

BENCHISTA Transparency Statement

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 is designed to understand more about why there are variations in childhood cancer survival rates between countries and to highlight any areas that require improvement.

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

This project will collect information about how far a tumour has spread (known as ‘tumour stage’) at diagnosis and follow-up survival information for all cases of six paediatric cancers: medulloblastoma, osteosarcoma, Ewing sarcoma, rhabdomyosarcoma, neuroblastoma, and Wilms tumours (diagnosed between 2014-17). The information will be collected from different cancer registries across the world in line with their national regulations for data collection and protection of data (including anonymisation) for research use. They will assign an internationally recognised cancer staging to the information collected at diagnosis, called “Toronto Stage”. The PBCRs will also collect additional data on other prognostic factors, such as types of treatment given, if tumour relapse or progression occurred and cause of death (if applicable). This will be collected only if this information is available to them.

To protect the privacy of people whose data is being studied, we are making sure that only essential information to answer the research questions is collected. Any information submitted to the central BENCHISTA project is maximally de-personalised (pseudonymised) and will be transferred through very secure channels, to comply with General Data Protection Regulation (GDPR) and other laws or legislations across each collaborating country to ensure data is secure and protected. Each participating PBCR will be responsible for guaranteeing that the collection and sharing of clinical data is in line with principles of confidentiality. The gathered information will be securely processed and saved under the direction of Fondazione IRCCS “Istituto Nazionale dei Tumori” (INT) in Milan, Italy which acts as data controller.

Only personnel authorised and involved in the project will have access to the database at the INT, Milan. UCL has a role in designing the project and how it will be run but will not receive or be given access to any patient-level data. INT will store the compiled information from each CR for up to 10 years. After this time, any data available will be deleted securely in accordance with the principles of data protection. However, it may be kept for a longer period of time if another research project is granted approval to use it.

The project’s results will be shared across different channels and audiences, including summaries written in accessible language aimed at patients, families and the wider public in different formats.

To promote transparency and awareness on our data processing methods, information can be found on the INT website <https://www.istitutotumori.mi.it/privacy> - in Italian, where different policies can be found for public knowledge. If you have any questions, or if you would like a translation of this information, please kindly contact the team at benchista@istitutotumori.mi.it