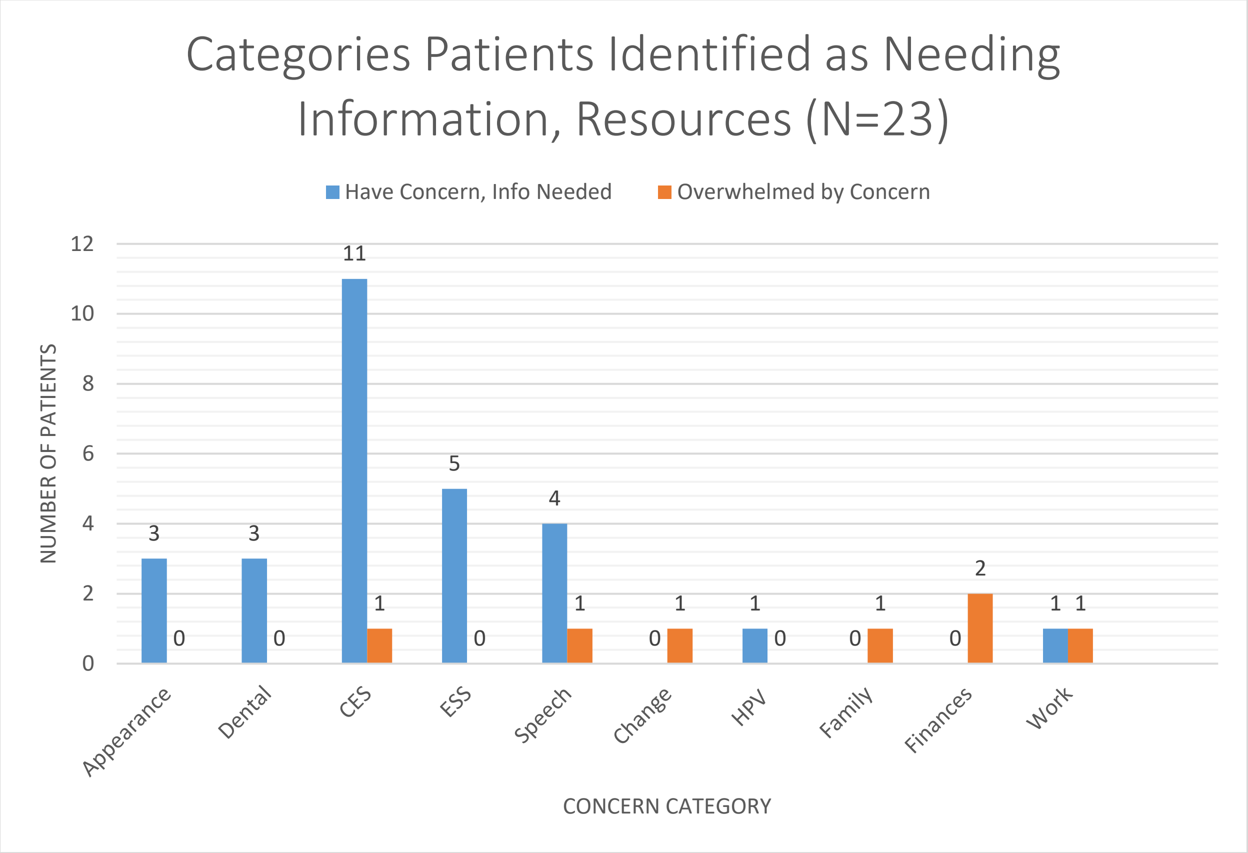


*Note:* CES=Chewing, eating and swallowing, ESS=Eating in a social situation

## Outcome 2

Frequency of information and resource needs were analyzed next for all patients. Patients were considered to need information and/or resources if they responded either “I have a concern and need information” or “These concerns are overwhelming me.” Only 23 patients identified as needing information or resources for a total of 87 concerns with patients having a minimum of 0 concerns to a maximum of 9 total concerns. Patients responded they needed more information and resources most with CES (20, 23%), dental (16, 18.4%), and speech (12, 13.8%) concerns; this is consistent with overall information and resource needs. Notably few patients responded they needed information and resources with HPV transmission (1, 1.1%). See Figure 2 for a visual representation of these results.

**Figure F2**



*Note:* CES=Chewing, eating and swallowing, ESS=Eating in a social situation

## Outcome 3

Next, the patients who responded they were overwhelmed by a particular concern were analyzed; 4 patients responded they were overwhelmed 7 different times all less than 5 years post-treatment completion. Half of these patients had a HPV-associated cancer. This patient sub-population represents only 2.7% of the patients surveyed suggesting few are overwhelmed by concerns. Patients noted they were overwhelmed by concerns with CES (1), speech (1), change in relationships (1) resumption of family roles (1), finances (2), and return to work (1). See Table 2 for full all concern results in these categories.

**Table 2**

*Difference in responses for patients needing additional information, resources and patients overwhelmed by concern*

| | Appearance | Dental | CES | ESS | Speech | Change in Relationship | HPV Transmission | Family | Finances | Work |
|---|---|---|---|---|---|---|---|---|---|---|
| Need Information, Resources | 3 | 6 | 11 | 5 | 4 | 0 | 1 | 0 | 0 | 1 |
| Overwhelmed by Concern | 0 | 0 | 1 | 0 | 1 | 1 | 0 | 1 | 2 | 1 |

*Note:* CES=Chewing, eating and swallowing, ESS=Eating in a social situation

### Outcome 4

Patients were also stratified by time from treatment. A majority of patients were surveyed within 2 years of treatment completion (71 patients or 47.3%). Similar to outcome 1, results showed a majority of patients had no concerns regardless of time from treatment completion (1135 no concern responses versus 290 have concerns). Patients were most likely to have a concern within the first 2 years following treatment completion (155, 53%) than from 2-5 years (86, 30%) or greater than 5 years (49, 17%) from treatment completion. Information and resource needs were highest within the first two years from treatment completion, decreasing as time from treatment completion increased. See Figure 3 and Figure 4 for visual data representation.

