

# “Moving On” After Head & Neck Cancer - Development of Patient-Centered Education Materials for Physical and Functional Recovery

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## ABSTRACT

**Purpose.** This project will: (1) identify thematic content to revise an existing physical therapy (PT) education booklet “Moving On” for head and neck cancer survivors (HNCS); (2) elicit feedback from HNC survivors, supportive others, and HNC medical experts.

**Methods & Data.** Our sample will be a convenience sample drawn from local HNCS groups, local and regional hospitals. We will conduct 4 focus groups and use an iterative qualitative approach to revise “Moving On” for HNCS. Group (GP) 1 will consist of HNCS; GP 2, HNC supportive others; GP 3, HNC medical experts; GP 4, HNCS and supportive others. We will recruit 4 - 6 participants per focus group (total of 16-24) who are over the age of 18 are either a HNCS, supportive other or medical expert. Feedback elicited includes recommendations on content to be revised, layout, design, literacy level, acceptability and feasibility, mode and timing of education delivery for the HNCS.

**Expected Results.** We expect that the focus groups will identify and prioritize topics such as neck, jaw and shoulder range of motion, postural education, pain, fatigue, lymphedema, post-operative movement precautions, exercise guidelines, and skin care. We expect the participants to make recommendations on plain language, organization, style, layout, design and potential for acceptability and feasibility and timing of delivery for “Moving On” for the HNCS.

**Significance.** Our intervention may improve physical/functional outcomes after HNC treatment. These data will be used to inform a larger pilot test to determine acceptability and feasibility of delivery of the education materials.

## PURPOSE & BACKGROUND

The purpose of our study is to develop evidence-based & patient informed early PT education materials targeted & tailored for the unique physical recovery needs of survivors of HNC & their families.

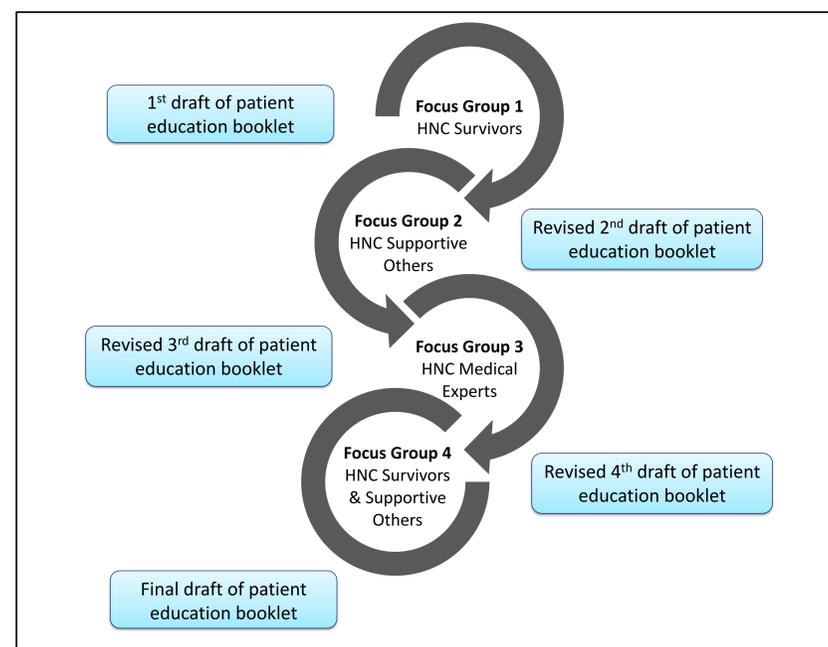
- In 2014, there were 14.5 million cancer survivors in the United States – 4% constitute those with head & neck cancers (HNC).<sup>1</sup>
- While HNC is considered rare, disability from HNC treatment is not.
- HNC treatment is grueling - surgery, combined chemotherapy & radiation (CCR) & in some cases, reconstruction of the face and/or neck (e.g.: mandibulectomy, auriculectomy, facial bones, floor/roof of mouth, carotid & jugular vasculature, etc.).<sup>2</sup>
- HNC treatment can be disfiguring resulting in serious physical impairments such as limited arm and/or neck range of motion, abnormal posture, vocalization, swallowing, muscle weakness & wasting.
- The National Cancer Institute’s (NCI/NIH) Office of Cancer Survivorship prioritizes research on chronic/late effects of cancer and its treatment.<sup>3</sup> Physical therapy (PT) may be a critical “missing link” in reducing HNC treatment –related impairments and disability. Our research is well-aligned with national research priorities.

## AIMS

**Aim 1:** Develop a evidence and physical therapy-based and patient centered HNC survivor’s guide to physical and functional recovery.

**Aim 2:** Explore acceptability, feasibility, and mode and timing of delivery of early physical therapy based education materials on HNC side effects and physical and functional recovery after treatment.

## DATA & METHODS



## EXPECTED RESULTS

This study protocol is currently under review at the Northeastern University Institutional Review Board. We expect the following:

- To create patient-centered education materials for early PT education to be delivered prior to HNC treatment.
- Our focus group participants will identify:
  - Plain language, organization, style, layout, & deign for the education materials.
  - Priority topics to be included in the education materials.
  - Barriers & solutions to early, pre-treatment delivery of PT/patient centered education on physical and functional recovery from HNC treatment.
  - Rate the final patient education materials (booklet and video) positively and the pre-operative timing of education delivery by physical therapy as acceptable and feasible.

## CONCLUSIONS

We expect our study to produce targeted, tailored physical therapy and patient-centered education materials on HNC recovery that will:

- Hasten physical & functional recovery
- Reduce fear and anxiety of physical and functional recovery through delivery of knowledge
- Improve physical/functional outcomes & quality of life in head and neck cancer survivors faster than current interventions.

These data will be used to inform a larger pilot test to determine acceptability and feasibility of delivery of the education materials.

## SELECTED REFERENCES

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