

Disease-Specific Patient-Reported Outcome Tool in Head and Neck Cancer Patients

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A DNP Project Manuscript  
Submitted in Partial Fulfillment of the Requirements for the  
Doctor of Nursing Practice Degree

University of Maryland School of Nursing  
May 2020

## **Abstract**

### **Problem and Purpose**

Head and neck cancers (HNC) have a five-year survival rate of 62%. The effects of treatment and the disease can be debilitating. Symptoms are subjective and frequently go undetected during clinic visits. Patient reported outcome tools (PROs) provide a quantitative measurement of symptoms and improve symptom management, communication, and patient satisfaction. The Functional Assessment of Cancer Therapy: Head and Neck Symptom Index (FACT: HNSI) is a validated and reliable PRO which can improve symptom reporting and management for HNC patients. The purpose of this project was to implement this tool among HNC patients receiving treatment.

### **Methods**

Structure changes included imbedding the PRO in the patient portal. Process changes included patients completing weekly PROs, treatment team reviewing responses during visits and integrating results in progress notes. A retrospective chart audit evaluated staff's consistency of capturing symptoms listed in the FACT: HNSI prior to implementation. Descriptive data was used to evaluate compliance and effectiveness of implementation. Pre- and post-implementation surveys were administered to staff to evaluate perceptions of the PRO. Patient compliance was defined as percentage of patients who successfully completed the PRO compared to the number who agreed to participate each week. Staff compliance was defined as the percentage of staff who used the smartphrase in patient progress notes compared to the number of patients who completed a PRO each week.

### **Results**

The integration of the PRO into the patient portal was essential to the success of the project. Overall patient compliance was 68.2% while staff compliance was 78.8%. Staff opinions of the project improved by 0.38-1.37 points on a five-point scale between the pre- and post-implementation surveys. The chart audit revealed 46% of the symptoms listed in the FACT: HNSI were routinely captured before implementation.

**Conclusion**

The culture of the organization supported adaptation of PROs in outpatient oncology. Staff education and development of an HNC note template will take place for future sustainability. The FACT: HNSI is a useful tool for the HNC population. Other facilities treating outpatient HNC patients should incorporate PROs to improve the detection and management of symptoms, and patient and staff communication.

## Disease-Specific Patient-Reported Outcome Tool in Head and Neck Cancer Patients

### **Introduction**

The incidence of head and neck cancers (HNC) is increasing and have an overall five-year survival rate of 62%. Effects of treatment modalities and the disease process itself can be severe and debilitating (Mercieca-Bebber et al., 2015; Jackson et al., 2016). Common side effects from dual-modality HNC (DMHNC) treatment include dysphagia, dysgeusia, nausea, vomiting, mucositis, and anorexia (Jackson et al., 2016; Niska et al., 2017). Subjective symptoms frequently go undetected during clinic visits with providers underestimating the impact on quality of life. Patient reported outcome tools (PROs) provide a quantitative measurement of qualitative symptoms, can improve symptom management, communication, and patient and provider satisfaction, all without increasing clinic visit duration (Dobrozsi & Panepinto, 2015; Silveira, Monteiro, & Sequeira, 2018). The Functional Assessment of Cancer Therapy: Head and Neck Symptom Index (FACT: HNSI) is a validated and reliable disease-specific PRO which can improve symptom reporting and management for this patient population (Peng et al., 2018; see Appendix A).

Short-term goals of this project included 1) assessing barriers to using or viewing the PRO, 2) greater than 65% of DMHNC patients completing the PRO before weekly provider appointments, and 3) greater than 65% of the HNC treatment team referring to the PRO results in their progress notes. The desired long-term impact was a decrease in DMHNC patients' treatment deviations, unplanned admissions, emergency department (ED) visits, and oncology urgent care visits by 15% by December 31, 2020. The purpose of this project was to implement an evidence-based, disease-specific PRO among DMHNC patients during outpatient treatment at a large, academic, urban hospital by December 1, 2019.

### **Literature Review**

There is a growing desire among health care professionals to utilize disease-specific PROs in the management of head and neck cancer patients. The ease of use, accessibility to the patient, and a focus on side effects specific to this population were essential components in selecting a PRO and are the focus of this literature review (see Appendix B). The overall level and quality of evidence for the reviewed articles was VI B, good quality (Melnik & Fineout-Overholt, 2014; Newhouse, 2006).

All studies involved the development or utilization of a PRO. Four out of the six studies focused on oncology populations and three focused specifically on HNC patients. Fayanju et al. (2016) developed and implemented a breast cancer PRO through their EHR. The authors conducted a focus group of breast cancer patients who selected topics they felt were key to include throughout their treatment. The author's PRO was a new development but has not been proven effective in practice. Bayliss et al. (2018) collected PRO data from a single health care system of non-oncology specialty sites. The study concluded that to be effective, PROs need to be accessible in the EHR for individual evaluation and focus on patient-reported data.

All studies adequately demonstrated that PROs are a useful clinical tool for patient engagement, symptom management, and patient and provider communication and emphasized the benefits of disease-specific PROs. Jackson et al. (2016) and Niska et al. (2017) utilized online formats that were available to providers through an additional program while Fayanju et al. (2016), Owen-Smith et al. (2018), and Peng et al. (2018) utilized a patient portal for PRO collection. The format utilized could affect results as PROs collected through the patient portal become part of the EHR and were more widely available to the team, unlike those collected in an

online format. The three studies which used the patient portal additionally established patients' willingness to participate (Fayanju et al., 2016; Owen-Smith et al., 2018, & Peng et al., 2018).

Limitations of the studies varied from limited generalizability to development of a tool that is not yet validated and reliable (Fayanju et al., 2016; Jackson et al., 2016). Jackson et al. (2016) developed a new PRO specific to metastatic HNC patients, the Vanderbilt Head and Neck Symptom Survey- Recurrent/Metastatic. This was based on an existing validated and reliable tool at their facility that they tailored to their patient population. Niska et al. (2017) utilized the Linear Analogue Self Assessment tool, a validated and reliable online PRO in outpatient HNC patients. This study had an adequate sample size (n=65) but the mean age was five to ten years older than the general HNC population, which may affect generalizability. Peng et al. (2018) had the only prospective study in an online format, which compared multiple disease-specific HNC PROs. The authors identified the Functional Assessment of Cancer Therapy-Head and Neck Cancer Subscale (FACT: HNCS) and the FACT: HNSI as superior when it is important to capture measures of swallow function.

