

INTERNATIONAL VARIATION IN CHILD HEALTH SURVEILLANCE AND ACUTE CARE PRACTICES: A MIXED METHODS ANALYSIS

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Introduction

Variation in childhood cancer (CC) survival rates observed across countries might be partly explained by differences in pathways to medical attention and timely diagnosis for symptomatic children.

This study aims to assess current practices in child health surveillance and acute care assessment, and to perform a descriptive comparative analysis of child health practices in countries participating in the International Benchmarking of Childhood Cancer Survival by Stage also called **BENCHISTA Project**.

Methods

A mixed methods approach comprising the development of:

1. A **literature review** with systematic approach of articles published in the last 10 years from five academic and referential databases and conducted according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA).

Terms including *paediatrics/child, diagnosis, cancer, population surveillance*, among others were used to create the search strategy.

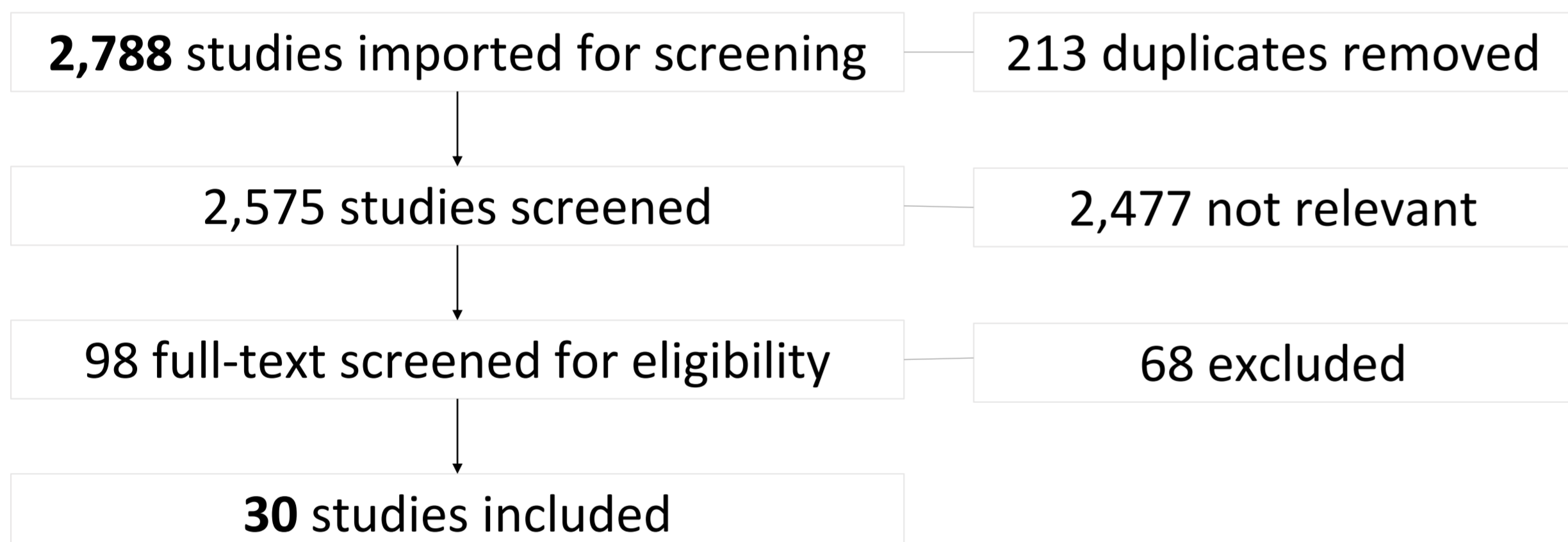
Two independent reviewers screened abstracts for full text selection and data extraction; a third reviewer (paediatric oncology expert) resolved conflicts.

2. A **Semi-structured questionnaire** to collect standardised data on child health practices within each country participating in the BENCHISTA Project.

Focused on *routine surveillance check-ups* (frequency and type of practitioner) universally offered at a national level, *routes to medical attention for acute symptoms*, and if new parents are provided routinely with information about *alarm symptoms*.

Addressed to *one general practitioner and one general paediatrician* to provide relevant information about country's national health policies and practices.

Results



Three **main topics** were identified:

1. Pathways to diagnosis
2. Alarm signs/symptoms of childhood cancer
3. Factors affecting the timely diagnosis of childhood illnesses.

- The questionnaire was piloted, and vocabulary refined.
- 51 answers from practitioners from 25 countries within and outside Europe were obtained.
- Noticeable variation in child health surveillance practices, particularly in the number of universally offered check-ups with physical examination provided in children under 5 years old (median: 10 and range:2-21) was found.
- Validation against national published guidance was performed.

