

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

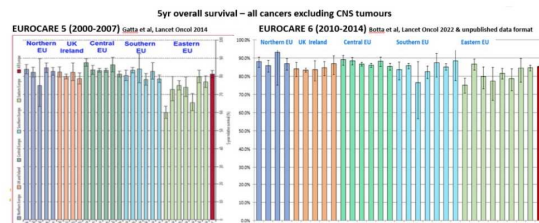
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INTRODUCTION

Different childhood cancer population-based studies have demonstrated **survival disparities** between countries and European regions. Potential causes of this survival heterogeneity between countries include the stage distribution at diagnosis



The International Benchmarking of Childhood Cancer Survival by Stage, also called **BENCHISTA Project**, is a research collaboration between multiple population-based cancer registries (PBCRs) from European and non-European countries.

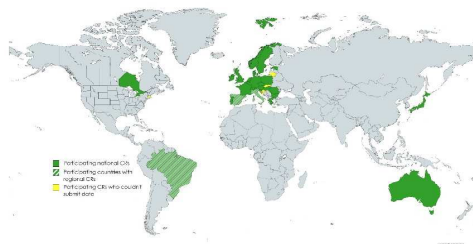
It **aims** to stimulate the application of Toronto Stage Guidelines (TG) by participating PBCRs for six of the most common paediatric solid cancers to lead to a better understanding of the reasons for variation in childhood cancer survival between countries and to highlight areas for improvement.

METHODS

Sixty-nine PBCRs worldwide agreed to take part in the project and to collect and send all cases in the period 2014-2017 for six paediatric solid tumours (Ewing sarcoma, osteosarcoma, rhabdomyosarcoma – for ages 0 to 19 years old – and neuroblastoma, medulloblastoma and Wilms Tumour – for ages 0 to 14 years old). The TG endorse a two-tier approach. Tier 1 requires less detailed criteria and stage categories and Tier 2 involves detailed criteria for cancer registries with further access.

The resources that the project established to ensure **high quality data, harmonization and standardization** were:

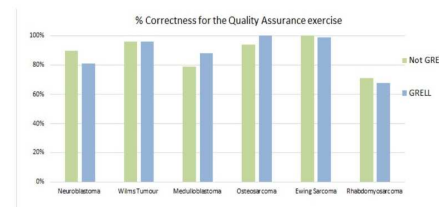
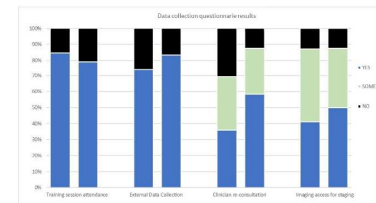
- On-line training sessions
- A questionnaire, focused on data collection processes
- A quality assurance exercise, including 12 fictitious cases to be staged
- Help-desk



Cancer Registries Participating in the BENCHISTA Project

RESULTS (GRELL vs Not GRELL countries)

STANDARDIZATION AND HARMONIZATION



12 fictitious cases (2 per tumour type) to be staged blind by each PBCR.

COMPLETENESS

So far, **10,500** cases have been received (>90% of expected total).



	Completeness: all six tumour						
	Surgery	Chemotherapy	Radiotherapy	NSP	Relapse	Cause of death	Total N° of cases
Not GRELL*	78%	80%	77%	39%	85%	76%	6,695
GRELL**	92%	96%	89%	54%	51%	60%	3,809

*2 countries had no access to treatment data and cause of death; 3 countries had no access to relapse data; 4 countries had no
** 1 country had no access to Relapse

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OVERALL BENCHISTA results:

Tier 2 completeness is **>87%** for all cancers except Medulloblastoma (83%).
More than 80% of all cases have the information on treatment but Non-stage prognostic factors are difficult to find for PBCRs (<50%).

CONCLUSION

BENCHISTA put in place all the key elements including training and quality assurance to improve standardisation and enhance understanding of TG demonstrating the feasibility of routinely collection of clinical variables by PBCRs. No major problems of standardization or completeness were found for the GRELL countries

This collaborative effort represents the **first step** towards understanding reasons for variation in overall survival for childhood cancer at a population-level, **strengthening relations** between cancer registries, clinicians, public/parent/patient representatives and other stakeholders to encourage research and outcome improvement.

WHAT'S NEXT ?

First in-person Meeting of the BENCHISTA Project Working Group (PWG) will be held on the 19th -20th June 2023 in Milan, Italy.

The meeting aims to:

- gather the members of the PWG, tumour specific clinical experts, parent and patient representatives and other key stakeholders to hear and discuss the first results of the population-based data analyses.
- discuss about future perspectives and plans for grant applications to support a potential next phase for the project

For more information please visit our website

<https://bit.ly/BENCHISTA>



ACKNOWLEDGEMENTS

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The data used in this project have been generated during the treatment and care of patients