All of the studies were in agreement regarding PROs' ease of use, application to a variety of patient populations, and the benefits in treatment and symptom management. Although there was a risk of missing a symptom if the PRO does not specifically cover an item, no direct harm was immediately identified among patients in the studies. Additionally, a disease specific PRO minimizes this risk. If successful, the implementation of an HNC-specific PRO will improve symptom management, which will ultimately lead to decreased resources, time and cost required to complete the patient's treatment and follow-up. In summary, there is ample evidence to support implementation and utilization of an HNC-specific PRO in the outpatient oncology center.

### **Theoretical Framework**

The Symptom Management Model is an evidence-based theoretical framework to improve management of disease or treatment-related experiences (Dodd et al., 2001). This model is based on understanding three central concepts: symptom experience, symptom management strategies, and outcomes. One must also understand the variables that influence each of these concepts: the person, their environment, and the health and illness of the individual. To effectively manage symptoms, all three central concepts and their external influences must be assessed (see Appendix C). The symptom experience includes accepting side effects as reported by the patient (Dodd et al., 2001). Symptom management includes the appropriate treatment of disease or treatment-related symptoms to avoid or delay negative outcomes. Effectiveness is measured by the patient experience. This is a dynamic process and often requires changes in strategy for optimal effect (Dodd et al., 2001). A critical factor of the outcomes is adherence to the agreed upon management plan between the patient and their treatment team. To effectively treat each individual, practitioners need to understand all the variables at play and be willing to take a dynamic and individualized approach to symptom management (Dodd et al., 2001).

The Symptom Management Model was the central concept of this project because of its focus on partnering with the patient to improve management of disease and treatment-related experiences (Dodd et al., 2001). Patient reported outcome tools are intended to collect individualized assessments of the patient's experience while he or she goes through treatment. While utilizing the PRO, patients and providers can work together to effectively manage symptoms to improve the patient's experience and quality of life. As the model stresses, this is a dynamic and evolving process that requires the patient and treatment team to partner and meet the needs of each individual patient.

## **Methods**

### **Project Type, Population and Setting**

Inclusion criteria included all adult DMHNC patients, who had a mobile or home device with access to the patient portal and were within their first one to three weeks of treatment as of October 1, 2019. All new DMHNC patients who started treatment during implementation were also included. Exclusion criteria included patients who declined to participate, non-DMHNC patients, patients who did not have access to the patient portal or who could not demonstrate understanding of the tool. The HNC treatment team consisted of one physician, nurse practitioner, and physician assistant, and four HNC infusion nurses. The implementation site was a large, urban, outpatient oncology center. The project aimed to have at least twenty patient participants, which was based on the volume of weekly DMHNC patients in the fall of 2018.

### **Change in Structures and Processes**

The largest structure change was imbedding the FACT: HNSI into the patient portal with visibility of patient responses in the EPIC electronic health record system. This required approval from the PRO's developer, an application process at the implementation site to proceed with access to the patient portal, then widespread approval from oncology leadership, the HNC treatment team, and quality improvement committee. A dedicated information technology (IT) specialist was also needed, as was funding for an expedited build, and dry runs of the PRO and panic alerts. The project lead was responsible for scheduling the PROs to be delivered to patients each week. The treatment team, change champions (HNC infusion nurses), and patients were educated by the project lead on the benefits and use of PROs including manual entry of patient responses (see Appendix D). Patient education emphasized that surveys would not be reviewed until their scheduled appointments and the PROs were not a substitute for going to the ED or

calling the oncology triage line. Process changes included patients completing the PRO on a weekly basis, the treatment team reviewing their responses during clinic visits and noting the results in progress notes by using the dedicated smartphrase. An algorithm was put in place for responding to panic values entered by patients as a safety measure (see Appendix E).

### **Data Collection**

A retrospective chart audit was conducted on 20 encounters, the data was recorded in a chart audit tool in excel that supported weekly comparisons and an overall analysis (see Appendix F). Pre- and post-implementation surveys were administered to participating staff to evaluate perceived usefulness of the PRO (see Appendix G). Answers were in the form of a Likert-scale with one representing “strongly disagree” and five representing “strongly agree.” To minimize the risk to human subjects, de-identified data was collected using the facility’s secured, password protected, charting system. The project proposal was approved by both the University of Maryland, Baltimore’s and the implementation facility’s Institutional Review Boards with a Non-Human Subjects Research determination.

### **Data Analysis**

Descriptive data was used to evaluate patient and staff compliance and the effectiveness of implementation. The results of the retrospective chart audit were compared to the patient and staff compliance during implementation to demonstrate an opportunity for improved symptom identification. Patient compliance was defined as the percentage of patients who successfully completed the PRO each week compared to the number of patients who agreed to complete a PRO each week. Staff compliance was defined as the percentage of staff who used the smartphrase in progress notes on patients who successfully complete a PRO compared to the number of patients who complete a PRO each week.

## **Results**

The most complex part of this project was imbedding the PRO into the patient portal of the EHR. This process was essential to the success of the rest of the project. The project lead was able to secure a grant from the HNC attending physician so the full vision of the project could be realized. During the first week of implementation providers did not have access to the PRO results. The PRO access was updated by the IT specialist, and providers had access starting week two of implementation.

There was a total of 11 patients who agreed to participate during implementation of the PRO over the course of nine weeks starting October 1, 2019. Overall patient compliance was 68.2% (see Appendix H). The weekly patient compliance varied between 25% to 100%. Six patients verbalized to staff the tool was easy to use and helped them communicate their symptoms to their treatment team. One patient provided feedback that it was difficult to keep up with the PROs due to the severity of their side effects, two patients who agreed to participate did not follow-through with completing the tool, and one patient reported difficulty with technology in general.

Overall staff compliance was 78.8% during the implementation period (see Appendix H). Weekly compliance rates varied between 50% to 100%. The treatment team verbalized that they felt the PRO was useful in their visits with patients and was easy to locate the results. Feedback from the team regarding lack of compliance focused on the unintentional omission of the PRO's smartphrase. Facilitators to staff compliance included the use of project champions to ensure the HNC infusion nurses were treating the patients who agreed to participate in implementation. Barriers included staffing limitations which at times prevented enrolled patients from being seen by participating infusion nurses.

Seven staff members completed pre- and post-implementation surveys. Pre-implementation surveys reflected an overall positive view of the PRO and the process surrounding it. The post-implementation surveys all demonstrated positive improvement with opinions improving from 0.38-1.37 points on a five-point scale (of note- the third question in the survey was phrased in the negative and the downward trend of this response indicated the staff members did not believe the tool extended the length of the visit) (see Appendix I).

