



benchista

international benchmarking of childhood cancer survival by stage

BENCHISTA: INTERNATIONAL BENCHMARKING OF CHILDHOOD CANCER SURVIVAL BY STAGE

Newsletter N.2, July 2022



Sistema Socio Sanitario



Welcome to the second edition of the BENCHISTA newsletter. Thank you for your participation and continuous support towards the study!

In this issue, we provide information about general progress of the project, including the Data Transfer Agreement process, activities undertaken since March 2022, communication and dissemination of the project and future opportunities.

Highlights

The BENCHISTA Project has participation from 60 population-based cancer registries (PBCRs). Currently, databases from 4 PBCRs have been securely transferred to the data controller (INT).

The INT and its legal office have been working hard with PBCR leads and legal office representatives to achieve final signature of the Data Transfer Agreement (DTA).

Key documents, several tools and questionnaires have been generated and uploaded in the BENCHISTA website for public overview and download when required.

Meet the Team!



Prof. Kathy Pritchard-Jones¹



Dr. Gemma Gatta²



Laura Botta²



Fabio Didonè²



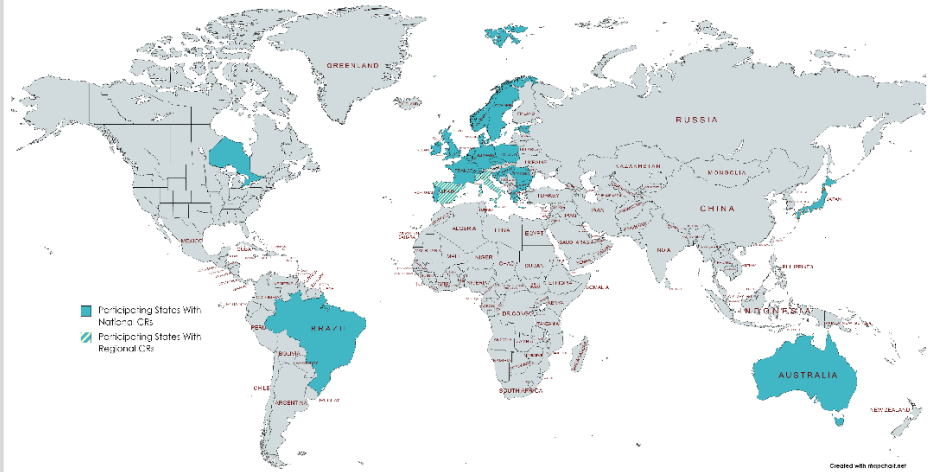
Angela Lopez-Cortes¹

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

The **Data Sharing Agreement** produced initially (version 1, Dec 2021) was reviewed and changed to **Data Transfer Agreement** (version 2, Mar 2022). This change was made to reflect the practicalities of the project.

After including requirements and feedback from population-based cancer registries (PBCRs) an updated document was circulated across participating centres (version 3, May 2022).

Deadline to send signed contract: First week of September 2022.



Up to the first week of July 2022:

23 signatures to the DTA had been received, 9 PBCRs approved with signature pending, 6 with other reasons for delay, and 3 pending a reply from the PBCR legal office.

Due to delays in finalizing the DTA, the project funder has agreed a 7 month no-cost extension of the project with a new end date of 31st January 2024.

After consideration of updated information on cases numbers to be provided by PBCRs, the per case reimbursement is now estimated as ~£8.2. The amount might vary slightly depending on the final number of cases submitted.

Please remember that the three training sessions focused on Neuroblastoma, Medulloblastoma, Wilms Tumour, Rhabdomyosarcoma, Ewing sarcoma and Osteosarcoma remain available on our website, see links below or easily accessible by scanning the following QR codes:



SESSION 1



SESSION 2



SESSION 3



For more information about the **CanStaging⁺** Tool please click [HERE](#)

Other Resources and Tools

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 the 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

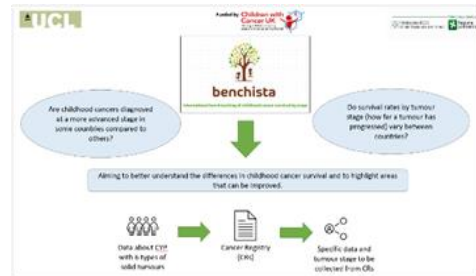
Patient and Public Involvement and Engagement (PPIE) news!

