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international benchmarking of childhood cancer survival by stage

BENCHISTA:
INTERNATIONAL BENCHMARKING OF CHILDHOOD CANCER SURVIVAL BY STAGE

Newsletter No.3, December 2022

UCL

Fondazione IRCCS Istituto Nazionale dei Tumori

Sistema Socio Sanitario
Regione Lombardia

Welcome to the third edition of the BENCHISTA Newsletter. We are very grateful for your continued support and participation in the study.

In this issue, we provide information about the project's progress, activities completed since our last update in July 2022, communication and dissemination opportunities.

Highlights

The BENCHISTA Project has current participation from 69 Population-Based Cancer Registries (PBCRs) from 25 European countries, Australia, Brazil, Japan, and Canada.

To the third week of December, the data controller (INT) has received 41 databases.

The Data Transfer Agreement (DTA) developed to meet specific legislations to adhere to GDPR and relevant laws has been finalised and signed.

Meet the Team!

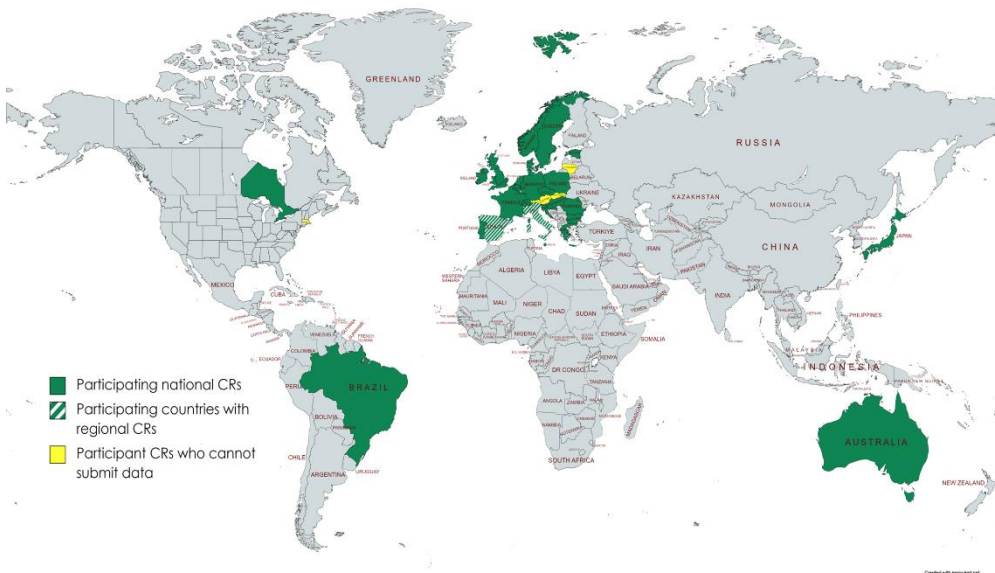|				
Prof. Kathy Pritchard-Jones[1]	Dr. Gemma Gatta[2]	Laura Botta[2]	Fabio Didonè[2]	Angela Lopez-Cortes[1]

[1] University College London (UCL), [2] Fondazione IRCCS Istituto Nazionale dei Tumori, Milano, Italy

Participating national CRs
Participating countries with regional CRs
Participant CRs who cannot submit data

The Data Transfer Agreement (DTA) was fully executed on 14th of November 2022. Thanks to the team and legal officer at INT, who is currently distributing the complete signed document to the PBCRs for their availability.

A new 'accession document' has been created. This is addressed to new parties who would like to join the BENCHISTA Project. Noting that *no* changes to the initial format are allowed. Further information can be provided by contacting the BENCHISTA team via **email**.

Amendment No.2 (updated protocol and appendix v4.4, 22 Sep 2022) was approved by the UCL Ethics Committee on 03rd of October 2022.

We highlight the importance of the dataset transfers within the previously agreed timeline as it will allow us to start the data analysis accordingly.

Once we have all information on the cases numbers submitted by PBCRs, we will be able to start generating the reimbursement per case.

