



benchista

international benchmarking of childhood cancer survival by stage

BENCHISTA: INTERNATIONAL BENCHMARKING OF CHILDHOOD CANCER SURVIVAL BY STAGE

Newsletter N.1, March 2022



Sistema Socio Sanitario



Welcome to the first edition of the BENCHISTA newsletter. We would like to thank you for your continued commitment towards and participation in the study.

In this issue, we provide information about progress of the project, including data sharing agreements, the current number of participating population-based cancer registries (PBCRs), where to find available training and relevant documents, planned and achieved outcomes, and dissemination opportunities.

Highlights

The BENCHISTA project has commitment from more than 65 cancer registries from 29 countries to participate.

A Data Sharing Agreement has been developed and adjusted to meet specific legislations to adhere to GDPR or similar laws across countries.

Training on Toronto staging led by clinical experts, involvement of parents and public (PPIE), and tools development have been active through the first phase of the project.

Meet the Team!



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The Data Sharing Agreement is a document developed by the legal office at INT that ensures all information that will be shared from the cancer registries to the data controller (INT) is adequately managed and is in line with principles of data safety and governance of information.

Up to February 2022, 61 PBCRs confirmed that they could provide population-base data, 44 of them require a DSA, which has been agreed with 21 of them.

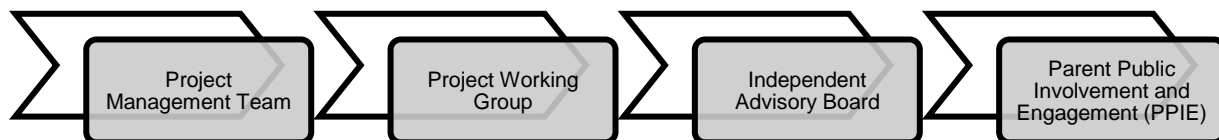


UCL Ethical approval granted on the 22nd of April 2021 & INT Ethical approval granted on the 27th of May 2021

Amendment N.1 (updated protocol and appendix v4.3 08Oct2021) approved by the UCL Ethics committee on 08th of February 2022.

**Generation of three key documents:
Transparency statement
Publication Policy
Communications & Dissemination Policy**

The project's progress, planned activities, new documentation/trainings/workshops or any procedures are overseen by the following structure:



Clinical experts, cancer registry leaders and personnel related to registration and staging processes (special thanks to the Belgian Cancer Registry) created a series of training sessions focused on the six solids tumours included in the BENCHISTA Project, to assist the cancer registries.



Three training sessions addressed to cancer registries regarding Neuroblastoma, Medulloblastoma, Wilms Tumour, Rhabdomyosarcoma, Ewing sarcoma and Osteosarcoma were developed, completed, and shared with the participants and public.

These are available in the following links:

- Session 1: <https://mediacentral.ucl.ac.uk/Play/71900>
- Session 2: <https://mediacentral.ucl.ac.uk/Play/71797>
- Session 3: <https://mediacentral.ucl.ac.uk/Play/72207>

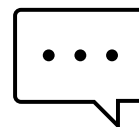


Additional news!

A PPIE workshop at UK level supported and led by DATA-CAN (<https://www.data-can.org.uk/>) was held on 27th January 2022, focused on understanding health care data by children and young people with cancer.

15 young people/parents/guardians who experienced childhood cancer participated providing their opinion and feedback from their perspectives.

This is the first of a planned series of workshops where BENCHISTA can be used as a real-world example of how patient-level data can be shared in a safe environment and contribute to knowledge.



Would sharing my data help someone else?



Importance of TRUST and open communication.

Raised importance of having all the information in one place and making it accessible to patient.

Diagnosis is a stressful time for the family/patient to discuss data sharing.



Initial discussion on challenges and barriers of data sharing between countries.

Among other important remarks...

In terms of **communication channels**, there are achievements, plans and updates to be shared which include the creation of different platforms and tools to disseminate the progress, updates, and outcomes of the BENCHISTA Project.

Upcoming dissemination/publication opportunities:

- Article to be submitted to Implementation Science Journal currently in preparation.
- Poster to be presented during the [CCLG](#) Winter Meeting, 4th - 5th April 2022.
- Presence in the [GRELL](#) Conference which will be carried out on 18th-20th May 2022.
- Abstract planned to be submitted to [SIOP](#) 2022 congress, Barcelona in October 2022.

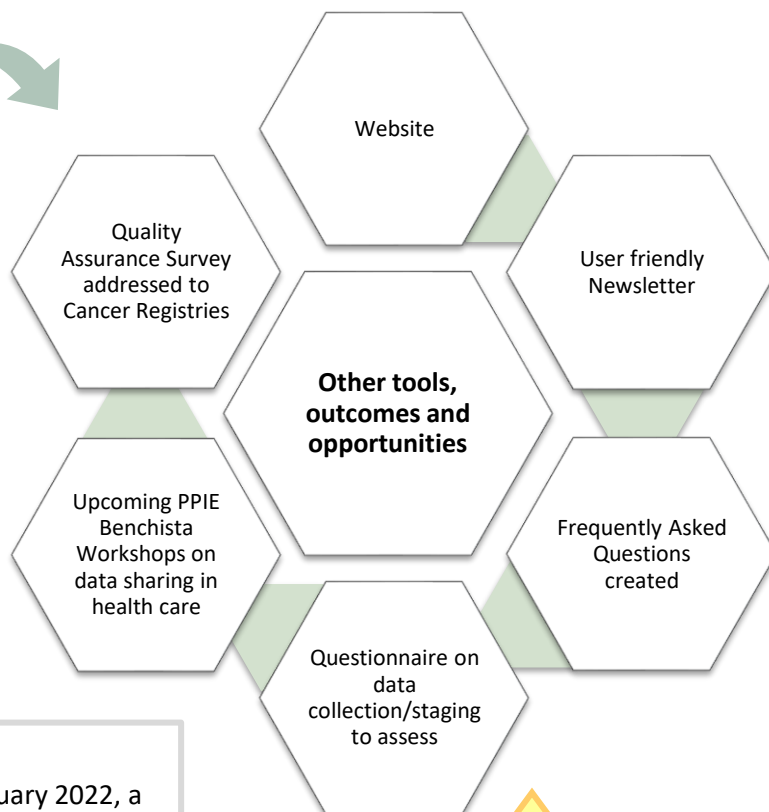
Other news:

For the International Childhood Cancer Day held on 15th February 2022, a space was dedicated to introduce the BENCHISTA Project in the FIAGOP (Italian Federation of Parents and Survivors' Oncological Organizations).

The aims of the project, issues related to the use of personal data, relevance of data usage and impact on research were among the topics discussed. Also, stressed and supported by the president of the Association.

Upcoming Meetings:

Project Working Group → Thursday 24th March 2022
Independent Advisory Board → Monday 28th March 2022



SPECIAL MENTION AND CONGRATULATIONS!

Best Poster Award at the [ENCR](#) Scientific Meeting 2021

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

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Funder: Children with Cancer, UK