**Figure 3**

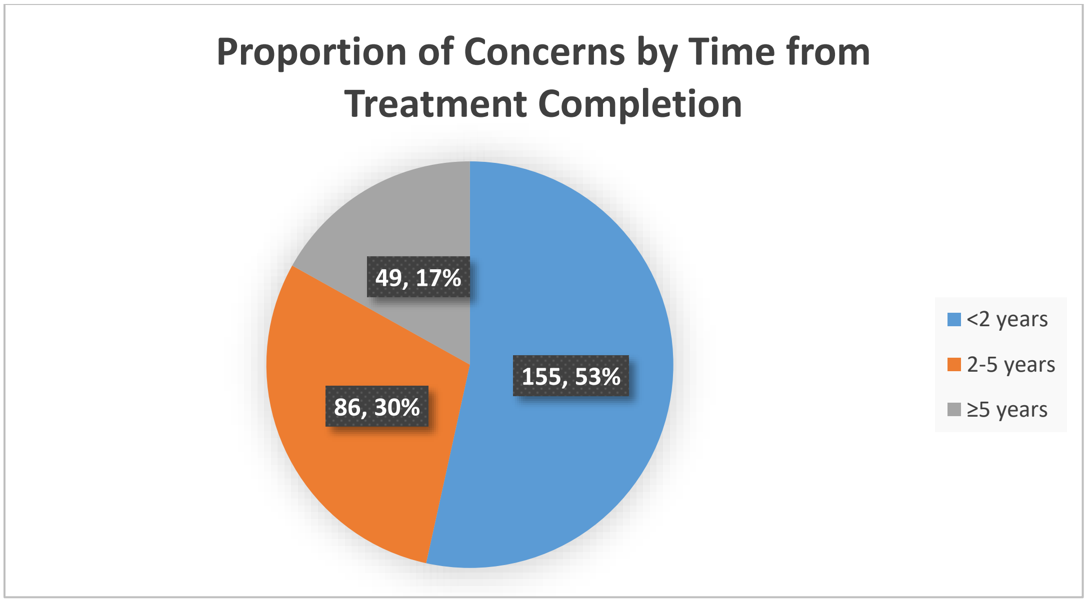
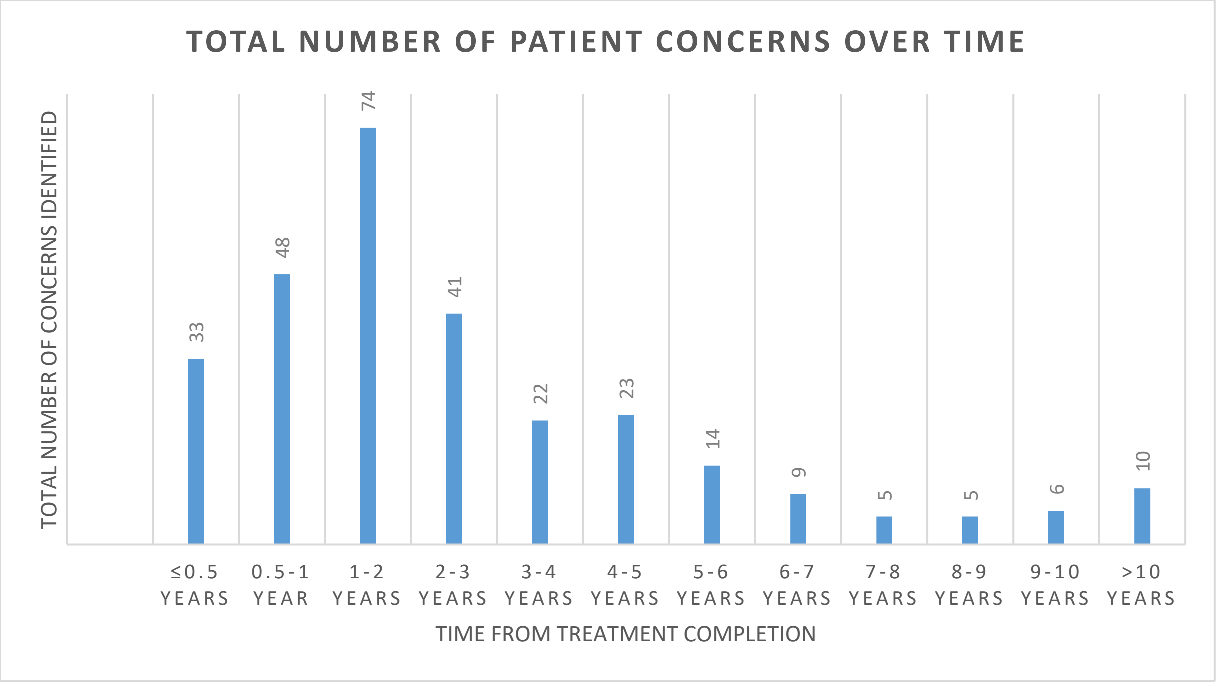