Other resources and tools

During our last Project Working Group meeting – held on 14th December 2022, we shared the PBCRs/Countries pending to submit their answers to the registry questionnaire and the fictitious cases staging exercise. Please remember that these are open and expected to be completed by all.

Your help is greatly appreciated and having complete data will allow us to produce the results sooner!
Do not hesitate to contact us via **email** in case you have further questions or desire to confirm your answer has been received.

①
Questionnaire for Clinical and Non-clinical staff collecting data/staging for the BENCHISTA Project

This tool helps us understand the modalities of data collection and staging used by the participating PBCRs.

Currently, we have received ~50% responses. If you have not yet answered the questionnaire, please remember to complete it following the link:
https://it.surveymonkey.com/r/SX5JDN5

②
Quality Assurance Tool (Containing 12 fictitious cases)

We aim to assess how standardized is the collection of Toronto Staging across the participating PBCRs.

Up to July and from the answers received, the average correct score was 89% and the median score 92%.

If you/your PBCR has not yet staged the fictitious cases, please follow this link:
https://it.surveymonkey.com/r/BENCHISTA_fictitious_cases

③
Child Health Practices Survey by Country

Short survey focusing on national mandatory health checks (child health surveillance) and acute care practices.
We only require one general practitioner and one general paediatrician from each country to complete it.
The link was already distributed across participating countries, but should you have any questions, please message us at:
angela.lopez@ucl.ac.uk

In terms of **communication channels**, there are updated documents for public overview and further information in terms of dissemination and communication opportunities.

BENCHISTA
Active website & twitter account

Questionnaire on child health practices in progress of being completed by participating countries

1st and 2nd Newsletters published and publicly available

Other tools, outcomes and opportunities

Quality Assurance Tool in progress of compeltion

Updated:
Protocol & appendix v4.4
Frequently asked questions

Questionnaire on data collection /staging in progress of completion

Meetings during 2022:

- ✓ ENCR Scientific Meeting: Poster award, participants vote.
- ✓ CCLG Winter Meeting, April 2022: Poster presentation. Congratulations to Prof Kathy Pritchard-Jones as she received the Lifetime Awards at the CCLG winter conference!
- ✓ GRELL Conference, May 2022: Participation.
- ✓ SIOP September 2022: Poster presentation.
- ✓ World Cancer Congress, October 2022: Abstract accepted and side presentation with key stakeholders.
- ✓ IARC November 2022: Poster presentation.
- ✓ Internal meeting UCL Developmental Biology & Cancer Research Department: Oral presentation (online meeting).
- ✓ ENCR Data Quality and Harmonization → Call for papers (Frontiers in Oncology), submission accepted – Manuscript in process.

Other news:
The project's protocol was published in PLOS ONE, to access it please click on the image.
An opportunity for a face-to-face meeting is being planned for 19-20th June 2023 in Milan, Italy – more updates coming soon!

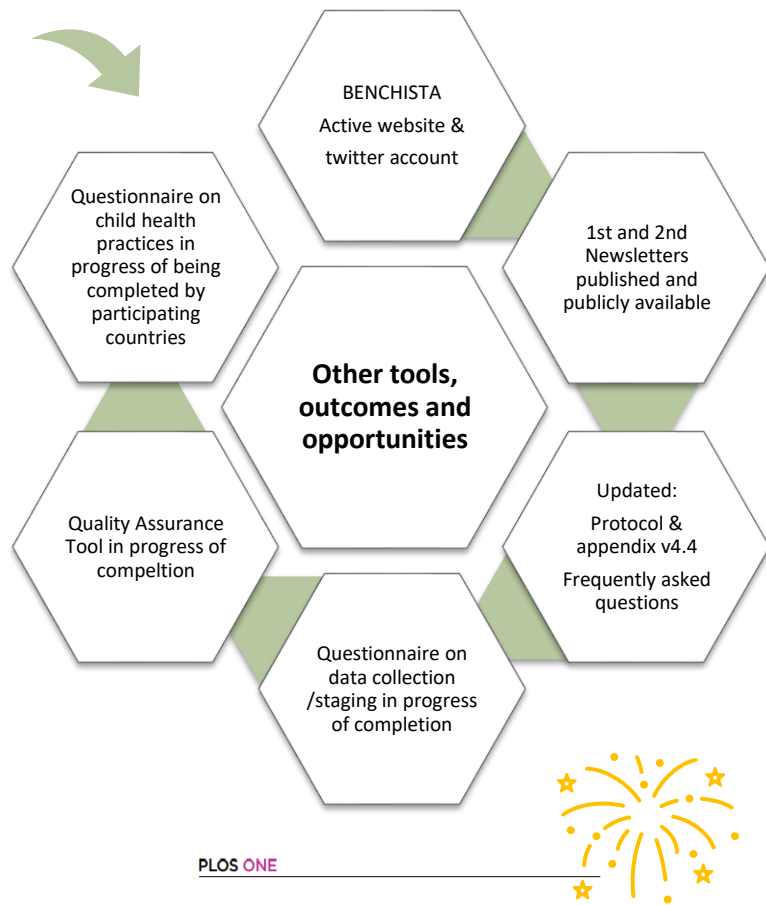### Upcoming dissemination and communication opportunities