There was one panic alert triggered during implementation for a patient reporting difficulty breathing. The electronic alert was received by staff the same day the patient's PRO was submitted. The nurse who was assigned to monitor for these appropriately alerted the treatment team and called the patient. The nurse was able to confirm the patient was calling 911 due to the severity of the symptoms. The patient arrived in the ED shortly thereafter and was admitted.

The retrospective chart audit demonstrated 46% of the symptoms listed in the FACT: HNSI were routinely captured before PRO implementation. The most consistently captured symptoms during encounters included difficulty breathing (70%), nausea (70%), and generalized pain (65%). The ability to communicate with others and ability to eat solid foods were only noted in 10% of reviewed encounters, while worrying that their condition will worsen and satisfaction with their quality of life were not noted in any of the reviewed encounters (see Appendix J). These figures demonstrate the gap in key symptoms captured pre-implementation compared to the implementation period which captured all the FACT: HNSI symptoms with every completed survey that was reviewed with a member of the treatment team.

## **Discussion**

Overall the implementation of the FACT: HNSI was successful at this facility. Having a dedicated IT specialist working on the project was key to addressing issues, such as the providers not having access to the PRO results, in a timely manner. Eleven patients agreed to participate in this project, this number is attributable to the low patient volume during implementation. The previous year there were approximately 20-30 HNC patients treated on any given week. This decrease in patient volume was the result of a recent physician turn-over at the facility.

Continuity with nurse assignments is important to also facilitate patient compliance. This project had a small number of staff members who were educated on the PRO, with more widespread staff education this could become part of the normal routine for this patient population. It is also very important to have a plan for panic values reported by patients to ensure patient safety and understanding. The implementation of this project included an algorithm for this which was tested in real time and was successful resulting in appropriate and timely care for the patient. Having dedicated champions was important for the implementation period and would be recommended for long-term use to audit for staff compliance and encourage the ongoing use of the tool in patient assessments and documentation.

Strengths of the project included the patients' verbal feedback stating the tool was easy to use and one patient stated it help them communicate their symptoms to their treatment team. The treatment team was engaged from day one and felt the tool was going to be useful for this population, which also contributed to the project's success. The staff also reported reviewing PRO results did not extend the length of patient visits. The panic alert algorithm was essential to have in place as a patient safety net, as was demonstrated with the real-time test of the alerts.

A limitation of this study is that this tool is HNC-specific and would not be appropriate for other disease groups or the inpatient setting. Additionally, this project included a small

sample size of patients, a limited timeframe for implementation, and the required cost of the PRO build to get the project started. Use of technology presents a potential barrier for future studies for patient who struggle with illiteracy, do not have access to the patient portal, or are uncomfortably with technology. There is also no mechanism to ensure patients are the ones completing the survey and not a family member, which could introduce bias into the results. Education was performed with patients to try to mitigate this as well as checking in with patients at each appointment to ensure they are not having any difficulty completing the surveys. To maximize patient compliance, it was useful to have the change champions trained to enter patient responses. Although this helps bridge the gap for patients who cannot complete the PRO independently, it is not time efficient. The lack of patient participation due to a variety of factors was also noted in literature, with one study recommending having tablets available for patient use at the facility (Falchook et al., 2016). Although this is a reasonable solution, it would be costly and still would not address illiteracy or technological discomfort.

The head and neck attending was pleased with the use of this PRO during implementation and asked that the PRO be extended to all HNC patients on treatment. To ensure this practice is sustainable, criteria will be developed with the HNC attending, the clinical nurse specialist, and the IT specialist to identify patients with provider and infusion appointments to have surveys automatically distributed two to three days before each treatment for completion. Automating this process eliminates the need for a dedicated staff member to schedule survey distribution. A template for an HNC progress note, which will automatically incorporate the most recent patient responses, will also be shared with staff. Additionally, education for all infusion nurses will take place to establish a routine for this population and facilitate the use of the new note template.

## **Conclusion**

This quality improvement process analysis project achieved the short-term goals of 65% compliance for patient and staff participation during the nine-week implementation period. The retrospective chart audit revealed that the HNC team was only documenting the presence or absence of the symptoms listed in the FACT: HNSI 46% of the time prior to implementation. This demonstrates an opportunity for improved symptom reporting and communication between patients and staff as these symptoms will all be captured every time the PRO is completed by a patient and reviewed with a member of the treatment team. Use of the FACT: HNSI did not extend the length of visits and was easy to use in the electronic format. Staff satisfaction surveys revealed an overall positive view of PROs which is important for sustainability.

With the culture of the facility moving towards disease-specific PROs in the outpatient oncology setting, this was an opportune time to integrate the FACT: HNSI for the HNC population. The HNC treatment team was supportive of the adaptation of this validated and reliable tool in their daily practice. And the HNC attending physician verbalized they would like this PRO to be available for all HNC patients receiving medical treatment in the future. Future quality improvement projects can look at long-term patient and staff compliance with less restrictive exclusion criteria. The long-term impact of the use of the FACT: HSNI on unplanned admissions, ED visits, and oncology urgent care visits would be another focus for future projects.

The FACT: HNSI is a useful tool for the HNC population. Ease of use and willingness to participate was demonstrated during the implementation period. Other facilities treating outpatient HNC patients should incorporate disease-specific PROs to improve the detection and management of symptoms, and improve patient and staff communication.

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## Appendix A

## FACT: HNSI Tool

## FACT/NCCN HNSI

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.**

		Not at all	A little bit	Some- what	Quite a bit	Very much
GP4	I have pain.....	0	1	2	3	4
GP1	I have a lack of energy .....	0	1	2	3	4
H&N7	I can swallow naturally and easily .....	0	1	2	3	4
H&N 12	I have pain in my mouth, throat, or neck .....	0	1	2	3	4
H&N3	I have trouble breathing .....	0	1	2	3	4
H&N10	I am able to communicate with others .....	0	1	2	3	4
GP2	I have nausea.....	0	1	2	3	4
H&N11	I can eat solid foods .....	0	1	2	3	4
GE6	I worry that my condition will get worse.....	0	1	2	3	4
GF7	I am content with the quality of my life right now.....	0	1	2	3	4

*Permission for use of FACT: HNSI*



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May 1, 2019,

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*Email Correspondence for Permission of Use for FACT: HNSI Tool*

Hi Kathryn,

I've attached a license here which should cover it. The additions you want to make are fine, although keep in mind the FACIT measures are intended to be patient administered, so it's better if the patient completes the questionnaire rather than a family member. I would recommend a member of the staff administer the questionnaire over a family member, if necessary (because family members could introduce bias in the answers, or inhibit the patient's answers).

