

N. Ireland Cancer Registry Implications of Research for Services

	NICR Lead Author <i>(Office use only)</i>
	Paper ID <i>(Office use only)</i>
	Date Submitted to NICR Steering Group Click here to enter a date. <i>(Office use only)</i>
Paper Title	Cancer data quality and harmonization in Europe: the experience of the BENCHISTA Project - international benchmarking of childhood cancer survival by stage.
Authors	Lopez-Cortes A, Didonè F, Botta L, Hjalgrim LL, Jakab Z, Canete Nieto A, Stiller C, Zeller B, Gatta G, Pritchard-Jones K; BENCHISTA Project Working Group.
Journal	Front Oncol.
DOI	https://doi.org/10.3389/fonc.2023.1232451
Funders	Children With Cancer UK
Full paper available online	YES <input checked="" type="checkbox"/> NO <input type="checkbox"/> NOT YET <input type="checkbox"/>
Conclusion	<p>The BENCHISTA project investigates disparities in childhood cancer (CC) survival rates by analysing variation in CC stage at diagnosis across regions and promoting the use of Toronto Staging Guidelines (TSG) by Population-Based Cancer Registries (PBCRs). PBCRs worldwide identified cases of six common paediatric solid tumours from 2014 to 2017, applying TSG and collecting additional prognostic factors, treatment, and outcome data. Tumour-specific clinical experts led online workshops to standardize TSG application.</p> <p>67 PBCRs from 28 countries participated, providing de-personalized patient-level datasets. Legal heterogeneity among countries meant extensive time was spent for Data Transfer Agreement (DTA) finalization, delaying data sharing. A survey highlighted challenges in stage ascertainment, with 44% confirming clinician consultation when uncertain. 75% of PBCRs completed a staging quality assurance exercise, ensuring high data accuracy.</p>
What this means for the service	Despite regulatory challenges, the Benchista project fosters productive collaboration between PBCRs and clinicians, enhancing understanding of CC survival rate variation and supporting research. It highlights the need for streamlined

	data sharing processes to improve national and regional child health strategies.
--	--