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!**

1. Prof. Kathy Pritchard-Jones1
2. Dr. Gemma Gatta2
3. Laura Botta2
4. Fabio Didone2
5. Angela Lopez-Cortes1

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

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.

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.

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!
- 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!

SPECIAL MENTION AND THANKS TO:
All BENCHISTA Project members, collaborators, and funders! 2022 was a year of great teamwork and progress!

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

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