Once you register on our website, if you haven't already, you should be able to download and access all of the materials you need. Let me know if you have any other questions.

Kind regards,  
Jason

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## Appendix B Literature Review

### *Article Comparison*

Author, year	Study Objective/ Intervention Compared	Design	Sample (N)	Outcomes Studied	Results	Level and Quality Rating
Bayliss et al. (2018)	Data collection from HCSRN comparing PRO data  Focus on Medicare requirements and patients	Case study  Questionnaire	18 separate sites within the HCSRN were contacted, 15 sites provided responses	Content collected  Collection methods- varied between paper, patient portal, interactive voice response, and clinician entry  Data storage- in EHR from scanned documents, summary databases, and by free text  Extractability- accessible via EHR but not into other databases	Standardization of collecting and storing PROs can facilitate their use across multiple sites of care  Utilization of PRO data can facilitate collaboration of care between providers and patients  10 sites used EHR entry  Limitations: Single health care system  Only 15 of the 18 sites returned the questionnaires  Patient participation in completing PROs at the various sites ranged from less than 10 to 42%	VI C
Fayanju et al. (2016)	Development of PRO through EHR (EPIC)  Use of disease-specific metrics for health status, process of recovery, sustainability of health, which included 22 patient- centered	Tool development	n/a	Breast cancer patients at single facility  8 patients for focus group during PRO development  10 physicians as part of work group to establish outcome measures for the new tool	Provided rationale for use  Limitations: did not evaluate implementation, only developed the tool	VII C

	outcomes specific to breast cancer for optimal care delivery					
Jackson et al. (2016)	<p>Tool development: literature review, focus group- HNC providers/ nurses/ nutrition/ physical therapy/ case manager/ financial advisor- separate on-on-one interviews with recurrent metastatic HNC patients</p> <p>46 physical symptom issues, 13 psychosocial issues, Likert-type scale</p> <p>Online format</p>	Tool development	<p>Pilot: N=50 Recurrent metastatic HNC</p> <p>Preliminary testing: N=50, majority white males, median age 59 years</p>	<p>Symptom frequency related to: swallowing &amp; nutrition, speech, musculo-skeletal, wounds, secretions, xerostomia, respiratory/ nasal, lacrimation, &amp; pain</p> <p>Systemic: energy, weakness, sleep, changes in thinking/ focus/ memory</p> <p>Psychosocial: Problems relating to friends/ family, embarrassment</p>	<p>Feasible tool for this population, easy-to-use, takes a median of nine minutes to complete (range 6-11.5 minutes)</p> <p>Severe systemic symptoms were present in 30-36.7% of patients and severe psychosocial symptoms were present in 18-26.5% of patients.</p> <p>Tool covers 35 physical and 12 psychosocial issues</p> <p>Limitations: No other PROs specific to this subset of patients, this was a new tool development, needs further testing</p> <p>Small sample size</p> <p>Formal analysis required to confirm findings</p>	VI B
Niska et al. (2017)	<p>12-item LASA collected at baseline, biweekly, and during the last week of radiation treatment while in the radiation oncology department</p> <p>Immediately available to</p>	Retrospective collection of AEs	<p>N=65, primarily elderly white males, undergoing radiation therapy (with or without concurrent chemotherapy)</p> <p>Outpatient Oncology</p>	<p>Adverse events</p> <p>Electronic Patient- reported outcomes</p> <p>LASA is a validated and standardized tool for multiple oncology diagnoses</p>	<p>Compliance with completing surveys all &gt;89% each week</p> <p>Decreases throughout treatment: fatigue, social activity, and overall QOL</p> <p>Final week of treatment the LASA scores were all worse than baseline in all domains except financial concerns and support</p> <p>Chemoradiation had significantly worse change from baseline compared to radiation alone</p>	VI B

	<p>providers on desktop or tablet</p> <p>PRO results linked to distress management guidelines by the National Comprehensive Cancer Network for provider reference</p>				<p>AEs: Dermatitis, mucositis, dysgeusia, nausea, odynophagia, and xerostomia occurred in the majority of patients, with chemoradiation at a higher incidence and severity compared to radiation alone</p> <p>All patients at least had grade 1-2 AEs during treatment, 35.4% of chemoradiation and 3.1% of radiation only patients had grade 3 or 4 AEs</p> <p>Mean weight loss: 6.9kg for chemoradiation, 2.8kg for radiation only</p> <p>Limitations: Mean age was 5-10 years older than previously studied head and neck cancer groups</p> <p>Size: N=65</p> <p>Discussion about differences in reports between the chemoradiation and radiation groups was an unplanned analysis</p> <p>Retrospective design for AEs, often by clinician reporting which is known to have only slight agreement with patient-reported AEs</p>	
Owen-Smith et al. (2018)	Evaluate implementation of quarterly PROs using EHR and automated call system	Case study of PRO implementation in an outpatient, primary care chronic pain program	N=831	<p>Number of PRO assessments collected, completeness of PROs</p> <p>Method of completing PRO (EHR versus automated call system)</p>	<p>Age and automated call system increased patient's likelihood to respond</p> <p>Limitations: Only 22% of patients had an active patient portal</p> <p>High adherence overall</p>	VI C

				Respondent demographics: age, race, ethnicity, gender	Ancillary support may be needed for successful implementation and utilization  Single healthcare system  Pain specialty	
Peng et al. (2018)	Completed FACT, MDADI, and SSQ questionnaires in-house on tablets linked to Oncospace database  Compared: FACT-G, FACT-HN, FACT-HNSI, FACT-HNCS, FACT-PWB, FACT-EWB, FACT-FWB, MDADI, & SSQ	Prospective study in single outpatient oncology center with HNC patients	N=363  631 patient encounters  Majority male, Caucasian  96.1% were non-metastatic	Correlation between FACT, MDADI, and SSQ	FACT-HNCS and FACT-HNSI had the strongest correlation with the SSQ and MDADI swallow screenings (-0.669 and -0.625 respectively).  MDADI and FACT provide information on QOL  SSQ useful to group patients into severity of toxicity  FACT-HNSI is a validated and reliable tool.  Limitations: Many other potential PROs available for HNC	IV B
<p><i>Note:</i> AEs: Adverse Events, EHR: Electronic Health Recorder, FACT: Functional Assessment of Cancer Therapy, FACT-EWB: Emotional Well-Being, FACT-FWB: Functional Well-Being, FACT-G: General, FACT-HN: Head and Neck, FACT-HNCS: Head and Neck Cancer Subscale, FACT-HNSI: Head and Neck Symptom Index, FACT-PWB: Physical Well-Being, HCSRN: Health Care Systems Research Network, HNC: Head and Neck Cancer, ISOQOL: International Society for Quality of Life Research, LASA: Linear analog self-assessments, MDADI: MD Anderson Dysphagia Inventory, PRO: Patient Reported Outcomes, QOL: Quality of Life, RCTs: Randomized Control Trial, SSQ: Sydney Swallow Questionnaire</p>						

