

Patient Orientation and Navigation Binder for Head and Neck Cancer Care

1. Target population

A head and neck cancer diagnosis, especially at advanced stages, can be emotionally overwhelming for patients. Care for the disease can result in a sense of isolation and powerlessness, resulting from a lack of guidance about where additional, reliable information can be found about their disease or who to contact if they seek to understand their condition.¹ For the head and neck cancer population, there is additional stress resulting from concerns regarding potential loss of speech, change in appearance, respiratory challenges, and nutritional support.² Additionally, head and neck cancer care requires complex interdisciplinary care among several specialties in multiple settings, which often leads to fragmentation of care.³ This is further exacerbated by comorbidities that need to be concurrently managed and financial concerns that may impact the level of care a patient is able to access.⁴

Penn State Health is an integrated academic health system serving patients across 15 counties in central Pennsylvania. The system is comprised of 186 outpatient practices and five medical centers, including the flagship tertiary care Milton S. Hershey Medical Center, which also houses the Penn State Cancer Institute. Patients diagnosed with head and neck cancer are able to receive comprehensive care within the Penn State system, but its expansive nature creates barriers in patient navigation.

Currently, head and neck cancer patients are given paperwork from different specialties with no continuity or organizational framework. In this circumstance, it is up to the patient to keep their paperwork and educational material organized, which is especially burdensome for a patient recently diagnosed with cancer. In the context of complex diagnoses and treatment plans, patients often receive an overwhelming amount of information, so it's essential to keep this information organized and in a single location.

2. Methodology

We will develop a custom binder for patients diagnosed with head and neck cancer to aid in their ability to access information about their condition, potential treatments, and their resources within the Penn State Health system. This binder will contain documents and handouts to guide patients throughout their cancer journey.

During the first appointment, our cancer care nurse coordinator will explain the purpose of the binder to the patient and caregiver. Each binder will be personalized with contents such as business cards for their care team and educational materials related to their specific treatment plan. Additional easy-to-read educational materials such as information about clinical trials, details about therapy and radiology services, guidance on managing various side effects, and information about survivorship will be included within the binder.

Specifically, sections of these binders will include details on the proposed surgery, post-surgical instructions and expectations (including drain, feeding tube, and tracheostomy care), radiation oncology treatment, medical oncology treatment, pre-radiation speech pathology, and post-surgical speech therapy. There will also be details on support services including the outpatient head and neck cancer survivor support group and the cancer care center. Finally, there will be a section where patient thoughts, questions, and concerns can be documented and reviewed at upcoming visits.

The binders will be constructed by the nurse navigator who would be seeing the patient with the head and neck surgeon at the initial visit. Patients will be given the option to participate in brief

surveys on their perceptions of the binders, their utility, and the suggestions they have for improvement.

3. Expected outcome

Patients will be asked to bring this binder to every appointment to help track each stage of the treatment process and prepare for future appointments. It is our hope that access to this information will prompt patients to ask pertinent questions and make better-informed decisions about their care. Critically, patients will also have their questions and concerns validated, as they won't be asked to remember thoughts or concerns on the spot in a limited time window and will instead have their concerns better organized and able to be addressed.

4. Community health impact

One of the fundamental missions of The Pennsylvania State University, as Pennsylvania's only land-grant institution, is to promote the general welfare of the state's citizens. The project aligns with this institutional objective. By providing more organized, informed, and empowered care for head and neck patients within the Penn State system, it is our hope that patients local to the Penn State service area will be more confident seeking care locally in central Pennsylvania rather than receiving care at more distant, potentially more financially burdensome institutions.

On an institutional scale, having an increased patient population seeking care within the Penn State Health system allows for greater potential clinical trial enrollment and participation as well as the ability to conduct more expansive and impactful research studies, which help to advance cancer care locally and nationally.

5. Cost

The total cost to produce 500 binders for this project is estimated at \$4,000. We are requesting support for 125 binders at an estimated cost of \$8.00 per binder, totaling \$1,000. The materials within the binders—including printed content, organization, and assembly—will be created and provided at no additional cost.

6. Other available funding

Educational materials will be created and printed using funding from the Department of Otolaryngology – Head and Neck Surgery at Penn State Health. Any costs exceeding the grant amount, including the production of the remaining 375 binders, will be funded by our department to ensure project completion.

Following the demonstration of successful implementation and meaningful patient impact of this pilot, we will present our findings to Penn State Health with the intention of receiving additional funding from the health system for continuation of the program.

References:

1. Canadian Strategy for Cancer Control. Supportive Care and Rehabilitation Working Group Final Report. Jan 2002.
2. Whale Z. Head and neck cancer: an overview. *Eur J Oncol Nurs* 1998;2:99-105
3. Vennedey V. et al. Cologne Research and Development Network (CoRe-Net). Patients' perspectives of facilitators and barriers to patient-centred care: insights from qualitative patient interviews. *BMJ Open*. 2020 May 5;10(5):e033449.
4. Arastu A, et. al. Assessment of Financial Toxicity Among Older Adults With Advanced Cancer. *JAMA Netw Open*. 2020 Dec 1;3(12):e2025810.