

# headandneck 5000

## **The construction of a percentile calculator for identifying the rarity of fears of cancer recurrence (FCR) in head and neck cancer patients**

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### **Scientific outline**

Summary: The study will prepare a manuscript to assist H&N cancer specialist clinicians and their team members in their out-patient follow-up appointments to determine the level of fears of cancer recurrence (FCR) in their patients. There is a realization that this psychological construct is crucial as it influences distress levels, requests for additional tests and medication, and prevents patients from making future plans and generally returning to previously valued activities. A percentile rank will be computed from the 4 item FoR scale included in the HN5000 questionnaire which presents a rarity value with 95% confidence intervals of how concerned patients are of their cancer returning. A downloadable calculator for clinicians to print out this value will be made available for entering into the patient's case notes. Cases at the 10% level or less rarity (i.e. very high FCR intensity score) would trigger further questions by the team and consideration for referral for psychological support or intervention (Humphris and Rogers, 2012, Humphris and Ozakinci, 2008).

Proposal outline: Background

Fears of recurrence are one of the greatest unmet needs of cancer patients (Rogers et al., 2010, Simard et al., 2013) . This is acknowledged especially within the field of head and neck cancer where patients have to cope with multiple treatment modalities in many cases, including surgery, chemo- and radio-therapy. Approximately 35% of H&N cancer patients have significant FCR (Ghazali et al., 2013). The recovery period is peppered with multiple follow-up visits, checkup appointments and additional tests. Many of these activities are prompted by patient reports of unusual sensations, painful episodes and symptom complaints triggered more by uncertain meanings attributed to unusual perceptions of bodily symptoms such as: throbbing, itching, numbness, soreness, stabbing pain, discomfort, swelling, dryness etc. Such sensations trigger undue concern that on occasion may

be legitimate as they indicate a change in physiological process that may be symptomatic of a recurrent disease process (Lee-Jones et al., 1997). Unfortunately, the frequency of these changes experienced by patients is so strong that to infer a recurrent malignancy is to encourage too low a threshold. Hence, the task for the clinician is to respond empathically to patient concerns (Zhou et al., 2015) and to estimate when the fears that are being expressed begin to work negatively for the patient (the consequences of the experienced fears become too great to be ignored, e.g. multiple requests for biopsies, visual checks or imaging tests; inability of patient to concentrate, perform usual every day physical or social tasks not inhibited by physical condition alone). That is, the patient has become so fearful of the cancer returning, that they cannot lead, what might be considered, a normal life as far as is physically possible. Their interpretation of their bodily sensations and general fear towards recurrence therefore present a considerable challenge.

The assessment of FCR has depended heavily on self-report questionnaires (Thewes et al., 2012). Many measures have been reported, however the development of brief measures which might be used routinely has been relatively slow. There has been a call recently to examine the possibility of designing 'screening' assessments for FCR that will enable the possible identification of patients where further assessments might be considered to determine if additional patient support might be required (Lebel et al., 2016). What is lacking to date is a brief measure designed for head and neck cancer patients that provides estimates of rarity, that is, percentiles for various key groups of patients (demographic and possibly disease related variables). For example, it is clear that age of the patient is critical in predicting FCR level (Ghazali et al., 2013). Younger patients are more fearful (Simard et al., 2013, Ghazali et al., 2013). Hence rarity values will be significantly different across the age range. Hence percentile tables would be developed for publication for patients at different age levels (e.g. less than 55 years, 55-69 years, 70+ years). We plan to derive normative tables for the Fear of Recurrence 4ITEM scale construct and publish (including a downloadable tool freely available) a percentile calculator with confidence intervals.

#### Methods:

- Obtain ethical approval for access of data file.
- To transfer all cases collected in the HN5000 study to include the subset of variables specified above to 'safe haven' facility (Coding Room) in the Medical School of the University of St Andrews.
- Prepare normative tables with 95%CI's,
- Construct software (Delphi code) to make available a downloadable calculator with printable (or pdf file) results for inclusion in the case notes
- To publish this tool in a peer-review publication (preferably on-line journal) for easy access and encourage early and frequent use.