### Rating System for Hierarchy of Evidence

#### Level of the Evidence Type of the Evidence

- I (1) Evidence from systematic review, meta-analysis of randomized controlled trials (RCTs), or practice-guidelines based on systematic review of RCTs.
- II (2) Evidence obtained from well-designed RCT

III (3)	Evidence obtained from well-designed controlled trials without randomization
IV (4)	Evidence from well-designed case-control and cohort studies
V (5)	Evidence from systematic reviews of descriptive and qualitative studies
VI (6)	Evidence from a single descriptive or qualitative study
VII (7)	Evidence from the opinion of authorities and/or reports of expert committees

Melnyk, B.M. & Fineout-Overholt, E. (2014). *Evidence-based practice in nursing & healthcare: A guide to best practice* (3rd ed.). New York: Lippincott, Williams & Wilkins.

### **Rating Scale for Quality of Evidence**

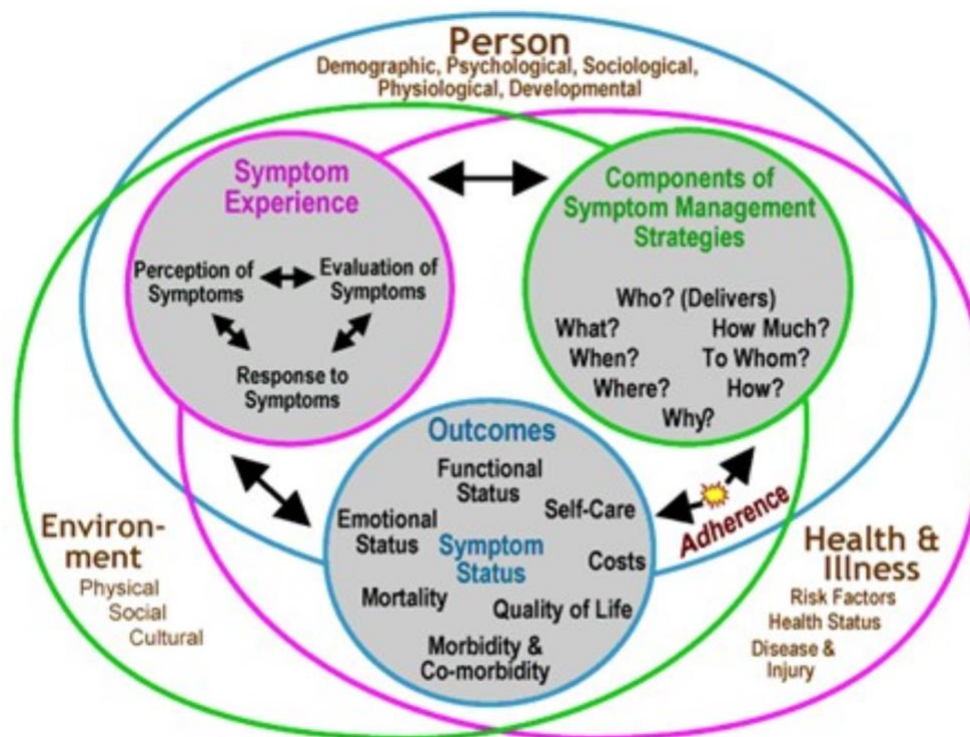
A: High – consistent results with sufficient sample, adequate control, and definitive conclusions; consistent recommendations based on extensive literature review that includes thoughtful reference to scientific literature

B: Good – reasonably consistent results; sufficient sample, some control, with fairly definitive conclusions; reasonably consistent recommendations based on fairly comprehensive literature review that includes some reference to scientific evidence

C: Low/major flaw – Little evidence with inconsistent results; insufficient sample size; conclusions cannot be drawn

Newhouse, R.P. (2006). Examining the support for evidence-based nursing practice. *Journal of Nursing Administration*, 36(7-8), 337-40.

Appendix C  
Symptom Management Conceptual Model



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Appendix D  
Education Materials

*Lesson Plan*

Learning Objectives	Content Outline	Method of Instruction	Time Spent	Method of Evaluation
<b>Staff</b>				
1. Will be able to verbalize the purpose of PROs in clinical practice.	<ul style="list-style-type: none"> <li>• Inclusion/exclusion criteria.</li> <li>• Benefits to patients and staff.</li> </ul>	Fast Fact Sheet with face-to-face to confirm understanding and address questions.	10 minutes	Indication of completed review of PowerPoint slides and Fast Fact sheet.  Teach-back method in one-on-one education.
2. Will be able to provide patients with education on completion of PRO.	<ul style="list-style-type: none"> <li>• How to get into PRO in a step by step process.</li> <li>• Identify location of learning materials.               <ul style="list-style-type: none"> <li>○ Fast Fact sheets.</li> </ul> </li> <li>• Family involvement.</li> </ul>			
3. Will be able to locate patients' completed PROs in EPIC.	<ul style="list-style-type: none"> <li>• Where completed PRO responses are located.</li> <li>• How to access patient responses.</li> </ul>			
4. Will be able to correctly verbalize how to respond to panic alerts and promote safety.	<ul style="list-style-type: none"> <li>• Patient and family education that PRO is not in place of calling triage/on-call provider.</li> <li>• 9-1-1 for emergencies.</li> <li>• If a patient responds with a "4" in any topic, notify physician or advanced practice provider.</li> </ul>			

