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international benchmarking of childhood cancer survival by stage

BENCHISTA: INTERNATIONAL BENCHMARKING OF CHILDHOOD CANCER SURVIVAL BY STAGE

Newsletter No.5, March 2024



Welcome to the 5th edition of the BENCHISTA Newsletter. We appreciate your continued participation and support towards the study.

In this issue, we provide an update on the project's progress, highlights of 2023, plans for 2024, key information regarding funding and further dissemination plans.

Highlights

67 population-based cancer registries (CRs) from 23 European countries, Australia, Brazil, Japan, and Canada currently participate in BENCHISTA.

10,939 cases were submitted. Stage completeness ranged between 92% to 97% (average 93.2%) across the six selected childhood solid tumours.

BENCHISTA represents a successful collaboration to interpret geographic variation in childhood cancer outcomes, allowing the estimation of overall survival by stage and event-free survival at a population level for the first time.

Meet the Core Team!



Prof. Kathy Pritchard-Jones¹



Dr. Gemma Gatta²



Laura Botta²



Fabio Didonè²



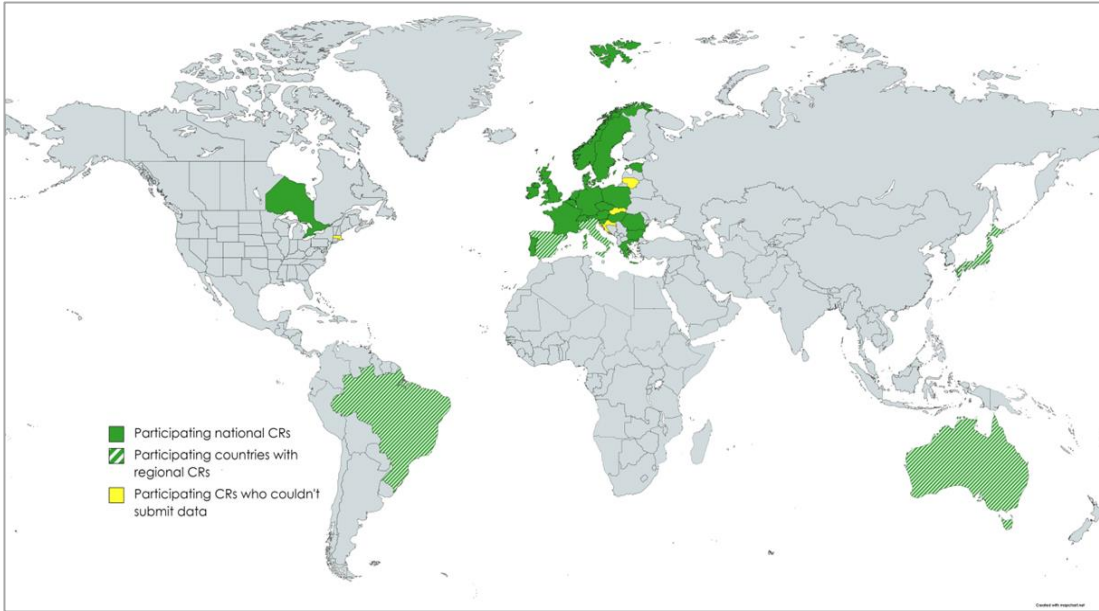
Angela Lopez-Cortes¹

Progress to date

International multidisciplinary collaboration

Collection of 10,939 cases in total, including compulsory and optional variables.

Data transfers completed with extensive quality checks from the data controller (INT).



An impressive effort was required from the data controller, CRs and – when possible – clinical networks to assign stage at diagnosis and collect other optional data items.

This work highlighted the importance of linkage between CRs and their clinical sources to achieve data completion.

Weekly meetings involving the core team.

Monthly Project Management Team meetings.

Quarterly Project Working group (PWG) meetings.

Independent advisory Board convenes twice a year.

PIIE support

Project's governance infrastructure

Publication in *Frontiers in Oncology*.