Country	N. mandatory national checks <5y	Intensity of Child surveillance	Initial Medical Assessment
Australia	2	Low	GP, after COVID ED most frequent
United Kingdom	2	Low	General Practitioner
Ireland	2	Low	General Practitioner
Norway [§]	4	Low	General Practitioner
Sweden	4	Low	General Practitioner
Denmark	7	Medium	General Practitioner
Hungary	9	Medium	Paediatrician
Malta	5	Medium	General Practitioner
Slovenia	8	Medium	Paediatrician
Switzerland	9	Medium	Paediatrician
Brazil [§]	12	High	General Practitioner
Bulgaria [§]	21	High	General Practitioner
Canada	11	High	GP, varies urban/rural setting
Czech Republic	12	High	GP for children and adolescents
Estonia	10	High	General Practitioner
Germany	10	High	Paediatrician
Greece	10	High	Paediatrician
Italy	15	High	Paediatrician
Portugal [§]	14	High	General Practitioner
Romania	11	High	General Practitioner
Spain	10	High	Paediatrician

Conclusions

Countries could be categorised according to the frequency of surveillance in the first 5 years of life. Furthermore, noticeable variation in terms of frequency of routine child health surveillance and in access to assessment by a paediatrician for children with acute symptoms was found across them. Similar variation in available guidelines to raise awareness of childhood cancer or serious conditions “alarm symptoms” is evident. The results may provide guidance to categorise countries for interpretation of variation in stage at diagnosis in the BENCHISTA Project.

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BENCHISTA PROJECT: INTERNATIONAL BENCHMARKING OF CHILDHOOD CANCER SURVIVAL BY STAGE – PRELIMINARY RESULTS FOR WILMS TUMOUR

Authors: Kathy Pritchard-Jones¹, Angela Lopez-Cortes¹, Adela Cañete², Charles Stiller², Lisa L. Hjalgrim², Zsuzsanna Jakab², Bernward Zeller², Fabio Didone³, Laura Botta³, Gemma Gatta³, and The BENCHISTA Project Working Group.

