NET-QUBIC newsletter

March 2024
First edition

Ten years ago the first patient was included in the NET-QUBIC consortium. Now 10 years later we have data and biobank samples of 739 head and neck cancer patients and 262 informal caregivers. Using NET-QUBIC data and samples we have increased our knowledge on swallowing and mastication (UMC Utrecht), fear of cancer recurrence (RadboudUMC), symptoms of depression, insomnia, and quality of life in relation to survival (AmsterdamUMC), supportive care needs of patients (AmsterdamUMC) and quality of life and supportive care needs of informal caregivers (ErasmusMC), and many other topics. NET-QUBIC samples were among others used for a high-impact paper on the detection and localization of cancers using platelet RNA (in 't Veld et al. Cancer Cell 2022).

The tremendous amount of data and biobank samples could not have been reached without the continuous willingness of patients and their informal caregivers to participate. At the end of the first part of NET-QUBIC (KWF-I), at 2 years follow-up, patients already completed up to 10 booklets of patient reported outcomes and participated in up to 4 home visits with collection of biobank samples. Time invested is estimated at 23 hours per patient and 10 hours in caregivers. Nevertheless patients were more than willing to continue participation in the follow-up project (KWF-II) with patient-reported outcomes at 3, 4 and 5 years and an additional home visit/ biobank sample collection at 5 years follow-up. Almost two thirds of all patients alive at 5 years follow-up participated. We are very grateful for this large response!

NET-QUBIC facts

- In 2024 we celebrate the 10-year anniversary of NET-QUBIC. March 2014 the first patients were included.

- So far, 31 NET-QUBIC studies have been published and 23 studies are ongoing.

- Patient-reported outcomes, interview data, biobank samples and clinical data from time of diagnosis up to 5 years follow-up are available.

- At 5 years follow-up, 65% of all patients alive still participate (n=325).

Besides the patients and informal caregivers, we would like to thank all fieldworkers, PhD-students, clinicians, data managers and researchers from all participating centers for their help on this project! We hope that the coming years many more researchers will make use of NET-QUBIC data and samples to improve the treatment and quality of life of head and neck cancer patients and their loved ones.

Call for research: 9th data release

New research proposals can be submitted up to May 26, 2024. Patient-reported outcomes, clinical data, fieldwork data and biobank samples from diagnosis up to 5 years follow-up are available!
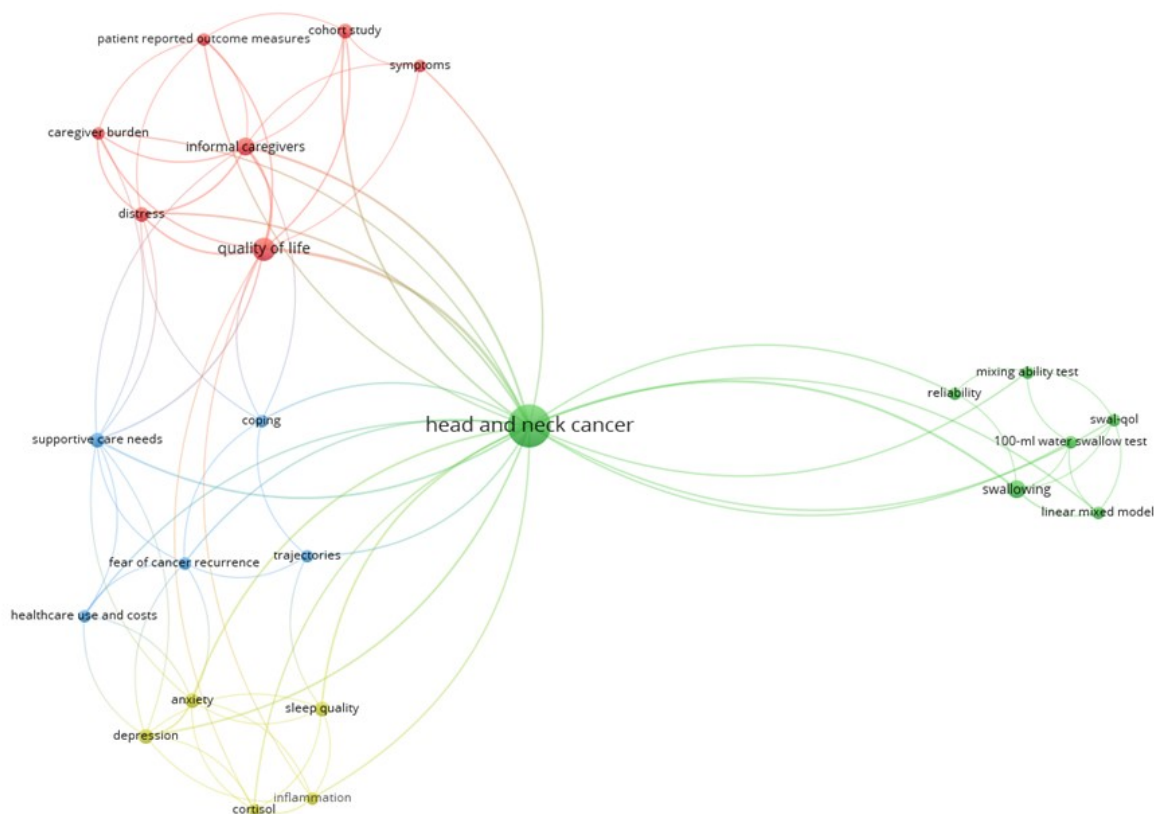
Data catalogue available!