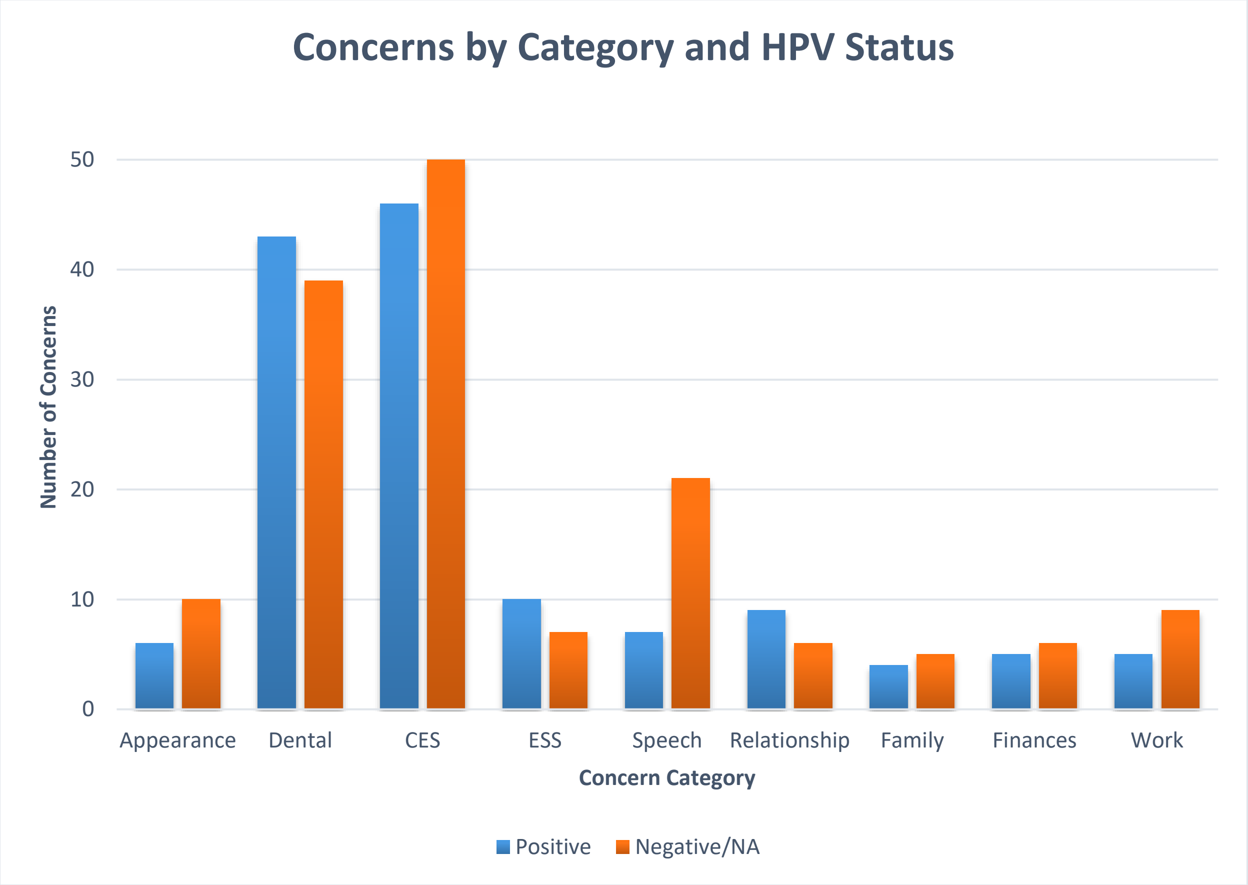
**Figure 4**



**Outcome 5**

Patients were also stratified by HPV-positive disease; if patients' cancer was not associated with the HPV, this concern was marked as not applicable during the survey. 50% of patients included in this project had a HPV-positive HNC. Overall, those with HPV-positive disease had fewer total concerns (137, 47.2%) than those with HPV-negative cancer (153, 52.8%). Similarly, individual concerns of those a HPV-positive cancer had lower average concerns than those with HPV-negative cancer (1.83 versus 2.04) and fewer concerns per patient (range: 0-5 versus range: 0-9 concerns). See Figure F5 in Appendix F for visual data representation.

**Figure 5**



*Note:* CES=Chewing, eating and swallowing, ESS=Eating in a social situation

## Limitations and Anticipated Problems

Prior surveys done in this ambulatory clinic have had difficulty both with patient identification and consistent survey administration. The DNP student anticipated that the current COVID pandemic would enhance these challenges. As such, the DNP student chose to limit personnel to only herself to ensure patients were appropriately identified and surveys were consistently given and recorded within the chart. During the project, some patients initially identified as eligible for inclusion were ultimately excluded due to competing patient agenda, problems. While these patients likely had one or more concerns, patient care took precedence over this project. Next, this project included only patients who came for routine follow up visits. Patients who choose to not follow up are not being represented in this project. Additionally, the project's sample size is small and limited; results may not be generalizable to the HNC population as a whole. Finally, patient and treatment characteristics were not collected due to patient confidentiality concerns. This makes it even more difficult to determine if this project is representative of the population as a whole.

## Impact of Results on Practice

The results of this DNP project will be utilized to focus future updates to the HNC program's patient education and resources. Quantifying concern frequencies within the HNC patient population allows the team to proactively provide education materials and resources to patients, potentially eliminating physical and mental distress unmet survivorship concerns may cause.

### Overall Concerns and Information, Resource Needs

The patients surveyed for this project had a low level of concerns post-treatment; this infers our multidisciplinary team adequately meets a majority of our patient's needs. This information correlates with a prior study done within our group that found despite patients not remembering receiving a formal survivorship visit, they were confident in management of disease and treatment related topics queried (Harr et al., 2016). Despite the overall low number of concerns, this project did show patients within this population have continued concerns specifically with CES as well as dental concerns. Further efforts to revise patient education and consideration of available resources should be undertaken by the primary team to attempt to meet these needs.

## Overwhelm

Few patients expressed “overwhelm” when identifying concerns. Those patients who did express overwhelm for one concern were more likely to identify overwhelm in other categories. Early identification of those patients who are having a difficult time managing physical and/or emotional concerns may be beneficial to improving a patient’s quality of life in this population. This finding validates prior discussion supporting the integration of Taussig Cancer Institute social work into routine follow up within this population; the addition of routine social work touch points adds another resource beneficial to addressing patient coping and well-being (Moore, 2014; NCCN, 2019; Obrien et al., 2017; Ringash, 2015).

## Time from Treatment Completion

Patient follow up intervals increase as time from treatment increases and risk of cancer recurrence decreases. The first 2 years post-treatment completion carry the most risk for cancer recurrence and, as such, patients are seen at a minimum every 3 months during this time. It is not surprising then the trend of patient concerns was the highest from year 1-2 post-treatment completion then gradually decreased from this time point. This infers patients are most likely to have unmet concerns during this time and would benefit the most from receiving additional education and resources based on anticipated concerns.

