Mapping the landscape of congenital anomaly registries worldwide - What role do health and economic factors play?

Martina Schatz[1] , Felicity Vidya Mehendale[2]

[1] Final Year Medical Student, University of Edinburgh Medical School, Teviot Place, Edinburgh, UK (s2018968@ed.ac.uk)
[2] Centre for Global Health Research, Usher Institute, University of Edinburgh, Edinburgh, UK (felicity.mehendale@ed.ac.uk)

Introduction:

Congenital anomalies (CA) are structural or functional changes that occur during intrauterine life. According to the WHO, every year, about 295,000 babies die within the first 4 weeks of birth due to a CA (1). It has been estimated that 94% of severe CA occur in LICs & LMICs (2). National CA Registries (CAR) can improve healthcare quality, access and planning (1). However, few countries report their use.

Objectives:

I. Study the prevalence of national and/or regional CARs globally.
II. Evaluate differences in key economic and health indicators in countries with and without CARs.

Data and Methods:

- Country CAR status was determined by searching literature and multiple global datasets (3-8).
- Countries were grouped based on CAR status into those with:
  - A national CAR with or without regional CARs (national CAR),
  - Only a regional CAR (regional CAR),
  - No CAR data available (no CAR).

- CAR status was correlated with data from:
  - UNICEF (9) - Birth registration rate (BRR) under 1 and 5 years
  - World Bank (WB) (10) - Infant mortality rate (IMR), Income Group, GDP per capita (in USD), average health expenditure (% of GDP) and IMR per 1000 births

- To analyse for existence of CAR, we included all 202 countries as listed by UNICEF. To study indicators from both the WB and UNICEF we included only the 196 countries that were present in both datasets.
- Analysis was performed on R version 4.3.

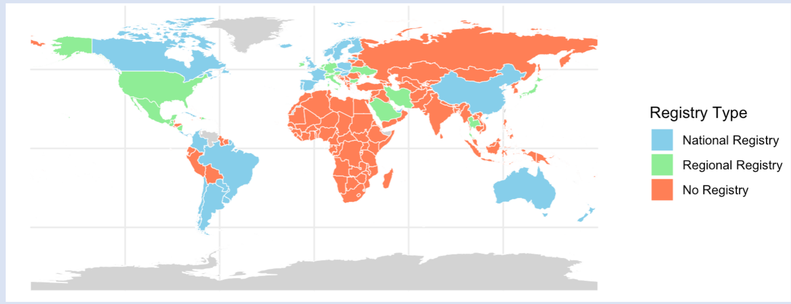
Results:

- Overall, only 14.9% of countries had national CARs.
- 0% of LMICs/LICs had a national CAR compared with 13% of UMICs and 35% of HICs (*Table 1)*.
- Countries lacking a national CAR have lower GDPs, increased IMR and lower BRR.
- A marked difference was noted between continents when CAR status was mapped globally (*Figure 1*).

Table 1: Registry Presence by Country Income Group

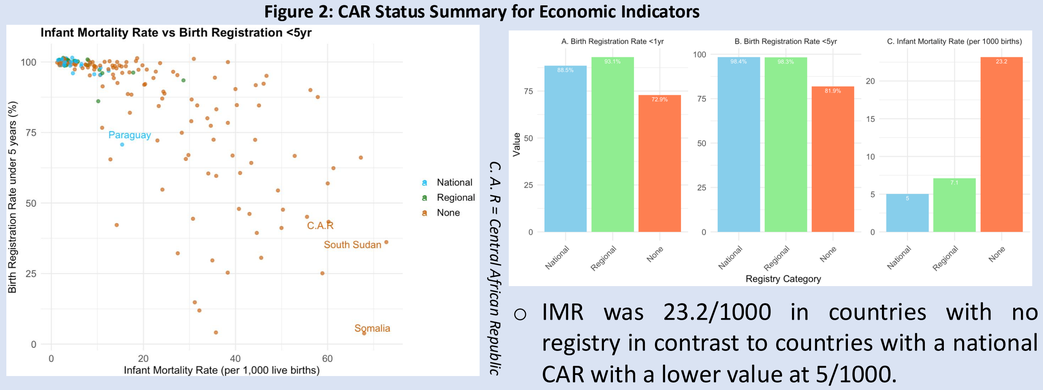
Income Group	Number and (%) of Countries	National Registry	Regional Registry	No Registry
HIC	65 (33.3%)	23 (35.4%)	12 (18.5%)	30 (46.2%)
UMIC	53 (27.2%)	7 (13.2%)	6 (11.3%)	40 (75.5%)
LMIC	51 (26.2%)	0 (0%)	1 (2%)	50 (98%)
LIC	26 (13.3%)	0 (0%)	0 (0%)	26 (100%)

