

THE BENCHISTA PROJECT: INTERNATIONAL BENCHMARKING OF CHILDHOOD CANCER SURVIVAL BY TUMOUR STAGE



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Background and Aims

Variation in stage at diagnosis of childhood cancers (CC) may explain variations in survival rates observed between countries. This project aims to understand these differences and to encourage the application of the Toronto Staging Guidelines (TG) by Population-Based Cancer Registries (PBCRs) to the most common solid paediatric cancers.

Methods

PBCRs within and outside Europe have been invited to participate in The BENCHISTA Project. PBCRs will identify all cases of **Neuroblastoma, Wilms Tumour, Medulloblastoma, Ewing Sarcoma, Rhabdomyosarcoma, and Osteosarcoma** diagnosed in a consecutive three-year period within 2014-2017 and apply the TG at diagnosis. Other non-stage prognostic factors, treatment and recurrence/progression will be collected. A minimum of 3-year follow-up has to be assured.

Results



Participation

67 PBCRs from 28 countries have committed to participate and have agreed a maximally depersonalised, patient-level data collection format. Based on the pilot study, a total of >8,000 staged cases are expected.

Stage distribution and survival analyses will be conducted by large geographical regions comparable to prior EURO CARE Studies.



Data Transfer Agreement (DTA)

40 PBCRs required a DTA to comply with data protection regulations. For 27 PBCRs the data format and ethical approval are sufficient for data transfer.

Due to heterogeneity encountered in legal aspects, ~15 months were spent on finalising the DTA.

Data started to flow to the data controller (INT) from March 2022.



TG Standardisation

To standardise TG application by cancer registries, three on-line training workshops led by six tumour-specific clinical experts were held.

These contain information about the solid tumours of interest and TG exercises.

The internationally recognised CanStaging+ tool is also mentioned to raise awareness and encouragement for use.



Tools and Quality Assurance

A questionnaire focused on data collection/data sharing processes and a quality assurance exercise consisting of 12 fictitious cases for TG staging were generated and currently open for completion by PBCRs.

A bank of questions from PBCRs and answers from the BENCHISTA Team was produced and is available for public overview in the project's website.



Other Developments

Communication and dissemination channels have been developed to link the project's content to different audiences. These include: website, social media content and quarterly newsletter.

Patient and Public Involvement and Engagement (PPIE) activities have been held with support of leads in the field with upcoming plans in process.

Conclusions

Despite efforts to harmonise General Data Protection Regulations across Europe, multiple differences in interpretation and required processes were encountered, causing delays to data transfer. The BENCHISTA Project has achieved a large-scale collaboration across PBCRs and with their clinical data sources to assign stage at diagnosis according to international consensus guidelines. This is a key aspect for improving patient outcomes and stimulating research.

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International benchmarking of childhood cancer survival by stage

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