A second video workshop at UK level supported and led by DATA-CAN (<https://www.data-can.org.uk/>) was held on 26th April 2022.

It focused on understanding what cancer health data looks like, linkage and data sharing concepts, and how the CTYA voice can be represented. The BENCHISTA Project was presented as a data usage case example.

16 attendees participated in the session and provided important feedback and participation interest.

A third session is in process of planning, focused on similar content but applicable to an international audience. We will provide updates via our Website and our Twitter page.



In terms of **communication channels**, there is progress on several activities including launch of sites/social platforms and tools to disseminate updates, and outcomes of the BENCHISTA Project.

Upcoming dissemination/publication opportunities:

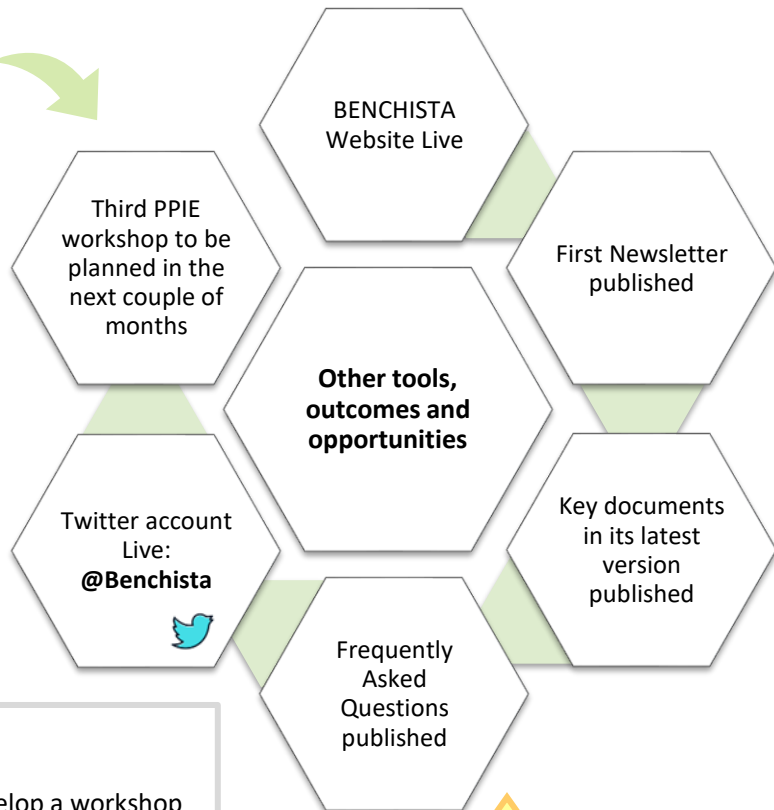
- BENCHISTA Protocol submitted to PLOS ONE Journal currently in process of review.
- [World Cancer Congress 2022](#) → Abstract accepted
- [SIOP 2022 Congress](#) → Abstract accepted for Poster.
- [IARC 2022](#) → Abstract submitted.
- [ENCR Data Quality and Harmonization](#) → Call for papers (Frontiers in Oncology), submission accepted.

Other News:

A meeting with lead PPIE representatives will be planned to develop a workshop involving patients/survivors/parents/guardians. The topics, content, potential dates, and recruitment of participants will be among the topics to be discussed in the meeting. The workshop is thought to have international reach/participation. If you have ideas or further comments, please share them with us [HERE!](#)

Upcoming Meetings:

Project Management Team → Held Monthly
Independent Advisory Board → Monday 12th September 2022
Project Working Group → Wednesday 21st September 2022



SPECIAL MENTION

Four registries have submitted their datasets, allowing us to test the quality check process.

Thank you!

BENCHISTA Website: <https://www.ucl.ac.uk/child-health/research/developmental-biology-and-cancer/benchista>

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Funder: Children with Cancer, UK