5. Will correctly identify and utilize the designated smartphrase in their progress notes.	<ul style="list-style-type: none"> <li>• .FACT: HNSI</li> <li>• Using the smartphrase in all progress notes for participating patients.</li> </ul>			
6. Will be able to locate data entry flowsheet to fill in patient answers if patient was unable to complete.	<ul style="list-style-type: none"> <li>• When it is appropriate to fill in responses for patient.</li> <li>• How to ask each question and document patient responses. <ul style="list-style-type: none"> <li>○ Read each question as written, do not paraphrase.</li> </ul> </li> <li>• Assess for technical difficulties if patient was unable to complete PRO responses. <ul style="list-style-type: none"> <li>○ Report technical issues to Kate Campion.</li> </ul> </li> </ul>			
<b>Patient</b>				
1. Will be able to verbalize the purpose of a PRO.	<ul style="list-style-type: none"> <li>• Improve symptom management.</li> <li>• Improve communication with treatment team.</li> <li>• Improve patient satisfaction.</li> </ul>	One on one education with a change champion nurse.	10 minutes	Successful completion of PROs from patients meeting eligibility criteria and who agree to participate.
2. Will be able to verbalize how to complete PRO in MyChart.	<ul style="list-style-type: none"> <li>• Submitting one PRO each week before seeing a member of the treatment team.</li> <li>• Family members cannot submit for the patient.</li> <li>• Steps to take to access weekly PRO and how to submit responses.</li> </ul>	Fast Fact sheet	5 minutes	Teach-back method during patient education.

	<ul style="list-style-type: none"><li>• Nurse can assist in completing that week's PRO responses if there were technical issues.</li></ul>			
3. Will be able to verbalize safety measures.	<ul style="list-style-type: none"><li>• Responses will be reviewed in clinic or treatment visits with staff.</li><li>• PROs are not a substitute for systems in place for urgent issues.<ul style="list-style-type: none"><li>○ Call triage or on-call provider for severe symptoms, concerns, or issues.</li><li>○ Call 9-1-1 for emergencies or go to the nearest emergency department.</li></ul></li></ul>			

### Fast Facts for Staff

#### Using the FACT-HNSI Tool in Dual Modality Treatments

1. Inclusion criteria:
  - a. Adult head and neck patients being treated as outpatients.
  - b. Dual modality patients.
  - c. Have access to home or mobile device with MyChart.
  - d. Agree to participate in completing the FACT-HNSI tool.
  - e. In their first 1-3 weeks of treatment as of September 1<sup>st</sup>
  - f. All new starts from September 1<sup>st</sup> – September 22<sup>nd</sup>
2. Exclusion criteria:
  - a. Patients in weeks 4-7 of dual modality treatment as of September 1<sup>st</sup>
  - b. Non-dual modality treatments.
  - c. Patients who decline to participate.
  - d. Patients who decline to use MyChart.
  - e. Patient who do not have access to a home or mobile device with MyChart.
3. Patient teaching:
  - a. FACT-HNSI can help with symptom management.
  - b. Responses will be reviewed with the treatment team during clinic and treatment visits.
  - c. Becomes part of the permanent health record.
  - d. Complete the FACT-HNSI before provider or treatment visits each week.
    - i. If are not able to complete it or if there are technical difficulties, treatment nurse can complete with the patient.
    - ii. Please do not have family members complete this for you.
  - e. Responses will not be reviewed until scheduled appointments.
    - i. If there is an emergency, call 9-1-1.
    - ii. If you have any questions or concerns, contact triage or the on-call provider. This tool is not a substitute for informing us of severe symptoms.
    - iii. If you mark “4” as a response to one of the questions you should contact triage or the on-call provider.
4. Steps for viewing patient responses:
  - a. Open the patient’s chart in EPIC.
  - b. Open **telephone encounters** select the patient response with the most recent date.
5. Steps for entering patient responses:
  - a. Open the patient’s chart in EPIC.
  - b. Go to **Flowsheets**.
  - c. Select PROs and ask the patient the questions as written and select their response.
6. Include smartphrase (.FACT-HNSI) in your progress note to indicate review of patient’s responses during their visit/treatment.