## HPV-Positive versus HPV-Negative Disease

Overall, patients with HPV-negative disease (total concerns 153, range: 0-9 concerns per patient, mean concerns per patient 2.04) had slightly more concerns than patients with HPV-positive disease (137, range: 0-5, mean 1.83). Those with HPV-negative disease are more likely to have a primary tumor requiring multimodal therapies utilizing surgery, radiation, and/or chemotherapy leading to the potential for more structural defects and quality of life changes (Obrien et al., 2017). Further, patients with HPV-positive cancers typically are younger with fewer co-morbidities. Given the small sample of patients, it is difficult to ascertain if time from treatment completion has any difference for HPV-positive versus HPV-negative disease. Further research efforts need to be completed to further quantify HPV-positive versus HPV-negative concerns including how, if any, time from treatment completion affects concerns.

## Dissemination Plan

The DNP student will meet with her APRN colleagues in the head and neck team. Results will be presented to the team and discussion will be facilitated specific to patient education and resource strengths, weaknesses, and needs. Following this meeting, the DNP student will write up a plan for updating our patient education and other referrals and present this at the HNC programming meeting to the physician directors of medical oncology, radiation oncology, and otolaryngology. The plan will be revised as needed throughout this process and, once all parties are in agreement, the APRNs within this disease team will update education, referral guidelines, and other patient resources.

Further, this project will be submitted for consideration of a poster presentation at one of two nation conferences, either Journal of the Advanced Practitioner in Oncology (JADPRO) Live 2022 or the 2023 Oncology Nursing Society Congress. Both of these conferences have abstract submission platforms opening in fall 2022. The submission for publication of this project will be determined by which conference this is presented at: *JADPRO* if JADPRO Live or the *Oncology Nursing Forum* if Congress.

## Future Implications and Conclusion

HNC patients are at risk for unmet concerns following definitive treatment completion due to the effects of diagnosis and treatment on key anatomy structures. While few, unmet concerns still were present within this population. This project was informative from a Taussig Cancer Institute standpoint in 2 ways. First, this project corroborated past findings that our patient education strategy works. Patients receive similar education at multiple time points throughout their cancer journey, often in different forms to enhance comprehension. This project validated a prior study's findings inferring Taussig Cancer Institute patients with HNC in general have access to desired education and resources. Second, this project highlighted some areas within our program (CES, dental concerns, and speech) where patient education and resources need to be enhanced.

Unfortunately, this project lacks the ability to definitively conclude assumptions regarding unmet concerns within the larger HNC population. This is due to not only the patient sample but also the lack of patient and treatment specific information necessary to determine additional variables within sub-populations that could contribute to unmet concerns. Future research should be done collecting patient and treatment information with a larger sample to better quantify these concerns and ensure these results are generalizable to the head and neck population as a whole.

# References

Badr, H, Herbert, K., Reckson, B., Rainey, H., Sallam, A., & Gupta, V. (2016). Unmet needs and relationship challenges of head and neck cancer patients and their spouses. *J Psychosoc Oncol*, *34*(4), 336–346. https://doi.org/doi:10.1080/07347332.2016.1195901

Badr, Hoda, Lipnick, D., Gupta, V., & Miles, B. (2017). Survivorship Challenges and Information Needs after Radiotherapy for Oral Cancer. *Journal of Cancer Education*, *32*(4), 799–807. https://doi.org/10.1007/s13187-016-1048-8

Fang, C. Y., & Heckman, C. J. (2016). Informational and support needs of patients with head and neck cancer: current status and emerging issues. *Cancers of the Head & Neck*, *1*(1), 1–9. https://doi.org/10.1186/s41199-016-0017-6

Fitchett, R. C., Aldus, E. J., Fitchett, L. R., & Cross, J. (2018). The lived experience of head and neck cancer patients receiving curative radiotherapy: A systematic review and meta-ethnography. *Psycho-Oncology*, *27*(9), 2077–2086. https://doi.org/10.1002/pon.4790

Ghazali, N., Roe, B., Lowe, D., & Rogers, S. N. (2015). Patients concerns inventory highlights perceived needs and concerns in head and neck cancer survivors and its impact on health-related quality of life. *British Journal of Oral and Maxillofacial Surgery*, *53*(4), 371–379. https://doi.org/10.1016/j.bjoms.2015.01.022

Giuliani, M., McQuestion, M., Jones, J., Papadakos, J., Le, L., Alkazaz, N., … Ringash, J. (2016). Prevalence and nature of survivorship needs in patients with head and neck cancer. *Head and Neck*, *38*(7), 1097–1103. https://doi.org/10.1002/HED

Gold, D. (2012). The Psychosocial Care Needs of Patients with HPV-Related Head and Neck

Cancer. *Otolaryngologic Clinics of North America*, *45*(4), 879–897. https://doi.org/10.1016/j.otc.2012.05.001

Harr, B.A., Bodmann, J.W, Reddy, C., Joshi, N.P., Geiger, J.L., Adelstein, D.J. (2016). Do patients learn from their survivorship care plans? Retreived from http://intranet.ccf.org/survivorship

Harr, B.A., Bodmann, J.W., Moeller, M., Thousand, R., & Tackitt, H. (2018). Cleveland Clinic survivorship survey. Retreived from http://intranet.ccf.org/survivorship

Henry, M., Habib, L. A., Morrison, M., Yang, J. W., Li, X. J., Lin, S., … Hier, M. (2013). Head and neck cancer patients want us to support them psychologically in the posttreatment period: Survey results. *Palliative and Supportive Care*, *12*(6), 481–493. https://doi.org/10.1017/S1478951513000771

Jabbour, J., Milross, C., Sundaresan, P., Ebrahimi, A., Shepherd, H. L., Dhillon, H. M., … Clark, J. R. (2017). Education and support needs in patients with head and neck cancer: A multi-institutional survey. *Cancer*, *123*(11), 1949–1957. https://doi.org/10.1002/cncr.30535

Jansen, F., Eerenstein, S. E. J., Lissenberg-Witte, B. I., van Uden-Kraan, C. F., Leemans, C. R., & Leeuw, I. M. V. de. (2018). Unmet supportive care needs in patients treated with total laryngectomy and its associated factors. *Head and Neck*, *40*(12), 2633–2641. https://doi.org/10.1002/hed.25358

Masters, K. (2014a). Framework for professional nursing practice. In K. Masters, *Nursing theories: A framework for professional practice* (2nd ed., pp.47-87). Burlington, MA: Jones & Bartlett.