On the NET-QUBIC website (www.kubusproject.nl/data-catalogue/) we have published the data catalogue in which you can find detailed information on all available data and types of biobank samples. The data catalogue is continuously updated with information on new derived data, for example, telomere length and cytokine levels measured in blood samples, cortisol levels from saliva samples, collected data on healthcare utilization and DICOM-RT data.

DICOM-RT data available!

The collection of available data and biobank samples of HNC patients and informal caregivers is still growing! With help from different radiation oncologists, prof Hans Langendijk and Dr. Niels Raaijmakers DICOM-RT was collected from all head and neck cancer patients. They are currently working on a shared taxonomy and dosimetry.

Published studies

So far 31 NET-QUBIC studies have been published. The figure below is based on the keywords of these publications and provides insight into the topics investigated so far. The largest nodes represent the most investigated topics. A keyword is presented as a node in case it was named at least twice.

Besides these published studies, additional studies are ongoing on for example liquid biopsy, the oral microbiome, waiting times, late toxicity, survival and lifestyle. For an overview of all ongoing studies, see www.kubusproject.nl/appendix-1/.

Two PhDs

In this news letter we present the work of two young researchers who used NET-QUBIC data in their PhD research.

Jorine Vermaire (UMC Utrecht) investigated deficits in mastication, salivary flow and swallowing among head and neck cancer patients. One of the studies presented in her thesis focused on the course of swallowing problems in the first two years after diagnosis. She found that about half of all head and neck cancer patients experience swallowing problems at 2 years after treatment. Jorine successfully defended her thesis in 2022.

Angelina Santoso (Vrije Universiteit Amsterdam) investigated the prevalence of sleep problems, trajectories of sleep quality and the role of biomarkers of stress and inflammation in a psychoneurological network consisting of sleep, anxiety, depression, fatigue and oral pain among head and neck cancer patients. She succesfully defended her thesis in 2023.

Two international visitors: Joan Medina (Spain) and Aurora Ninfa (Italy)

Also internationally there is increasing interest in NET-QUBIC data. In 2022 Dr. Aurora Ninfa visited AmsterdamUMC for 3 months. In 2023 Dr. Joan Medina visited Amsterdam as well.

Dr. Aurora Ninfa is a speech and language pathologist and researcher from Milan, Italy. She investigated changes in social eating over time among head and neck cancer patients in relation to swallowing, oral function and nutritional status. Her research has been published in Cancers.

Dr. Joan Medina is a psychologist and researcher from Barcelona, Spain. He received a visiting professorship grant from Cancer Center Amsterdam. During his stay he investigated psychoneurological symptom profiles among newly diagnosed head and neck cancer patients in relation to sociodemographic, clinical, lifestyle, and biological variables.

Questions?
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