Amended version with updated affiliations was re-submitted.



Cancer data quality and harmonization in Europe: the experience of the BENCHISTA Project – international benchmarking of childhood cancer survival by stage

Angela Lopez-Cortes^{1*}, Fabio Didone^{2*}, Laura Botta³, Lisa L. Hjalgrim⁴, Zsuzsanna Jakab⁵, Adela Canete Nieto⁶, Charles Stillier⁷, Bernward Zeller⁸, Gemma Gatta⁹, Kathy Pritchard-Jones¹⁰ and The BENCHISTA Project Working Group

¹University College London (UCL) Great Ormond Street Institute of Child Health, Developmental Biology & Cancer Research Department, London, United Kingdom; ²Fondazione IRCCS Istituto Nazionale dei Tumori di Milano (INT), Department of Evolutionary Epidemiology, Milan, Italy; ³BENCHISTA Project Management Team, London, United Kingdom

Data quality and harmonization

Manuscripts in preparation:

1st research hypothesis: Tumour stage variation (circulated to PWG 9 Mar 2024).

2nd hypothesis: Survival by stage (to follow in April).

Production of initial results

Constitution of statistical methodological group with multiple meetings in Autumn 2023 to agree the analytical approach.

Many thanks for your contribution!

Analysis plan

Collaborative work published on Parent & patient Involvement and Engagement.

PIIE

Frontiers in Oncology | Research Involvement and Engagement | 02023 | https://doi.org/10.3389/fonc.2023.1158585

RESEARCH Open Access

Patient and public involvement to inform priorities and practice for research using existing healthcare data for children's and young people's cancers

Nicola F. Hughes¹, Lorna A. Kerr², Angela Polanco³, Chris Carrigan⁴, Richard G. Feltbower⁵, Ashley Gambel⁶, Emily Corran⁷, Angela Lopez⁸, Ellen Bas⁹ and Kathy Pritchard-Jones¹⁰

We were pleased to have the opportunity to discuss results with the Project Working Group members in person in June & November 2023.

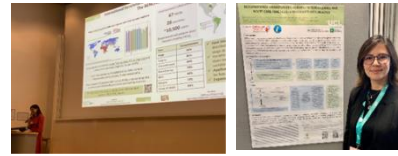
Everyone's valuable input, discussion and feedback has helped finalise the interpretation of the results and plan for the next steps for the BENCHISTA project.

Highlights of 2023



March

- On-site participation at the UK and Ireland Children's Cancer and Leukemia Group with a poster presentation.
- Oral presentation in the University College London (UCL) Developmental Biology and Cancer Symposium



May

- BENCHISTA was highlighted in the ENCR Newsflash.
- Poster presentation at the UCL Cancer Symposium.
- On-site attendance at SIOP Europe in conjunction with CCI-E, with a special session dedicated to BENCHISTA.



June

- On-site participation and poster presentation at the GRELL Meeting.
- First PWG face-to-face meeting gathering more than 70 participants on-site and on-line.
- On-site attendance with oral presentation focused on Wilms Tumour at SIOP Renal Tumour Study Group (RTSG) annual meeting.



September / October

- On-site attendance, oral presentation, and two poster presentations at the Children with Cancer UK 2023 Conference.
- Two poster presentations at the International Society of Paediatric Oncology (SIOP) 2023 Annual Conference.



November

- Attendance at the Paris Conference for an International Childhood Cancer Data Partnership, and contribution to workshops.
- On-site participation and oral presentation at the ENCR 2023 IACR, Granada. Opportunity to hold a PWG meeting.



What is coming in 2024?

BENCHISTA has proved to be a successful project achieving a remarkable international collaboration.

The work done reflects the significant effort from the cancer registries, the importance of involvement of clinical experts in the specific tumour types and close working with clinical data sources. We have all learnt from our participation about how to overcome challenges and define areas for improvement when processing, sharing, and analysing data from different sources. Together we have successfully achieved assignment of the international consensus Toronto Stage at diagnosis in 93.2% of cases, collecting optional variables and data related to tumour biology, treatment, relapse/progression and cause of death.

