

THE BENCHISTA PROJECT:

INTERNATIONAL BENCHMARKING OF CHILDHOOD CANCER SURVIVAL BY STAGE

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Background

Variation in tumour stage at diagnosis may explain international differences in childhood cancer (CC) survival. The aim is to improve understanding of the reasons for this variation and to encourage the application of Toronto Stage Guidelines (TG) by Population Based Cancer Registries (PBCRs) for future comparisons.

Methods

PBCRs within and outside Europe were invited to participate in the BENCHISTA Project. They agreed a depersonalised, patient-level dataset that includes TG at diagnosis for six paediatric solid tumours: **Osteoblastoma**, **Ewing Sarcoma**, **Wilms Tumour**, **Neuroblastoma**, **Rhabdomyosarcoma** and **Medulloblastoma** diagnosed 2014-2017. Treatment, relapse/progression, death and other non-stage prognostic factors are included where feasible.

To help PBCRs in TG staging, [training workshops](#) led by clinical and registration experts were developed and use of [CanStaging+](#) tool was recommended. Two other [standardisation tools](#) were generated:



1) *Questionnaire* on sources used for data collection and processes required for sharing/transfer by each participating PBCR;



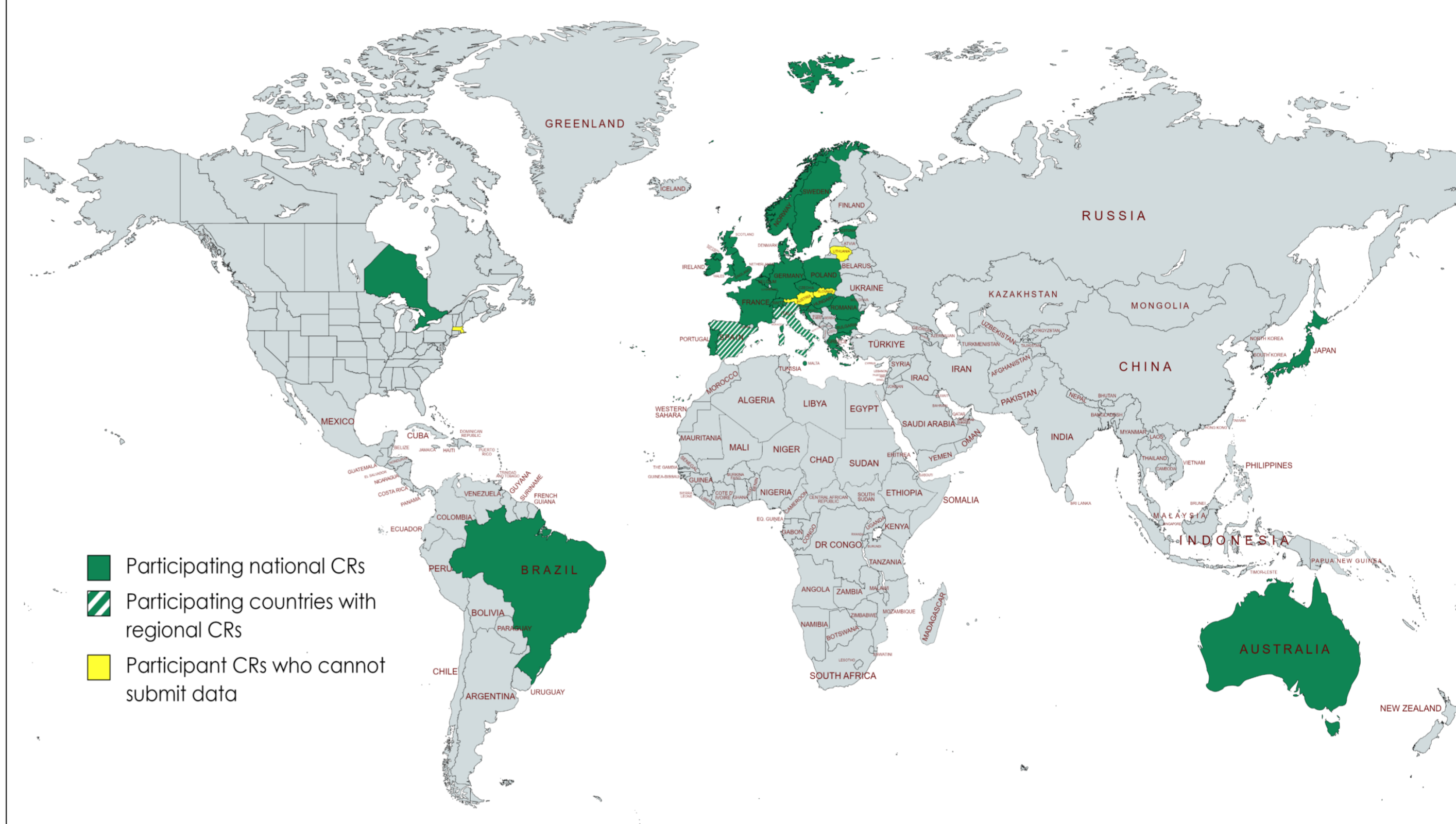
(2) *Quality assurance tool* (QAT) with fictitious cases to test TG standardisation across PBCRs.

Among other developments, communication and dissemination channels have been developed to link the project's content to different audiences. These include: website, social media content and quarterly newsletter.



Patient and Public Involvement and Engagement (PPIE) activities have been held with support of leads in the field with upcoming plans in process.

Results



PBCRs from twenty-seven European countries, Australia, Brazil, Canada and Japan agreed to participate and submit data. Data transfer from PBCRs to INT commenced in March 2022.

Heterogeneity in legal aspects was encountered when developing a Data Transfer Agreement required by the majority of PBCRs. When analysing preliminary QAT's results, the importance of vocabulary used, site definitions and testing/imaging, especially for medulloblastoma and rhabdomyosarcoma, were raised. Currently, ~50% of PBCRs have responded with an average score of correctness of 90%.

Discussion and Conclusion

Key elements including focused training and quality assurance have improved standardisation and enhanced understanding of TG by participating PBCRs.

The [BENCHISTA Project](#) is strengthening collaborative relationships between PBCRs and with clinicians to collect more detailed data on tumour stage at diagnosis and other prognostic factors at a population-level to better understand variations in childhood cancer outcomes.

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