Masters, K. (2014b). Roy adaptation model: Sister Callista Roy. In K. Masters, *Nursing theories: A framework for professional practice* (2nd ed., pp. 127-142). Burlington, MA: Jones & Bartlett.

Moore, K. A., Ford, P. J., & Farah, C. S. (2014). “I have quality of life. . .but. . .”: Exploring support needs important to quality of life in head and neck cancer. *European Journal of Oncology Nursing*, *18*(2), 192–200. https://doi.org/10.1016/j.ejon.2013.10.010

NCCN. (2019). *NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines): Survivorship (Version 2.2019)*. Retrieved from https://www.nccn.org/professionals/physician_gls/pdf/survivorship.pdf

Nguyen, N. T. A., & Ringash, J. (2018). Head and Neck Cancer Survivorship Care: A Review of the Current Guidelines and Remaining Unmet Needs. *Current Treatment Options in Oncology*, *19*(8). https://doi.org/10.1007/s11864-018-0554-9

O’Brien, K. M., Timmons, A., Butow, P., Gooberman-Hill, R., O’Sullivan, E., Balfe, M., & Sharp, L. (2017). Associations between neighbourhood support and financial burden with unmet needs of head and neck cancer survivors. *Oral Oncology*, *65*, 57–64. https://doi.org/10.1016/j.oraloncology.2016.12.019

Ringash, J. (2015). Survivorship and quality of life in head and neck cancer. *Journal of Clinical Oncology*, *33*(29), 3322–3327. https://doi.org/10.1200/JCO.2015.61.4115

Ringash, J. (2017). Quality of Life in Head and Neck Cancer: Where We Are, and Where We Are Going. *International Journal of Radiation Oncology Biology Physics*, *97*(4), 662–666. https://doi.org/10.1016/j.ijrobp.2016.12.033

Sandstrom, RN, MSN, APRN-BC, AOCN, S. K., R. Mazanec, PhD, RN, AOCN, S., Gittleman, MS, H., S. Barnholtz-Sloan, PhD, J., Tamburro, LISW-S, N., & J. Daly, PhD, RN, FAAN, B. (2016). A Descriptive, Longitudinal Study of Quality of Life and Perceived Health Needs in Patients With Head and Neck Cancer. *Journal of the Advanced Practitioner in Oncology, 7*(6), 640–651. https://doi.org/10.6004/jadpro.2016.7.6.6

Simcock, R., & Simo, R. (2016). Follow-up and Survivorship in Head and Neck Cancer. *Clinical Oncology*, *28*(7), 451–458. https://doi.org/10.1016/j.clon.2016.03.004

So, Winnie K.W., Wong, C. L., Choi, K. C., Chan, C. W. H., Chan, J. C. Y., Law, B. M. H., … Yu, B. W. L. (2019). A Mixed-Methods Study of Unmet Supportive Care Needs among Head and Neck Cancer Survivors. *Cancer Nursing*, *42*(1), 67–78. https://doi.org/10.1097/NCC.0000000000000542

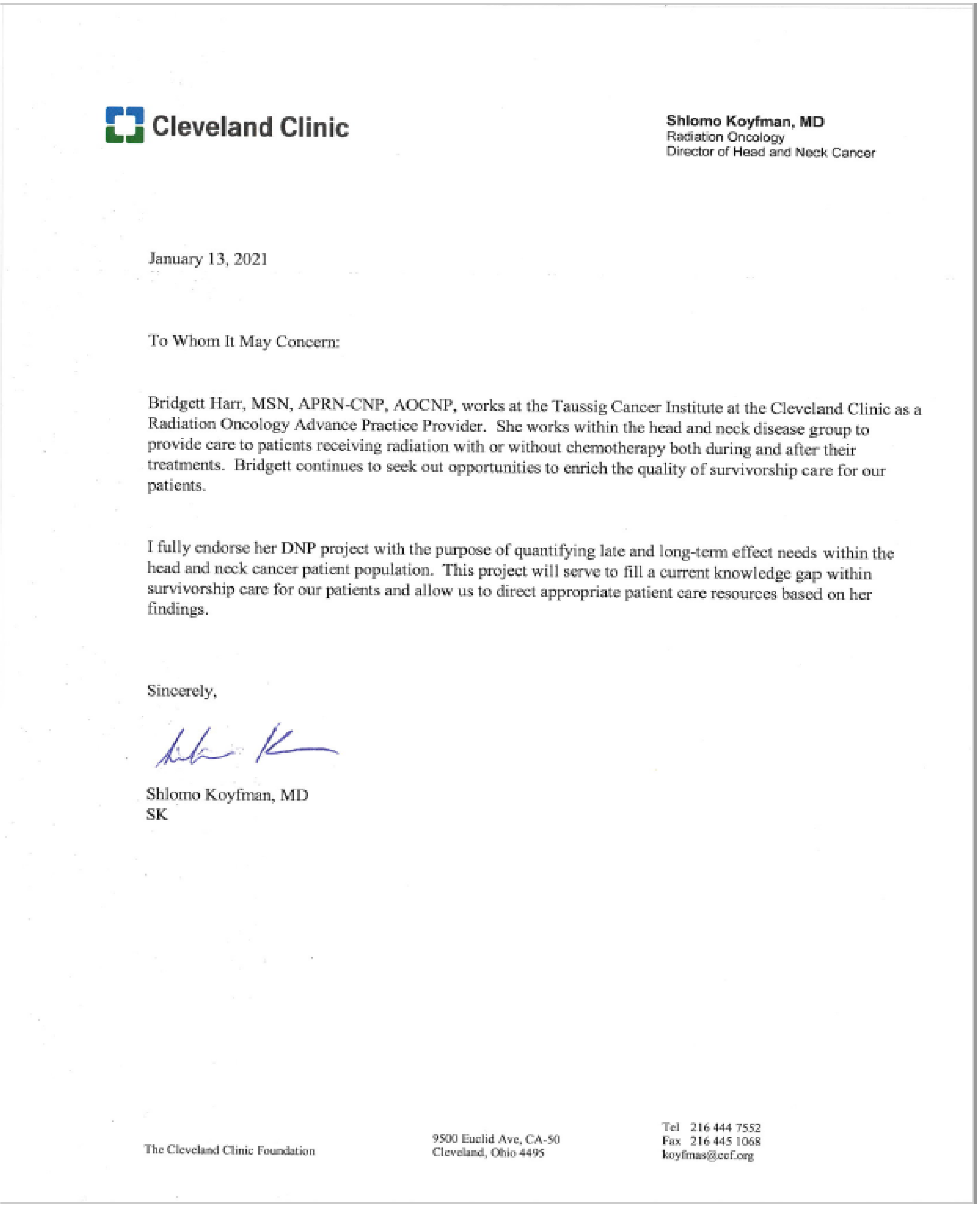
Wells, M., Cunningham, M., Lang, H., Swartzman, S., Philp, J., Taylor, L., & Thomson, J. (2015). Distress, concerns and unmet needs in survivors of head and neck cancer: a cross-sectional survey. *European Journal of Cancer Care*, *24*(5), 748–760. https://doi.org/10.1111/ecc.12370