Figure 1: Global Distribution of Congenital Anomaly Registries



Map of the world displaying countries and their CA registry status as recorded in data sources listed in the methods section. Blue box displays countries with national CARs (30/202; 14.9%). Green box displays countries with regional CARs only (19/202; 9.4%). Orange box displays countries with no registries at all (153/202, 75.7%).

Figure 2: CAR Status Summary for Economic Indicators

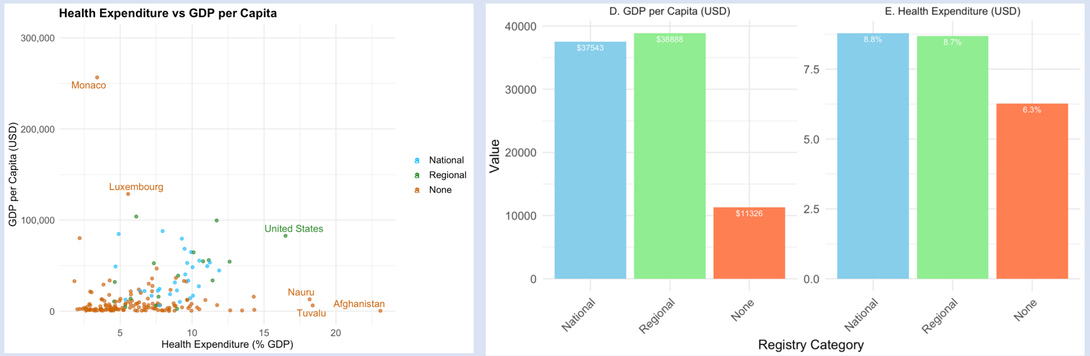


C.A.R = Central African Republic

Paraguay was the only country that had less than 75% coverage of birth registrations that had a CAR. All other countries below this threshold did not have a CAR (*Figure 2*).

- IMR was 23.2/1000 in countries with no registry in contrast to countries with a national CAR with a lower value at 5/1000.
- There was a larger spread between countries with no registry, with some such as Central African Republic, Sudan and Somalia having very low BRR (<50%) and high IMR (>60/1000).

Figure 3: CAR Status Summary for Population Health Indicators



There was a much wider variation in GDP compared with the variation in health expenditure with several low GDP countries spending a greater percentage on health. One example is Afghanistan that spends approximately 23% of their GDP on health although has a GDP of 415 and no CAR (*Figure 3*).

Discussion and Conclusion:

- While the importance of CARs to improve global health is widely recognised, no LMICs and LICs report having a national CAR.
- Our study suggests that countries without CARs have broader, more complex health systems challenges as reflected by lower BRR and higher IMR.
- Lack of a CAR and lower GDP were strongly correlated. But importantly, % of GDP spent on healthcare showed no correlation.
- This suggests that development and maintenance of CARs cannot be achieved in isolation, without addressing broad economic and health systems challenges.
- This interconnectedness is recognised in the sustainable development goals (SDGs). Progress towards SDG 16.9, which emphasises the importance of registration and a legal identity for all newborns, is vital if we are to achieve SDG 3, good health and well-being, by 2030 (11).

References: