

## Title

The International Benchmarking of Childhood Cancer Survival by Stage (BENCHISTA) Project

## Summary

BENCHISTA is a research collaboration between multiple population-based cancer registries within and outside of Europe looking to understand why there are variations in childhood cancer survival rates between countries and to highlight any areas that require improvement.

## Body

### Project aims

The International Benchmarking of Childhood Cancer Survival by Stage project, also called the BENCHISTA project, focuses on six childhood solid tumours: medulloblastoma, osteosarcoma, Ewing sarcoma, rhabdomyosarcoma, neuroblastoma, and Wilms tumours. It aims to improve understanding of the reasons for variation in childhood cancer survival and to highlight any areas that require improvement.

More than 60 population-based cancer registries will collect information for these tumours, diagnosed between 2014-2017. They will use an internationally standardised system developed for childhood cancers to assign Toronto Stage at diagnosis and collect other relevant data about the tumour prognosis and survival.

The BENCHISTA project aims to understand more about observed variations in survival rates from childhood cancer between populations. To do this the project will collect information about how far a tumour has spread (known as 'tumour stage') at diagnosis and additional data on other prognostic factors, types of treatment given, if tumour relapse or progression has occurred and cause of death (if applicable). These additional data items will be collected only if this information is available to the cancer registry. Using this information, the project will look at variations in tumour stage at diagnosis and compare this with data from different countries or larger areas.

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).

### Research questions

1. Are childhood cancers diagnosed at a more advanced stage in some countries compared to others?
2. 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.
3. 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?

### Planned outputs

The main output from the project will be the publication of two papers describing stage distribution and survival by stage for childhood cancer patients diagnosed with the six solid tumors in the time period 2014-2017. It is also likely that there will be number of tumour-specific sub-analyses in addition to the main papers.

## Transparency and data sharing

To protect the privacy of the people whose data is being studied, the project team will only collect information that is essential to answer the research questions.

All data will be collected under strict principles of data security, confidentiality, and data safety procedures. The cancer registries involved will provide the data directly to Fondazione IRCCS “Istituto Nazionale dei Tumori” (INT) in Milan, Italy who acts as data controller and will oversee and store the information in line with General Data Protection Regulations (GDPR) and pertinent laws to ensure data is protected.

Only personnel authorised and involved in the project will have access to the database at the INT, Milan. University College London (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 cancer registry 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.

The full BENCHISTA transparency statement is available on the [BENCHISTA website](#) alongside other key documents.

The Data Transfer Agreement for this study was approved by NHS Digital during the transition period of the National Disease Registration Service to NHS Digital. Therefore, this data approval could not go through the routine Data Access Request Service (DARS) at that time and has been released under exceptional circumstances.

## Find out more

[The BENCHISTA website](#) has more information about the project including the project teams and project resources.

You can also get further information by emailing the BENCHISTA team on [benchista@istitutotumori.mi.it](mailto:benchista@istitutotumori.mi.it)

[The INT website](#) has information on their institution and their data processing methods. The information on the INT website is in Italian but a translation can be requested by emailing [benchista@istitutitumori.mi.it](mailto:benchista@istitutitumori.mi.it)