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## BACKGROUND

- While external orofacial clefts such as cleft lip with or without cleft palate are easily identified, **isolated cleft palates (ICPs)** often remain **underdiagnosed** or even **unrepaired**.
- Unrepaired cleft palates** lead to **morbidity** (feeding, nutrition, growth, speech, hearing and airway problems) and **mortality**.
- The **diagnosis** of ICPs is **challenging** in high- and low/middle-income countries (LMICs), **LMICs are disproportionately affected**.
- ICPs** are often **missed** due to their non-external nature.

## PURPOSE

- To quantify the **proportion of ICPs repaired**, relative to all primary cleft surgery, **in LMICs** using a large cleft charity's electronic health record.

## METHODS

- Smile Train Express (STX)**, the electronic health record database developed by Smile Train, was retrospectively interrogated to identify ICP surgeries, as **matched** by both **diagnosis** and **surgery type**.
- Selection criteria** specific to **unique** entries with **hard and/or soft palate clefts** without history of cleft lip or alveolus were identified by country.
- Each country's **Human Development Index (HDI)** and **age at ICP repair** were collected.
- Data were analyzed and crosschecked against documented surgery methods with a **range of sensitivity and specificity**.

## RESULTS

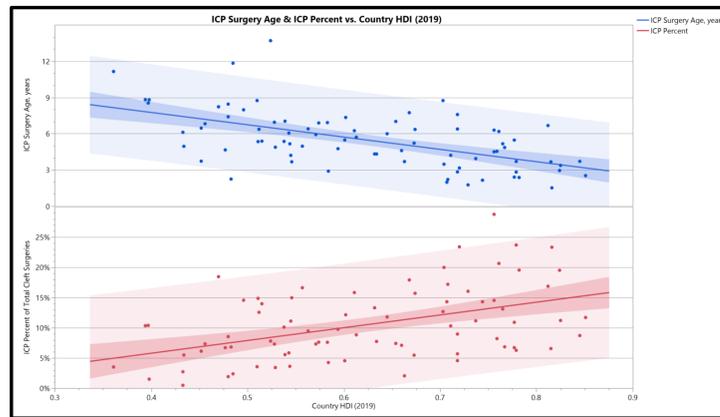


Figure 1. Age at ICP surgery and ICP surgery fraction (%) per Human Development Index, for 80 countries.

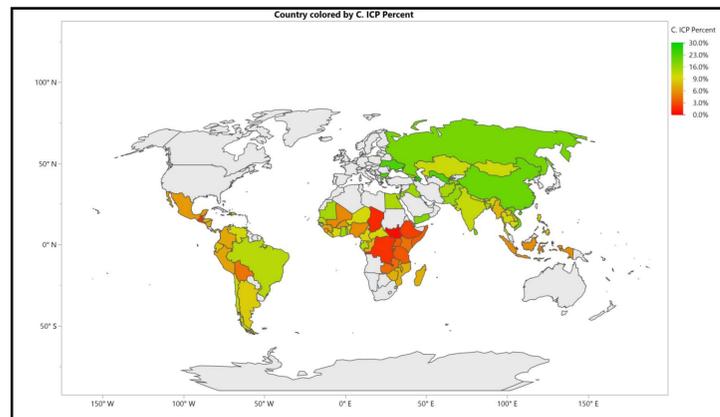


Figure 2. World map with countries shaded by ICP surgery fraction (%) Globally, the mean ICP surgery fraction was around 13%