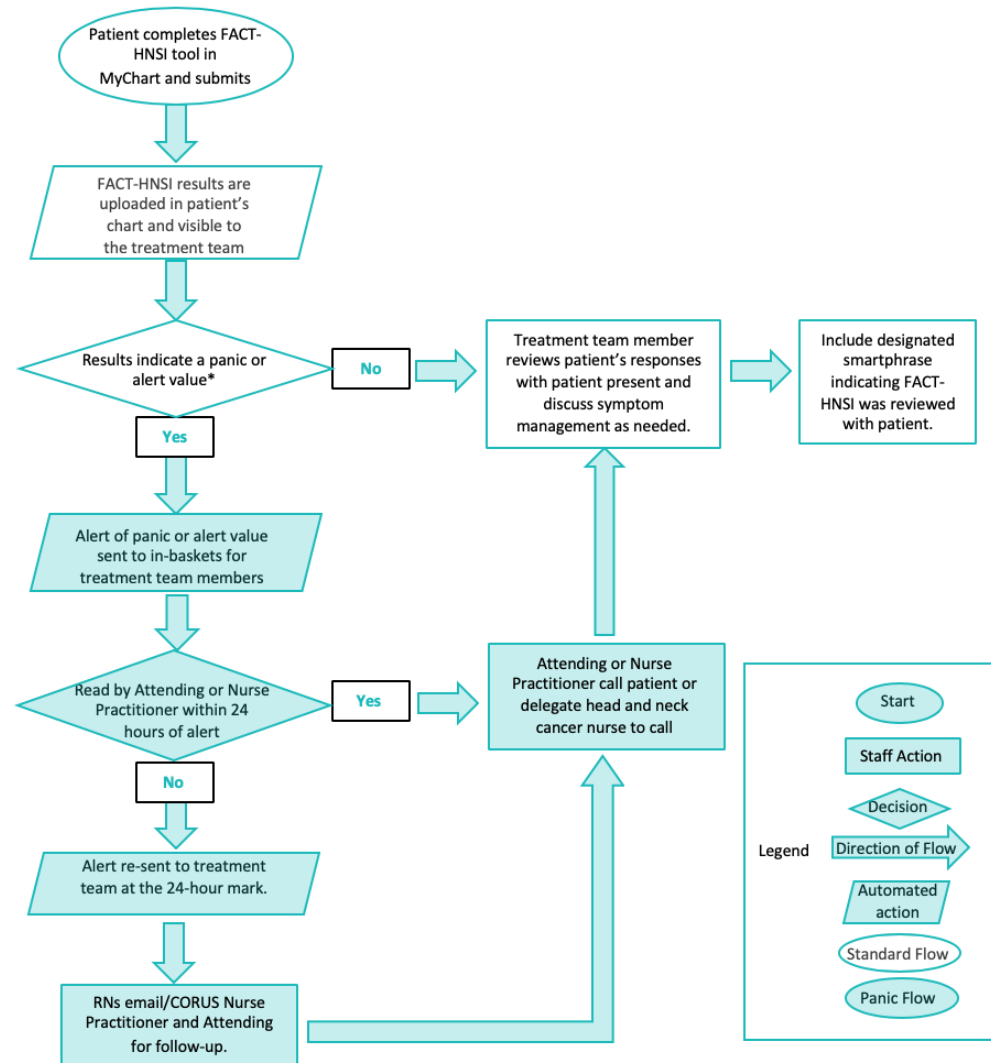
### **Fast Facts for Patients**

#### Completing the FACT-HNSI Tool in MyChart

1. The Functional Assessment of Cancer Therapy: Head and Neck Symptom Index
  - a. A tool used to help with symptom management.
  - b. Shown to increase patient satisfaction and communication with the treatment team.
  - c. This tool is specific to patients receiving chemotherapy and radiation for head and neck cancer.
2. How it will be used:
  - a. Responses will be reviewed with the treatment team during clinic and treatment visits.
  - b. Becomes part of the permanent health record.
3. How to complete it:
  - a. Complete the FACT-HNSI in MyChart before provider or treatment visits each week.
    - i. If you are not able to complete it or if there are technical difficulties, your treatment nurse can complete it with you.
    - ii. Please do not have family members complete this for you.
  - b. Responses will not be reviewed until scheduled appointments.
4. Safety:
  - a. If there is an emergency, call 9-1-1.
  - b. If you have any questions or concerns, contact triage or the on-call provider- this tool is not a substitute for informing us of severe symptoms.
  - c. If you mark “4” as a response to one of the questions you should contact triage or the on-call provider.
5. Steps for completing the FACT-HNSI in MyChart:
  - a. Open your MyChart Application on your home, tablet, or mobile device.
  - b. Log In.
  - c. Select **Inbox**.
  - d. Select the new message entitled, **Head and Neck Survey**.
  - e. Click **Reply**.
  - f. Select your responses to the survey questions.
  - g. Click **Send**.

## Appendix E

### Panic Alert Algorithm



\*Imbedded in the FACT-HNSI survey are reminders to call 9-1-1 for emergencies and numbers for the oncology triage and on-call phone numbers for urgent or emergent issues. There is also a disclaimer stating results may not be read for up to 72 business hours.

## Appendix F

### Chart Audit Tool

1	FACT-HNSI Weekly Chart Audit Tool									
2		Week 1- Oct 1	Week 2- Oct 7	Week 3- Oct 14	Week 4- Oct 21	Week 5- Oct 28	Week 6- Nov 4	Week 7- Nov 11	Week 8- Nov 18	Week 9- Nov 25
3	Number of Patients at each week timepoint.	4	4	4	4	4	7	7	6	8
4	Number of NEW patients enrolled each week.	4	0	0	0	0	4	1	0	2
5	Number of patients completing treatment.	0	0	0	0	0	1	1	1	0
6	Number of Completed PRO patient surveys.	4	3	4	4	2	4	4	3	2
7	Percent patient compliance	100	75	100	100	50	57	57	50	25
8	Number of Patients Reporting IT issues affecting ability to complete PRO.	0	0. programmed surveys to send once weekly for set amount of time	3 didn't receive the scheduled surveys, manually re-sent them.	0	0	0	0	0	0
9	Patient visits with RN/MD/NP/PA.	4	7	6	7	5	4	3	5	1
10	Number of MD progress notes with designated project smartphrase in progress notes.	0- build issue	1 out of 1	n/a	1 of 1	1 of 2	0 of 0	0	1 of 1	0
11	Advanced Practice Providers progress notes with designated project smartphrase in progress notes.	0- build issue	1 provider with 1 out of 2	1 of 2	2 of 2	1 of 1	0 of 0	0	1 of 1	0
12	Number of RN progress notes with designated project smartphrase in progress notes.	1 nurse- (4/4 encounters)	2 nurses- (3/4 encounters)	2 of 4	3 of 4	2 of 2	3 of 4	2 of 3	2 of 3	1 of 1
13	Number of staff who reporte IT issues affecting ability to complete PRO.	3- MD, PA, NP	0	0	0	0	0	0	0	0
14	Total number of smartphrases documented.	4	5	3	5	4	3	2	4	1
15	Percent compliance with use of smartphrase.	100	71	50	86	80	75	67	80	100

## Appendix G

### Pre- and Post- Surveys for Staff

#### Pre-Implementation Survey Staff Version

*Circle the numbers corresponding to how much you agree or disagree with each statement.*

**1. Patient reported outcome tools are beneficial for patient care.**

1	2	3	4	5
Strongly Disagree	Somewhat Agree	Neither Agree or Disagree	Somewhat Agree	Strongly Agree

**2. The FACT-HNSI will be a useful tool in alerting the treatment team of new or worsening symptoms.**

1	2	3	4	5
Strongly Disagree	Somewhat Agree	Neither Agree or Disagree	Somewhat Agree	Strongly Agree

**3. Integration of this tool will extend the length of patient visits/assessments.**

1	2	3	4	5
Strongly Disagree	Somewhat Agree	Neither Agree or Disagree	Somewhat Agree	Strongly Agree

**4. The EPIC build of this tool appears to be easy to use.**

1	2	3	4	5
Strongly Disagree	Somewhat Agree	Neither Agree or Disagree	Somewhat Agree	Strongly Agree

#### Post-Implementation Survey Staff Version

*Circle the numbers corresponding to how much you agree or disagree with each statement.*

**1. Patient reported outcome tools are beneficial for patient care.**

1	2	3	4	5
Strongly Disagree	Somewhat Agree	Neither Agree or Disagree	Somewhat Agree	Strongly Agree

**2. The FACT-HNSI is a useful tool in alerting the treatment team of new or worsening symptoms.**

1	2	3	4	5
Strongly Disagree	Somewhat Agree	Neither Agree or Disagree	Somewhat Agree	Strongly Agree

