

BENCHISTA Communication and Dissemination Policy

Introduction

The *International Benchmarking of Childhood Cancer Survival by Stage* project, also called the *BENCHISTA Project*, is a research collaboration between multiple population-based cancer registries (PBCRs) within and outside Europe. The project aims to understand more about observed variations in survival rates from childhood cancer (CC) between populations. We will look at variations in tumour stage at diagnosis and compare this with data from different countries or larger areas. The joint principal investigators of the project are Professor Kathy Pritchard-Jones, University College London, UCL Great Ormond Street Institute of Child Health, UK, and Dr Gemma Gatta, Fondazione IRCCS “Istituto Nazionale dei Tumori”, Milan, Italy (INT).

The BENCHISTA project is funded by Children with Cancer UK and the research sponsor is University College London (UCL). The project has ethical approval under UCL and the Fondazione IRCCS Istituto Nazionale dei Tumori (INT).

The project focuses on six childhood solid tumours: medulloblastoma, osteosarcoma, Ewing sarcoma, rhabdomyosarcoma, neuroblastoma, and Wilms Tumours. More than 60 PBCRs will collect information from these types of tumours, diagnosed between 2014-2017. The internationally agreed ‘Toronto stage’ at diagnosis will be assigned along with other relevant data about the tumour and prognosis or survival factors. The PBCRs will share the pseudo anonymised personal data and create a project database that will contain all the information in one place. This will be done under strict principles of data security, confidentiality, and data safety procedures. The PBCRs will provide their data via secure transfer directly to the INT who will oversee and store the information in line with General Data Protection Regulations (GDPR) and other laws that ensure the data is protected.

The BENCHISTA data remain the property of the PBCRs. Data will only be used for the purpose of the BENCHISTA protocol, and any further use will require consent from the PBCRs. All members of the PBCRs that form the BENCHISTA Working Group must be informed of any analysis being proposed and carried out using patient data.

The project database with pseudo anonymised data will be kept securely at INT for a maximum of 10 years, after which it will be securely destroyed. Data may however be kept for longer if further ethical and regulatory approval is granted for future research projects. The use of data within the project database is under strict controls of the Working Group and will only be used for projects that have been granted ethical approval.

a. Aims of the Project

The aim of this project is to improve understanding of the reasons for variation in childhood cancer survival between countries and to highlight areas that need to be targeted for improvement. The secondary aim is also to encourage the application of the Toronto staging Guidelines (TG) by a large number of European Cancer Registries (CRs) for the most common solid paediatric cancers (including Wilms Tumour, Neuroblastoma, Ewing Sarcoma, Osteosarcoma, Medulloblastoma and Rhabdomyosarcoma).

b. Questions to be addressed with the BENCHISTA project

- Are childhood cancers diagnosed at a more advanced stage in some countries compared to others?
- Do survival rates by tumour stage vary between countries/large geographic regions? Referring to differences in diagnostic and treatment practices or in the tumour biology?
- What are the different pathways of care for children in different countries and are there any potential opportunities for early diagnosis of the 6 childhood solid tumours?

The third question will be addressed by the development of a systematic review of child health surveillance and community paediatric health practices in the participant countries (Most of Europe, Brazil, Japan, Australia, Canada, USA).

c. Pre-existing communication and collaboration channels

The BENCHISTA project includes a patient and public involvement and engagement in research group (PPIE) as part of its structure and has support from several key organisations including CCLG, SIOP Europe, AIEOP, wider PPIE groups in Europe and other key stakeholders such as (HDR-UK DATA-CAN, CCI-Europe) and Charity/External Care Organisation partners.

The Independent Advisory Board (IAB) regularly communicates updates about the project's work and outputs to influential leaders in cancer epidemiology, cancer registration and national health service policy, clinical experts in childhood cancer and parent and survivors' representatives/organisations.

Objectives of Communication Plan

The communication strategy for BENCHISTA has two main channels:

- **Internal communication** with all members of the working group. This includes provision of sharable materials for their own communities.
- **External communication and dissemination** with key stakeholders to raise awareness of the project and its aims. Regular updates will be shared widely about progress of the project and to assist learning for similar research projects. This will help to show that sharing of large data sets is possible and may lead to future research collaborations (new registries joining, future joint research ideas and potential joint grant applications).

Open, assertive, timely and pertinent communication among involved parties allows full understanding of the project processes, highlights potential activities that require improvement, improves data flow and quality assurance, and enhances the importance of research in health and public policies.

The results obtained from research also help to identify new potential stakeholders, participants, and organisations interested in the progress of the study, its results and impact on families, research, and healthcare.

Among the objectives are:

- To increase awareness of the scope, aims, methodology and results of The BENCHISTA Project by:
 1. Sharing its findings with different audiences.
 2. Highlighting potential areas of improvement for cancer data collection in different countries.
 3. Improving understanding on earlier diagnosis of childhood cancer in healthcare settings and minimise survival outcome differences in population-based analysis.
- Increase engagement and cooperation with cancer registries to:
 1. Collect all pertinent data to allow adequate analysis for BENCHISTA and improve data collection for future research projects.
- Increase awareness of the differences in staging at diagnosis by participating countries for parents, patients, organisations/charities/care institutions.
- Increase awareness of the importance of using PBCRs health data for clinical outcomes in childhood cancer research and how this research can lead to the development of recommendations and public policy statements.
- Increase involvement and engagement with public-patient organisations to help strengthen partnerships for current and future research projects, ensuring that research is inclusive of the patient/parent voice.
- Increase knowledge about the benefits of patients sharing their data between cancer registration services, as it allows them to contribute in a positive way to national-level decision-making on this topic.