Key activities for the year ahead

Submit two separate publications, each addressing the two main hypotheses of the project; and submit the mixed-methods descriptive analysis of variation in child health practices between participating countries.

Finalise the distribution of per case reimbursement to cancer registries requiring this.

Generate more in-depth analysis of tumour-specific data and optional variables in conjunction with clinical experts.

Generation and submission of the new grant for BENCHISTA phase II to Children with Cancer UK.

Plan with PPIE representatives for further dissemination and communication of the results.

Continue regular project meetings and oversight from the Independent Advisory Board. Plan further meetings with potential collaborators outside BENCHISTA.

Opportunity for PWG members to present BENCHISTA data in national meetings - please **contact us**.

The new grant submission to Children with Cancer UK is focused on expanded follow-up period, encouragement and maximization of data completeness of previous optional variables, increased linkage between cancer registries and clinical sources and further exploration of the feasibility to include aggregated data.

An outline proposal submitted in February 2024 has been invited to the full proposal stage. The deadline for submission is 06th May 2024, please confirm your participation as soon as possible.





Brussels, 5.12.2023
C(2023) 8524 final

ANNEX 1

Other funding information:

The initiative [EU4Health Programme](#) supports the implementation of Union priorities.

Direct grants addressed to MEMBER STATES' AUTHORITIES

Aim: Support quality improvement of cancer registry data feeding the European Cancer Information System (ECIS).

Objective 1: Quality improvement of cancer registry data.

Objective 2: Improving survival and prevalence indicators in the ECIS.

Call opening: Q2-Q3-2024

Considering the experience of BENCHISTA and the required support to continue with Phase II, we invite members of the PWG to be proactive in reaching out to their relevant National Ministries to potentially exploit this opportunity and suggest childhood cancer as an excellent “use case” for this quality improvement initiative.

➔ Please follow the [LINK](#) for more information ➔

Communication, Dissemination and Acknowledgements

- ✓ Abstract accepted for poster presentation to the Children's Cancer and Leukaemia Group ([CCLG](#))
- ✓ Abstract accepted for oral presentation to the [BTEC 2024](#)
- ✓ Planned on-site representation at the [SIOP Europe 2024](#)
- ✓ Planned on-site representation and abstract submission to the [GRELL 2024](#)
- ✓ Planned on-site participation and abstract submission to [SIOP 2024](#)
- ✓ Abstract submission to [IACR 2024](#)
- ✓ Tumour-specific events: [Euro Ewing Consortium](#), [SIOPEN AGM 2024](#), [EpSSG Winter Meeting 2024](#)

Acknowledgements

Many thanks to the SIOPE/CCI-E organisers and the Granada Cancer Registry team for allowing us to hold a space to present BENCHISTA and meet the PWG.

We extend our gratitude to all members, collaborators, and funders, especially to Professor Joanne Aitken, who has retired from her role as director of the Australian Childhood Cancer Registry after more than 25 years at Cancer Council Queensland. Thank you for your legacy of research excellence, leadership, and wonderful contribution as chair of the BENCHISTA Independent Advisory Board.

We also remember our representative, Marceli De Oliveira Santos, from the National Cancer Institute of Brazil, who sadly passed away last year. She was a recognized authority in cancer surveillance and epidemiology and a dedicated expert in improving access to cancer information in Brazil.

Do not hesitate to contact us to the [BENCHISTA inbox](#) with further comments or questions.

Upcoming Meetings:

Project Management Team → Tuesday 09th April 2024, 13:00 (UK Time) / 14:00 (CET)

Project Working Group → Wednesday 17th April 2024, 13:00 (UK Time) / 14:00 (CET)

Independent Advisory Board → Tuesday 18th June 2024, 11:00am (UK Time) / 12:00 (CET)

