Fondazione IRCCS Istituto Nazionale dei Tumori







THE INTERNATIONAL BENCHMARKING OF CHILDHOOD CANCER SURVIVAL BY STAGE (BENCHISTA PROJECT)

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Introduction

Population-based overall survival rates for childhood cancers (CC) show variation by geography across Europe. This could be due to differences in stage at diagnosis.

The **BENCHISTA project** is a collaboration between population-based cancer registries (PBCRs) to *apply the International Consensus Toronto Staging Guidelines* to six childhood solid tumours to *assess the extent of variation in stage* at diagnosis at a population level and how much this contributes to the observed survival differences. The project will also *assess the feasibility* for PBCRs to collect additional information on treatment modalities, relapse, some non-stage prognostic factors and cause of death.

Method/Project description								
PBCRs across Europe and internationally have been invited to participate in the BENCHISTA project.		Participating PBCRs commit to identifying all cases of six solid tumour types diagnosed in a consecutive three year period within 2014-2017, with a		The six tumours are For ages 0-14 years: Neuroblastoma Wilms tumour Medulloblastoma For ages 0-19 years:		PBCRs will use the data sources available (under national laws and permissions) to assign the Toronto stage at diagnosis to		PBCRs are encouraged to involve clinicians to discuss "grey cases".
		minimum of 3 year follow-up to be		Ewing sarcoma Rhabdomyosarcoma		each patient.		



All data are submitted directly from each PBCR to INT, Milan, where the database is being assembled, processed and stored according to **strict GDPR principles**. Stage distribution and overall survival by stage will be **analysed by tumour type and by large geographical regions** (groupings similar to EUROCARE studies) or based on the number by country.

The project is led jointly between University College London and INT and funded by Children with Cancer, UK.

Results

Almost 70 PBCRs from 30 countries are active members of the Project Working Group (PWG). 64 PBCRs have already committed to collect and submit data. The others are still assessing their requirements (or capabilities) to take part.

For 20 PBCRs, ethical approval by UCL and INT was sufficient for data submission.

In process of getting further information

44 PBCRs required a Data Transfer Agreement (DTA).

Different data sources will be used to construct the Toronto Stage, depending on each PBCR's processes, data access and regulations. A series of **tumour-specific trainings** led by clinical experts and the Belgian PBCR were held to prepare the project data collection as part of quality assurance efforts to standardise staging.

Based on data held in the EUROCARE database at INT, we expect **>8.000 patients** to be included in the BENCHISTA database. Previous modelling has shown a difference in survival for Neuroblastoma that could be explained by difference in stage specific survival.

on DTA status from other PBCRs.

Discussion

The **BENCHISTA project** is a first step to understand reasons for international variation in overall survival for childhood cancer at a population level. It is expected to illuminate the relative importance of later diagnosis versus variation in treatments given. Participation will prepare PBCRs for the routine collection of Toronto Stage according to international consensus guidelines for future benchmarking studies anticipated by the European Network of Cancer Registries.

References:

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