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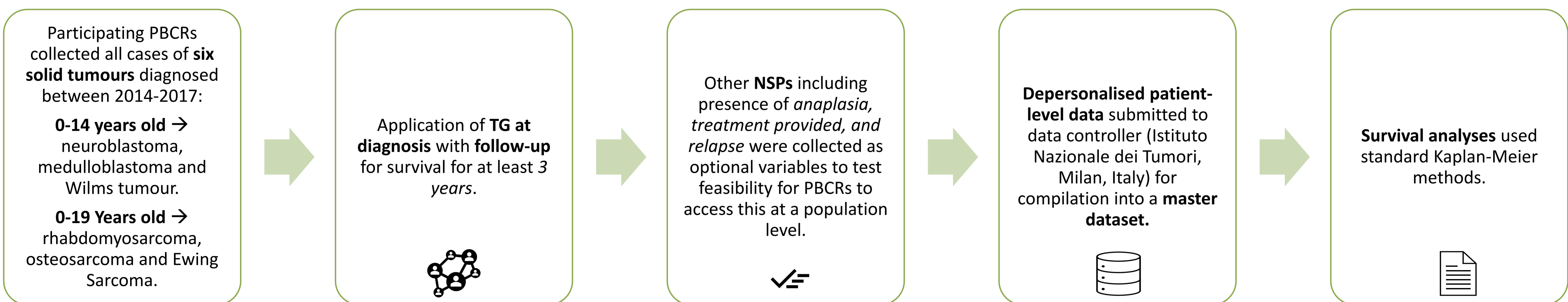
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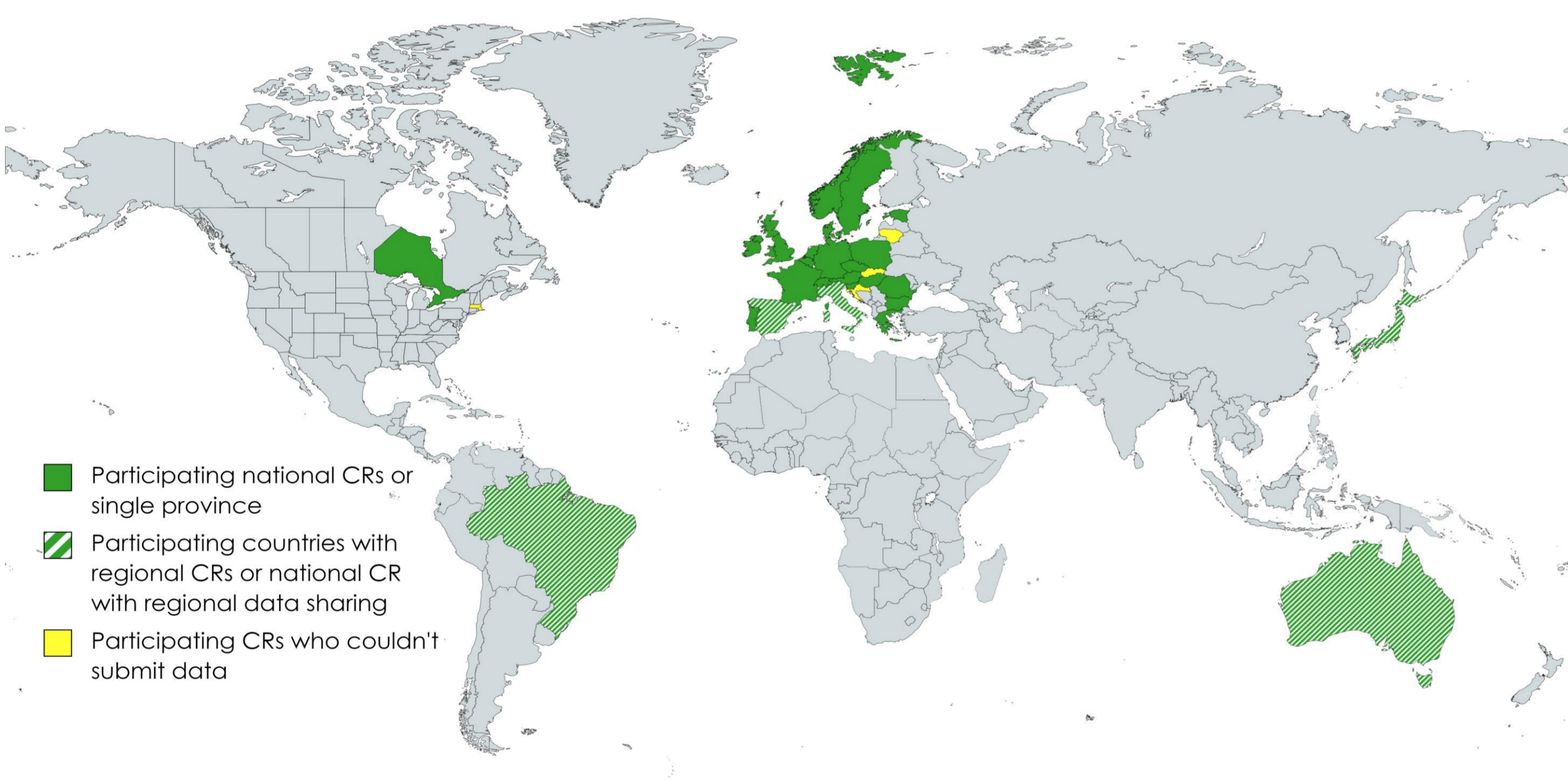
Introduction

Differences in childhood cancer (CC) survival rates across countries might be explained by variation in stage at diagnosis. The BENCHISTA project aims to understand this variation and stimulate the application of the internationally recognised Toronto Guidelines (TG) for documentation of tumour stage and other non-stage prognostic factors (NSPs) by population-based cancer registries (PBCRs) to the most common solid paediatric cancers, including Wilms tumour (WT).

Methods



Results



Wilms Tumour No. cases → 2,245 (20.5% of total)

Item	Completeness for WT
Stage	Tier 1 → 97% Tier 2 → 94%

At a population-level it was found:

Metastasis at diagnosis	18%
Bilateral disease	7%
Initial treatment approach	Immediate surgery in 291 (13%)
	Preoperative chemotherapy in 1,864 (83%)

Presence of absence of anaplasia could be documented in 54% of cases. Among whom reported prevalence of anaplasia was 9%

Overall 3-year survival (OS) = 95% (95%CI: 94-96%)

Stage I/II	99%
Stage IV	87%

Successful International Collaboration

Participation from 67 PBCRs from 24 European countries and Australia, Brazil, Japan and Canada.

By May 2023, 10,504 cases had been received. Current total ~10,950.

Agreement on data format reached by March 2021.

~18 months to finalise Data Transfer Agreement (DTA).

41 PBCRs required a DTA to share their data in compliance with national/regional legislations.

Depersonalised patient-level dataset (mainly HICs).

Conclusions

Heterogeneity in data availability and challenges related to data transfer/sharing processes were encountered. Despite this, PBCRs could achieve data collection and apply TG to a high proportion of WT cases. Access to NSPs requires close cooperation with clinicians and clinical registries. The BENCHISTA Project has established a large multi-disciplinary collaboration producing standardised data on stage at diagnosis. This will enable comparative analyses for a deeper understanding of the underlying reasons for international variations in survival rates.

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Data used in this project have been generated during the treatment and care of patients.