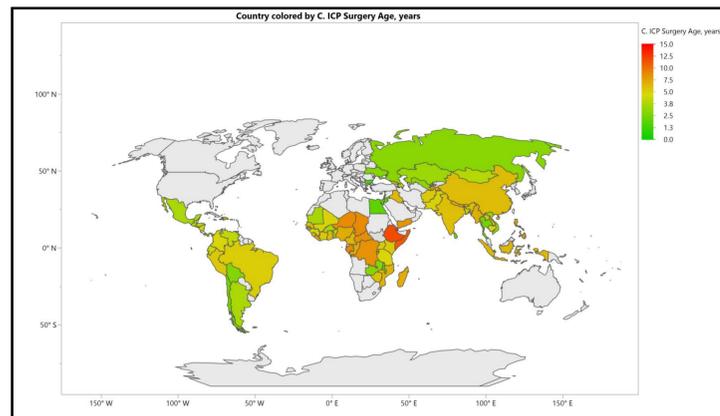
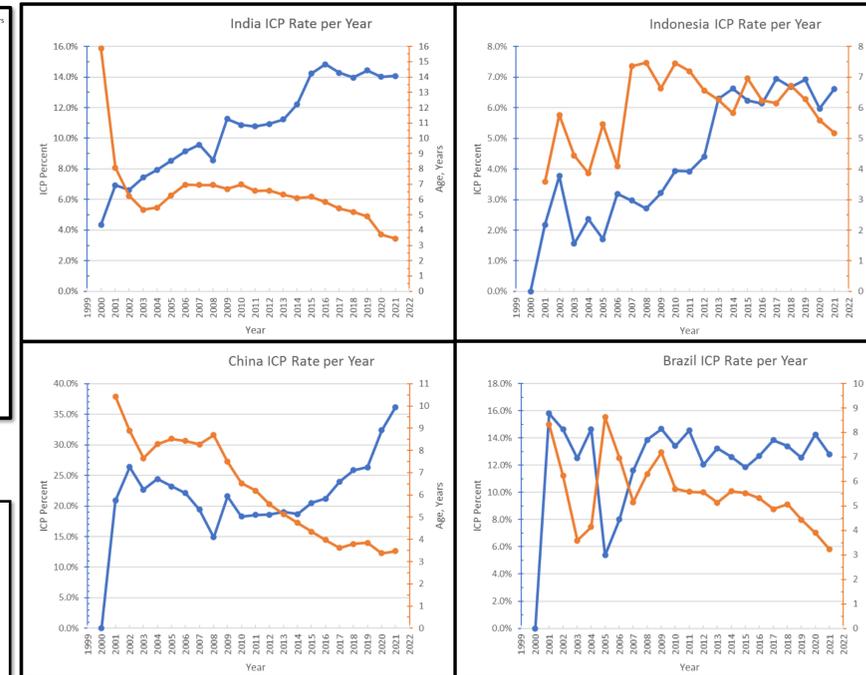
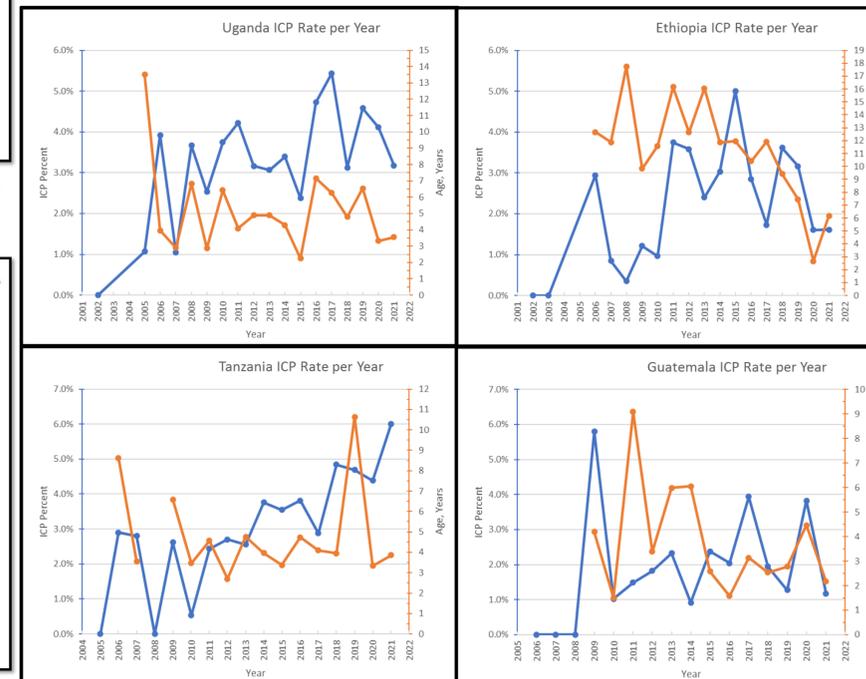


Figure 3. World map with countries shaded by age at ICP surgery Globally, the mean age at ICP surgery was around 5.5 years



Upper: Rate of ICP repair and age at surgery, per year, for 4 high volume LMICs  
Lower: Rate of ICP repair and age at surgery, per year, for LMICs with low ICP rates



LEGEND — ICP Rate — Age at Repair, Years

## RESULTS CONT.

- A total of **221,531** out of 1.6 million (**13%**) cleft surgeries were identified as **ICPs** across **80 LMICs**.
- The ICP intervention fraction varied between **1.4% - 29%**.
- Countries with the **lowest ICP fractions** (<5%, n=12) were all located in **Africa** and **Central/South America**. These included 2,653 ICP out of 86,902 interventions, with an average age at ICP repair of 6.7 years.
- Age at ICP repair** correlated negatively with HDI ( $p < 0.01$ ).
- The **fraction of ICP surgery** out of total clefts correlated positively with HDI ( $p < 0.01$ ).

## CONCLUSIONS

- A significantly **low fraction of primary cleft surgery** was for ICP repair in countries with the lowest HDI.
- In high income countries, **ICPs range from 25-50% of all clefts**.
- In this analysis LMICs had **very low numbers of ICP repairs**, despite cleft palate with cleft lip being commonly repaired in these countries.
- Countries that began with low rates/high ages** became **more favorable over time**, presumably due to system strengthening and training
- Intensive **efforts** must be placed on **ICP diagnosis** and **earlier surgery** to prevent morbidity and mortality.
- Further work is needed to identify the **cause of seemingly lower rates** in certain LMICs

## REFERENCES

- Wilson J, Hodges A. Cleft lip and palate surgery carried out by one team in Uganda: where have all the palates gone?. Cleft Palate Craniofac J. 2012;49(3):299-304. doi:10.1597/09-039