Ursavas, FE, Karayurt, O, Iseri, O. (2014). Nursing approach based on Roy adaptation model in a patient undergoing breast conserving surgery for breast cancer. *Journal of Breast Health*, *10*, 134–140.

Zaccagnini, M.E. & White, K.W. (2011). *The doctor of nursing practice essentials: A new model for advanced practice nursing* (Custom Ed.). Laureate Education, Inc.

# Appendix A

*Letter of Endorsement*



Cleveland Clinic

**Shlomo Koyfman, MD**
Radiation Oncology
Director of Head and Neck Cancer

January 13, 2021

To Whom It May Concern:

Bridgett Harr, MSN, APRN-CNP, AOCNP, works at the Taussig Cancer Institute at the Cleveland Clinic as a Radiation Oncology Advance Practice Provider. She works within the head and neck disease group to provide care to patients receiving radiation with or without chemotherapy both during and after their treatments. Bridgett continues to seek out opportunities to enrich the quality of survivorship care for our patients.

I fully endorse her DNP project with the purpose of quantifying late and long-term effect needs within the head and neck cancer patient population. This project will serve to fill a current knowledge gap within survivorship care for our patients and allow us to direct appropriate patient care resources based on her findings.

Sincerely,

Shlomo Koyfman, MD
SK

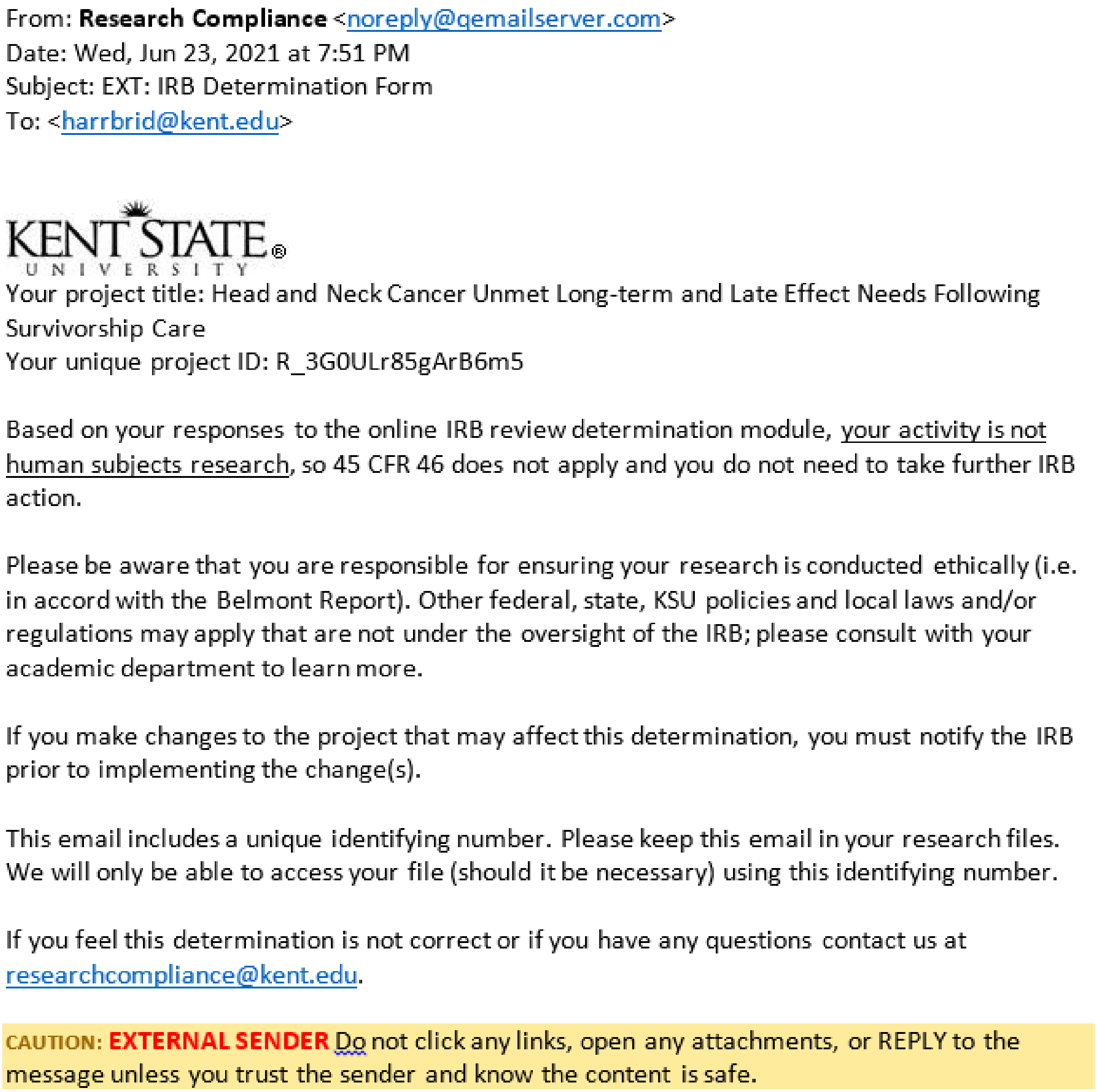
The Cleveland Clinic Foundation

9500 Euclid Ave, CA-50
Cleveland, Ohio 44195

Tel 216 444 7552
Fax 216 445 1068
koyfmas@ccf.org

# Appendix B

*Kent State IRB Exemption Documentation*



From: **Research Compliance** <noreply@qemailserver.com>
Date: Wed, Jun 23, 2021 at 7:51 PM
Subject: EXT: IRB Determination Form
To: <harrbrid@kent.edu>

KENT STATE UNIVERSITY®

Your project title: Head and Neck Cancer Unmet Long-term and Late Effect Needs Following Survivorship Care
Your unique project ID: R_3G0ULr85gArB6m5

Based on your responses to the online IRB review determination module, your activity is not human subjects research, so 45 CFR 46 does not apply and you do not need to take further IRB action.

Please be aware that you are responsible for ensuring your research is conducted ethically (i.e. in accord with the Belmont Report). Other federal, state, KSU policies and local laws and/or regulations may apply that are not under the oversight of the IRB; please consult with your academic department to learn more.

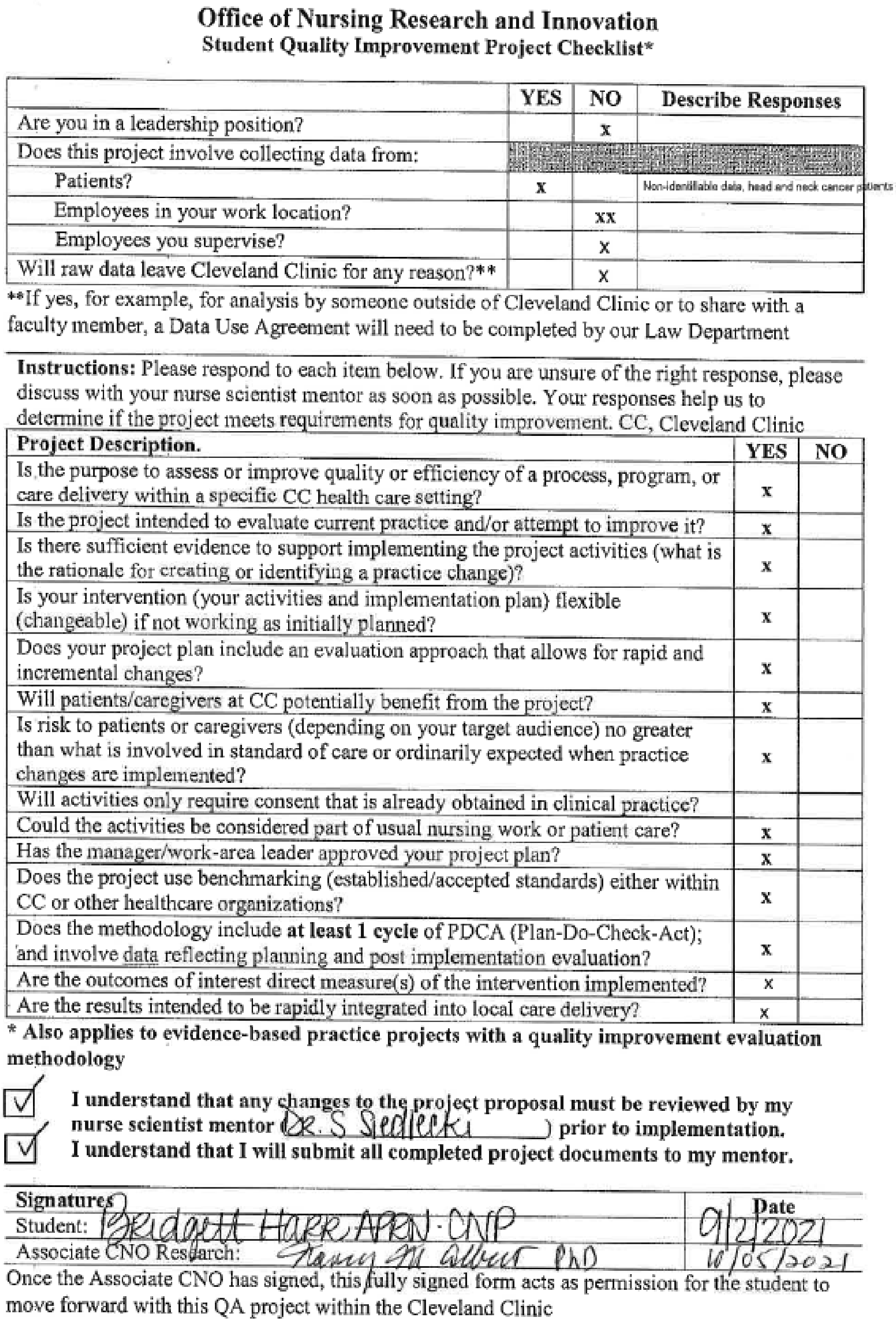
If you make changes to the project that may affect this determination, you must notify the IRB prior to implementing the change(s).