Children's Cancer and Leukaemia Group (CCLG), March 2023
European Society of Paediatric Oncology (SIOPE), May 2023
GRELL Ascension Meeting, Spring 2023
International Society of Paediatric Oncology (SIOP), October 2023
Among others!

PLOS ONE

STUDY PROTOCOL
International benchmarking of childhood cancer survival by stage at diagnosis: The BENCHISTA project protocol

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‡ LB and GG share first authorship on this work.
¶ Members of the BENCHISTA Project Working Group are mentioned in the Acknowledgments section.
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Abstract

Background
Several studies have shown significant variation in overall survival rates from childhood cancer between countries, using population-based cancer registry (PBCR) data for all cancers combined and for many individual tumour types among children. Without accurate and comparable data on Tumour stage at diagnosis, it is difficult to define the reasons for these survival differences. This is because measurement systems designed for adult cancers do not apply to children's cancers and cancer registries often hold limited information on paediatric tumour stage and the data sources used to define it.

Aims
The BENCHISTA project aims to test the application of the international consensus "Toronto Staging Guidelines" (TG) for paediatric tumours by European and non-European PBCRs for six common paediatric solid tumours so that reliable comparisons of stage at diagnosis and survival rates by stage can be made to understand any differences. A secondary aim is to test the data availability and completeness of collection of several 'Toronto' consensus non-stage prognostic factors, treatment types given, occurrence of relapse/progression and cause of death as a descriptive feasibility study.

Methods
PBCRs will use their permitted data access channels to apply the Toronto staging guidelines to all incident cases of six solid childhood cancers (medulloblastoma, osteosarcoma, Ewings sarcoma, rhabdomyosarcoma, neuroblastoma and Wilms tumour) diagnosed in a consecutive three-year period within 2014–2017 in their population. Each registry will provide a de-identified patient-level dataset including tumour stage at diagnosis, with only the contributing registry holding the information that would be needed to re-identify the patients. Where available to the registry, patient-level data on 'Toronto' non-stage prognostic factors,
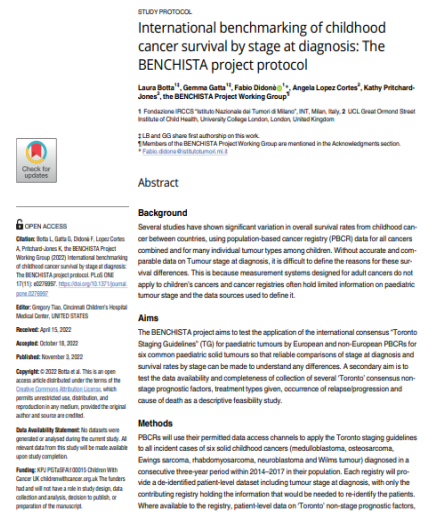
Upcoming Meetings:
Project Management Team → Wednesday 18th January 2023
Project Working Group → Wednesday 08th March 2023
Independent Advisory Board → Monday 13th March 2023

BENCHISTA Website: **https://bit.ly/BENCHISTA**