**Radiotherapy Head and Neck Clinical Dataset (RT-HaND\_C) User Guide Summary**

Last updated: 11/11/2024

This document briefly sets out a user summary guide to the Head and Neck Retrospective Cohort Clinical Dataset. For further detail on exact aspects of data categories available, data sources and data completeness please see the full ‘Head and Neck Retrospective Cohort Clinical Dataset’ SOP and Data Dictionary documents.

**The Clinical Dataset**

Comprised of demographic, disease, treatment and outcome data from 2895 patients seen by the GSTT Head and Neck Oncology team between 1/1/2010 and 4/10/2023. Data is up-to-date (e.g. follow-up dates) to the point of 4/10/2023.

**Data Requests by Researchers**

*Definition of Population Required by Researcher*

The dataset will be filtered (essentially ‘searched’) for the data requested by the researcher to meet their use case requirement applying principles of data minimisation. Data requirements will vary depending on the nature of the research project but it is suggested areas for data requirement specification may include primary tumour site, disease staging, and treatment received.

Population request example:

“AJCC stage 3 and 4 (TNM 7) larynx cancer patients treated with radical radiotherapy +/- concomitant or induction chemotherapy”. Researchers are asked to provide, in addition, the timeframe for the data requested.

Please note that data for patients whose initial treatment was at a different centre (n=41) or who were diagnosed before 2010 (n=40) may be less comprehensive and therefore by default will not be supplied unless specifically requested.

*Data Categories of Interest to Researcher*

Researchers will be asked to specify and justify the specific data categories they require and demonstrate data minimisation principles. Data available can be broadly subdivided into (see summary figure below):

Patient factors

* Demographics
* Co-morbidities
* Deprivation indices

Disease factors

* Site
* Staging
* Histopathological factors

Treatment factors

* Overall treatment plan
* Surgery
* Chemotherapy (induction/concomitant/palliative)
* Radiotherapy (including dosimetry)

Outcomes

* Toxicity – CTCAEv.4.0 and v.5.0/RTOG grading, PROMs
* Follow-up/death date
* Disease outcomes

**Data Supply**

Once data requests have been through the necessary approval process, clinical data will be supplied as a CSV file for the user to analyse for their use case.

**Data Usage and Linking to XNAT Imaging Data**

Data provided to members of the Head and Neck oncology team will contain a subject ID for each patient that will correspond with the subject ID for patients’ imaging/radiotherapy data (if imaging/radiotherapy data also requested and supplied) so that updated spreadsheets are shared back with the database for future use. Data to other researchers will be provided anonymised. Data is provided *temporarily* for the completion of a particular study.

**Data Citation**

Please see SOP Appendix 3 on any names that need to be acknowledged in the work (dependent on the type of data used).

**Research Commitment**

In exchange for data provided, we request that researchers from within our organisation commit to making their own contribution to our dataset by validating a small proportion of data provided to them and to add missing data they require (in data category specific format as described within the data dictionary). We request this validated and updated dataset is then shared with the database for future use. This contribution will help increase our dataset’s validation and completeness for future research.