This email includes a unique identifying number. Please keep this email in your research files. We will only be able to access your file (should it be necessary) using this identifying number.

If you feel this determination is not correct or if you have any questions contact us at researchcompliance@kent.edu.

**CAUTION: EXTERNAL SENDER** Do not click any links, open any attachments, or REPLY to the message unless you trust the sender and know the content is safe.

*Cleveland Clinic IRB Exemption Documentation*



## Office of Nursing Research and Innovation

### Student Quality Improvement Project Checklist*

| | YES | NO | Describe Responses |
|---|---|---|---|
| Are you in a leadership position? | | x | |
| Does this project involve collecting data from: | | | |
| Patients? | x | | Non-identifiable data, head and neck cancer patients |
| Employees in your work location? | | xx | |
| Employees you supervise? | | x | |
| Will raw data leave Cleveland Clinic for any reason?** | | x | |

**If yes, for example, for analysis by someone outside of Cleveland Clinic or to share with a faculty member, a Data Use Agreement will need to be completed by our Law Department

**Instructions:** Please respond to each item below. If you are unsure of the right response, please discuss with your nurse scientist mentor as soon as possible. Your responses help us to determine if the project meets requirements for quality improvement. CC, Cleveland Clinic

| **Project Description.** | YES | NO |
|---|---|---|
| Is the purpose to assess or improve quality or efficiency of a process, program, or care delivery within a specific CC health care setting? | x | |
| Is the project intended to evaluate current practice and/or attempt to improve it? | x | |
| Is there sufficient evidence to support implementing the project activities (what is the rationale for creating or identifying a practice change)? | x | |
| Is your intervention (your activities and implementation plan) flexible (changeable) if not working as initially planned? | x | |
| Does your project plan include an evaluation approach that allows for rapid and incremental changes? | x | |
| Will patients/caregivers at CC potentially benefit from the project? | x | |
| Is risk to patients or caregivers (depending on your target audience) no greater than what is involved in standard of care or ordinarily expected when practice changes are implemented? | x | |
| Will activities only require consent that is already obtained in clinical practice? | | |
| Could the activities be considered part of usual nursing work or patient care? | x | |
| Has the manager/work-area leader approved your project plan? | x | |
| Does the project use benchmarking (established/accepted standards) either within CC or other healthcare organizations? | x | |
| Does the methodology include **at least 1 cycle** of PDCA (Plan-Do-Check-Act); and involve data reflecting planning and post implementation evaluation? | x | |
| Are the outcomes of interest direct measure(s) of the intervention implemented? | x | |
| Are the results intended to be rapidly integrated into local care delivery? | x | |

*** Also applies to evidence-based practice projects with a quality improvement evaluation methodology**

☑ **I understand that any changes to the project proposal must be reviewed by my nurse scientist mentor (**Dr. S Siedlecki**) prior to implementation.**

☑ **I understand that I will submit all completed project documents to my mentor.**

| **Signatures** | **Date** |
|---|---|
| Student: Bridgett Harr, APRN-CNP | 9/2/2021 |
| Associate CNO Research: Nancy M Albert PhD | 10/05/2021 |

Once the Associate CNO has signed, this fully signed form acts as permission for the student to move forward with this QA project within the Cleveland Clinic

# Appendix C

*Data Collection Form B*

| | |
|---|---|
| Patient Project Number | |
| Survivorship Visit Date | |

| Identified Need(s): | If yes, addressed in previous visits? |
|---|---|
| ☐ Appearance | ☐ Yes ☐ No |
| ☐ Appearance relating to tracheostomy, feeding tube | ☐ Yes ☐ No |
| ☐ Dental health | ☐ Yes ☐ No |
| ☐ Chewing, eating, or swallowing | ☐ Yes ☐ No |
| ☐ Eating in a social setting | ☐ Yes ☐ No |
| ☐ Speech | ☐ Yes ☐ No |
| ☐ Intimacy | ☐ Yes ☐ No |
| ☐ Change in relationship with significant other | ☐ Yes ☐ No |
| ☐ HPV transmission | ☐ Yes ☐ No |
| ☐ Role changes within family | ☐ Yes ☐ No |
| ☐ Finances | ☐ Yes ☐ No |
| ☐ Work | ☐ Yes ☐ No |

*EMR Dotphrase (.unmet)*

**Patient has questions or concerns regarding:**

Appearance {TCI ASCO GENERAL YES/NO:120467}

Dental health: {TCI ASCO GENERAL YES/NO:120467}

Chewing, eating or swallowing: {TCI ASCO GENERAL YES/NO:120467}

Eating in a social situation: {TCI ASCO GENERAL YES/NO:120467}

Speech: {TCI ASCO GENERAL YES/NO:120467}

Intimacy: {TCI ASCO GENERAL YES/NO:120467}

HPV transmission: {TCI ASCO GENERAL YES/NO:120467}

Change in relationship with significant other: {TCI ASCO GENERAL YES/NO:120467}

Role change within family: {TCI ASCO GENERAL YES/NO:120467}

Finances: {TCI ASCO GENERAL YES/NO:120467}

Work: {TCI ASCO GENERAL YES/NO:120467}

# Appendix D

Table E1

*Cost-Benefit Analysis*

| **Service and Materials** | **Cost** | **Benefit** |
|---|---|---|
| Dot phrase creation within EMR | Usual documentation tool = $0.00 additional cost | Ease of administration of project and identifying patient's perceived needs for future follow up |
| QI project administered during SOC follow up by APRN | 5 minutes x 150 patients = 12.5 total hours during work<br>$52.88 / hour salary for APRN x 12.5 hours = $661.00 APRN time | Identification of patient's perceived concerns to allow for individualization of care and ability to provide patients with specific education and resources |