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Registration practices of CNS tumours in children: analysis of population-based cancer registry data

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Background:
Central nervous system tumours (CNS) represent 20% of childhood cancers. Among them, up to 40% are non-malignant (nmCNS). Untreated nmCNS are life threatening. We analysed registration practices of childhood CNS in population-based cancer registries to highlight the importance of registration of nmCNS.

Methods:
Tumours classified as intracranial and intraspinal in the International Classification of Childhood Cancer were extracted from the database of the International Incidence of Childhood Cancer volume 3 study. Overall, 188 registries operating in 82 countries and territories, covering populations aged 0-14 over variable time periods during 1982-2015, were included. Age-standardised incidence rates per million (ASR) and their confidence intervals (95% CI) were calculated for pools of registries classified by registration and coding practice and the Human Development Index (HDI).

Results:
Based on a total of 113,539 CNS, the overall ASR=29.94 (27.0-32.9). For 60 registries registering only malignant CNS tumours, the pooled ASR=18.5 (13.7-23.3). For 128 registries with systematic registration of nmCNS ASR=33.3 (29.8-36.8). Among 100 registries in countries with very high HDI, 82 (82.0%) registered nmCNS, while among 24 registries in countries with low or medium HDI levels only 9 (37.5%) did.

These data included 18,527 cases of pilocytic astrocytoma (PA) with pooled ASR=5.3 (3.9-6.6). The total CNS incidence varied according to registration of PA. In the 39 registries excluding PA the pooled ASR=13.0 (8.4-17.6), among 103 registries with PA considered non-malignant ASR=31.7 (26.3-37.1), in the pool of 26 registries with malignant PA ASR=36.0 (30.4-41.5) and among 20 registries coding PA with any behaviour ASR=32.3 (25.0-39.5).

Discussion and Conclusion:
Restrictive eligibility criteria results in underestimation of CNS incidence and overall cancer burden in children. The sporadic registration of nmCNS in countries with low HDI may be linked to limited diagnostic facilities. These results produced in ChildGICR collaboration (https://gicr.iarc.fr/childgicr) validate the importance of registration of nmCNS in children.

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