Priority audiences and key messages

Audience	Topic	Key messages from the project
Project funder: Children with Cancer, UK	Protocol-related information/updates, amendments, results, and outputs of the project.	Updates to research, team information and new appointments, abstracts, conference presentations, research papers for publication.
Participating and potentially interested Cancer Registries, as well as leaders of similar work at a National or Regional level.	Project methodology, results, and implications.	Publication of the protocol in a peer-reviewed journal
Childhood cancer clinical services – health care professionals and policy makers	Project methodology, results, and implications.	Regular newsletters Up to date project website (UCL) Dissemination of conference abstracts, presentations, and full papers
SIOP Europe – especially the clinical research council and links to CCI-Europe PPIE in research work	Project methodology, results, and implications.	As above plus cooperate on supporting closer involvement of clinicians in improving Toronto stage capture by PBCRs and joint work to identify further funding opportunities for future ‘deep dive’ research on additional factors used in clinical risk stratification.

CCLG, AIEOP and other National and Regional childhood cancer organisations.	Project methodology, results, and implications.	As above
Childhood Cancer Patients, Survivors, Families and Support Organisations	Cancer patient and survivor networks parent/carer networks Cancer Research UK Other institutions / organisations / charities involved (NCRI, CCLG etc.).	Regular newsletters Lay summary of project aims outcomes and progress reports Lay summary of findings
Academic Researchers	Project aims, methodology and findings.	Up to date project website (UCL) Dissemination of conference abstracts, presentations, and full papers. Involvement of new parties in research according to the aims of BENCHISTA.
National policy Makers – health services and cancer registration services	Results and implications Barriers to data sharing at patient level	Value of data-driven comparative research to understand outcomes

Table 1. Priority audiences and key messages.

Communication Channels

As we are surpassing an unprecedented time with the COVID-19 pandemic and its changes over time, different types of channels will be used to provide open communication on the progress and eventual results of the project, which include:

- Zoom/WebEx/Teams Meetings with internal Project groups (PMT, PWG, IAB< PPIE) and with external stakeholders.
- Internal communication channels through emails, texts, electronic newsletters. All addressed to the teams involved, including parent-patient involvement in research groups. Confidentiality of PPIE members will be upheld and considered in all communications.
- Development of webinars to disseminate and discuss information of the project among the pertinent teams.
- Social media: Twitter, Instagram, Facebook, LinkedIn, among others.
- Open and periodic communication with communication teams across other teams within and outside Europe.
- When allowed and under COVID-19 safety measures, to plan up to two project specific workshops held as face-to-face meetings, the first with all members of the Project Working Group and key stakeholders supporting the project, to discuss the results of the first analyses; the second to include the IAB and interested external stakeholders. Envisaged these will be held in late 2022 and mid 2023 (close to project end date of June 2023), but may need to combine into a two-day meeting, especially if COVID travel restrictions continue.
- Others: according to each participant country, its stakeholders and collaborators and their interest on support further dissemination and communication plans.

Planned outputs and presentation opportunities

PLANNED OUTPUTS
Electronic newsletter distribution including user-friendly summaries for different types of audiences.
Publication of two main papers describing stage distribution and survival by stage for childhood cancer patients diagnosed with these six solid tumours in the period 2014-2017.
Generation of tumour-specific sub-analyses which are expected to be shared as scientific abstracts or articles.
Generation of report that compares the national practices for routine child health surveillance and acute paediatric care in participating countries.
Generation of report with practical recommendations for closer cooperation between PBCRs and clinical/medical centres.
Increased communication measures amongst clinical and administrative teams on how information should flow from clinical centres to cancer registries depending on the collaborative country and its procedures.
The use of the BENCHISTA dataset for specific studies and/or further analysis will be promoted.
Publication of the PPIE approach and design to be published in a leading PPIE journal to demonstrate best practice

Table 2. Planned Outputs

PLANNED PRESENTATION OPPORTUNITIES
Invitations to present abstracts, articles, project at National Health Institutions, governmental Institutions, academic and parent/patient involvement conferences, and scientific events.
Participation in National Cancer Institute's (NCI) Childhood Cancer Data Initiative (CCDI)
International Association of Cancer Registries (IACR) – annual meeting
Group for Cancer Epidemiology and Registration in Latin Language Countries (GRELL), 18 th -20 th May 2022.
International Society of Paediatric Oncology (SIOP) - 2022 Barcelona & 2023 Ottawa
European Society for Paediatric Oncology (SIOPE) - 2022/23
Childhood Cancer Conference (organised by CCLG and Bethany's Wish annually in summer/autumn) – aim for 2022
CCI-Europe meeting
European Network of Cancer Registries (ENCR), 2023 – biannual meeting
Others: which will have future confirmation closer to the date

Table 3. Planned Opportunities

Evaluation and Impact measures

IMPACT MEASURES
Potential future use of BENCHISTA dataset for specific and approved studies.
Awareness and engagement on use of CanStaging+ tool (Toronto Staging).
Promotion and awareness of the project and partnership between SIOPE-CCI, helping to strengthen partnerships and meaningful parent-patient involvement and engagement activities.
Engagement with national and international population-based cancer registries.

Engagement with parents, patients and organisations involved in childhood cancer care.
Engagement with key opinion leaders, researchers, and policy makers.
Engagement with national and regional public health planners and policy makers.
Engagement with national academic investigators and clinical trial units not directly involved in the project.
Promotion, awareness, and provision of information to international academic parties for future collaborative research projects.
Increased social media and local media engagement.
Press releases disseminated by PMT through institutional/association/organisation websites.

Table 4. Planned Impact Measures