

THE BENCHISTA PROJECT: INTERNATIONAL BENCHMARKING OF CHILDHOOD CANCER SURVIVAL BY TUMOUR STAGE

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Background

Significant disparities in childhood cancer (CC) survival rates are reported across geographical regions. More advanced tumour stage at diagnosis may contribute to this observed variation. Comparable data recording at a population-level is required to analyse these variations and highlight the need for earlier diagnosis and improvements in treatment.

Aim

To test the hypothesis that variation in tumour stage at diagnosis underlie variations in childhood cancer survival rates between countries and to stimulate use of the internationally recognised consensus “Toronto Staging Guidelines” for paediatric cancers (TG) by participating Population Based Cancer Registries (PBCRs). Lastly, the project aims to further enhance working relationships between PBCRs, clinical services and tumour-specific clinical study groups.

Methods

PBCRs apply TG at diagnosis to six specific tumours (Neuroblastoma, Wilms Tumour, Medulloblastoma, Rhabdomyosarcoma, Ewing Sarcoma and Osteosarcoma) diagnosed 2014-2017. Variables related to relapse, treatment and other non-stage prognostic factors will be also collected where feasible. A depersonalised patient-level dataset is transferred to the INT for analysis of survival by stage and stage distribution, with international comparisons between large geographical regions comparable to previous EUROCARE studies.

Results

Sixty-six PBCRs from twenty-four European countries, Australia, Brazil, Canada, Japan, and USA have joined the project. Forty-four PBCRs require a Data Transfer Agreement (DTA) whereas for twenty-one PBCRs the project’s ethical approvals are sufficient. The DTA has required >15 months to be finalised between legal parties. To standardise application of TG, on-line training workshops have been held and are available publicly (<https://bit.ly/Training-and-Workshops>). A total of >8,000 staged cases are expected, with datasets already flowing to the INT. Regular updates are provided at <https://bit.ly/BENCHISTA>.

Conclusions

Differences in interpretation of data protection laws and definitions of anonymous versus depersonalised for data sharing have been found. Despite this, a strong collaborative effort has been established between the participating PBCRs to comply with data protection and information governance. This project makes effective use of PBCRs’ capabilities to enrich registry data with information to understand reasons for variation in outcomes at a population level.