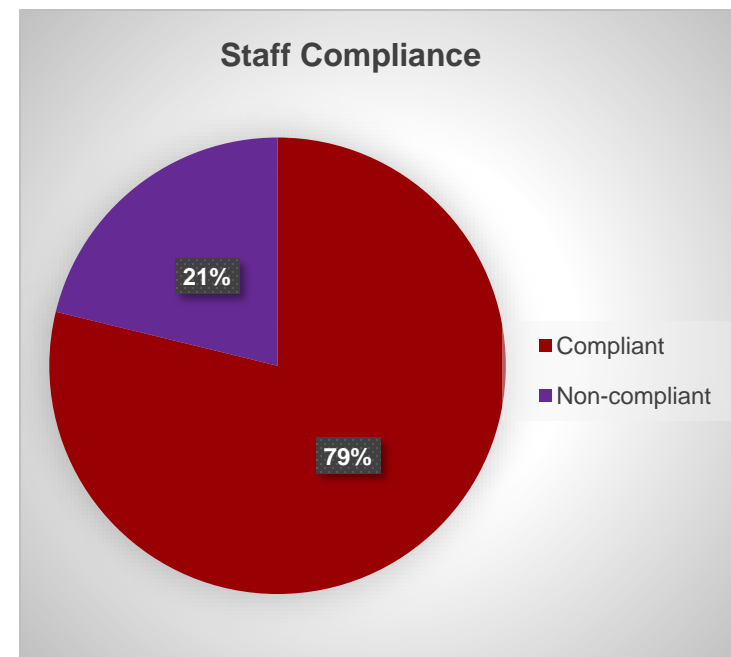
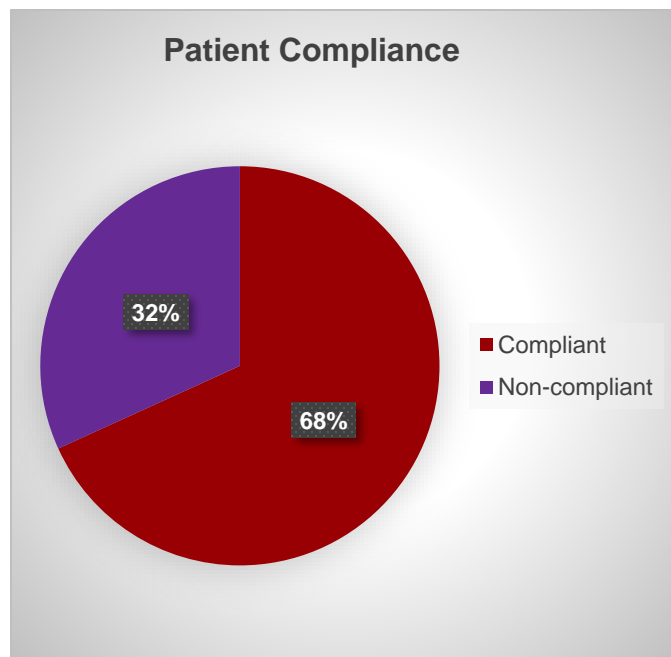
**3. Integration of this tool extends the length of patient visits/assessments.**

1	2	3	4	5
Strongly Disagree	Somewhat Agree	Neither Agree or Disagree	Somewhat Agree	Strongly Agree

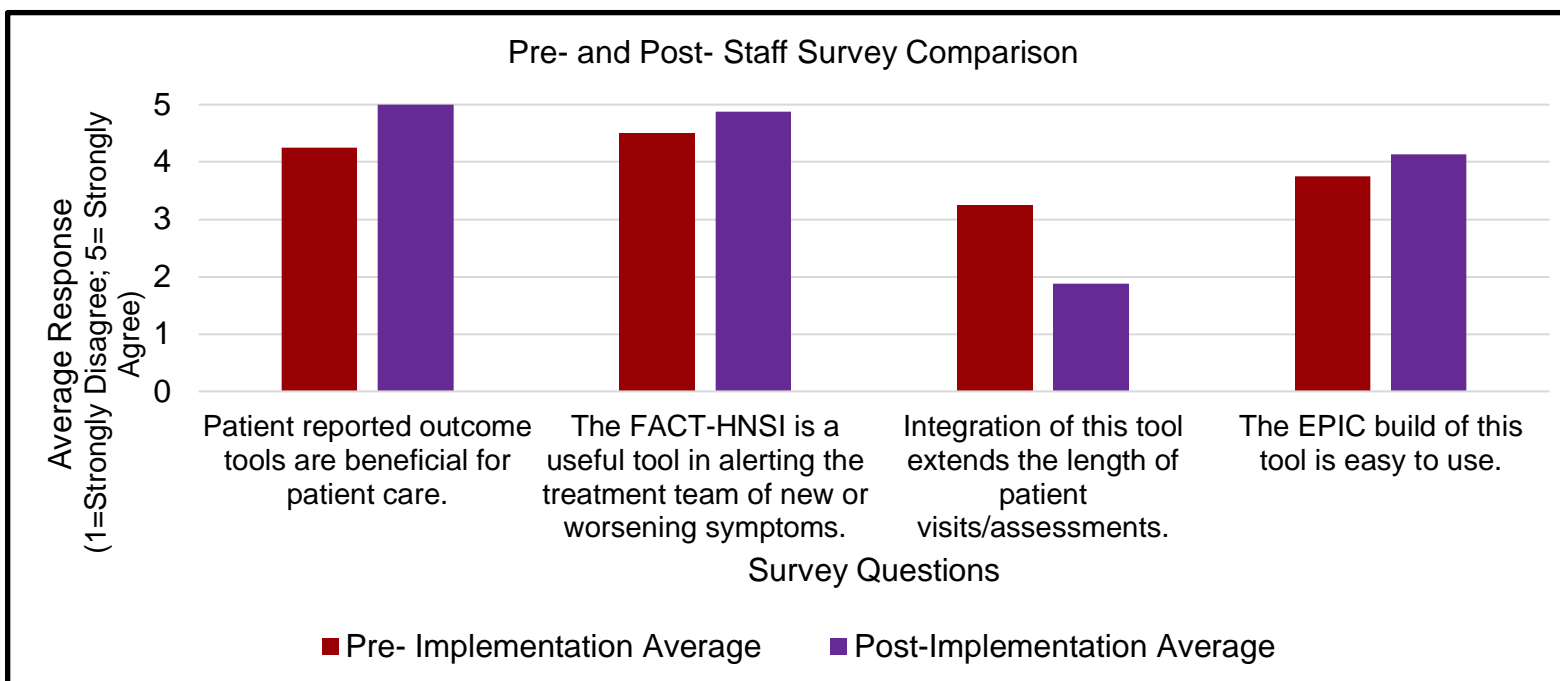
**4. The EPIC build of this tool is easy to use.**

1	2	3	4	5
Strongly Disagree	Somewhat Agree	Neither Agree or Disagree	Somewhat Agree	Strongly Agree

Appendix H  
Results of Patient and Staff Compliance



Appendix I  
Pre- and Post- Staff Survey Results



Appendix J  
Results from Retrospective Chart Audit

