

# UTILISATION OF THE I-CAH REGISTRY FOR FACILITATING QUALITY IMPROVEMENT- RESULTS OF AN INTERNATIONAL SURVEY

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## INTRODUCTION

Recent studies using data from the International Congenital Adrenal Hyperplasia (CAH) Registry ([www.i-cah.org](http://www.i-cah.org)) (1), have provided valuable insight into the determinants and variation of reported acute adrenal insufficiency (AI) related adverse events amongst specialist centres, demonstrating that the I-CAH Registry could be used as a tool for quality improvement.

## AIMS

- To incorporate clinical benchmarks for quality of data and quality of care in the I-CAH Registry into individualized centre reports
- Develop an online survey to obtain feedback from centres regarding the content and structure of the care quality reports

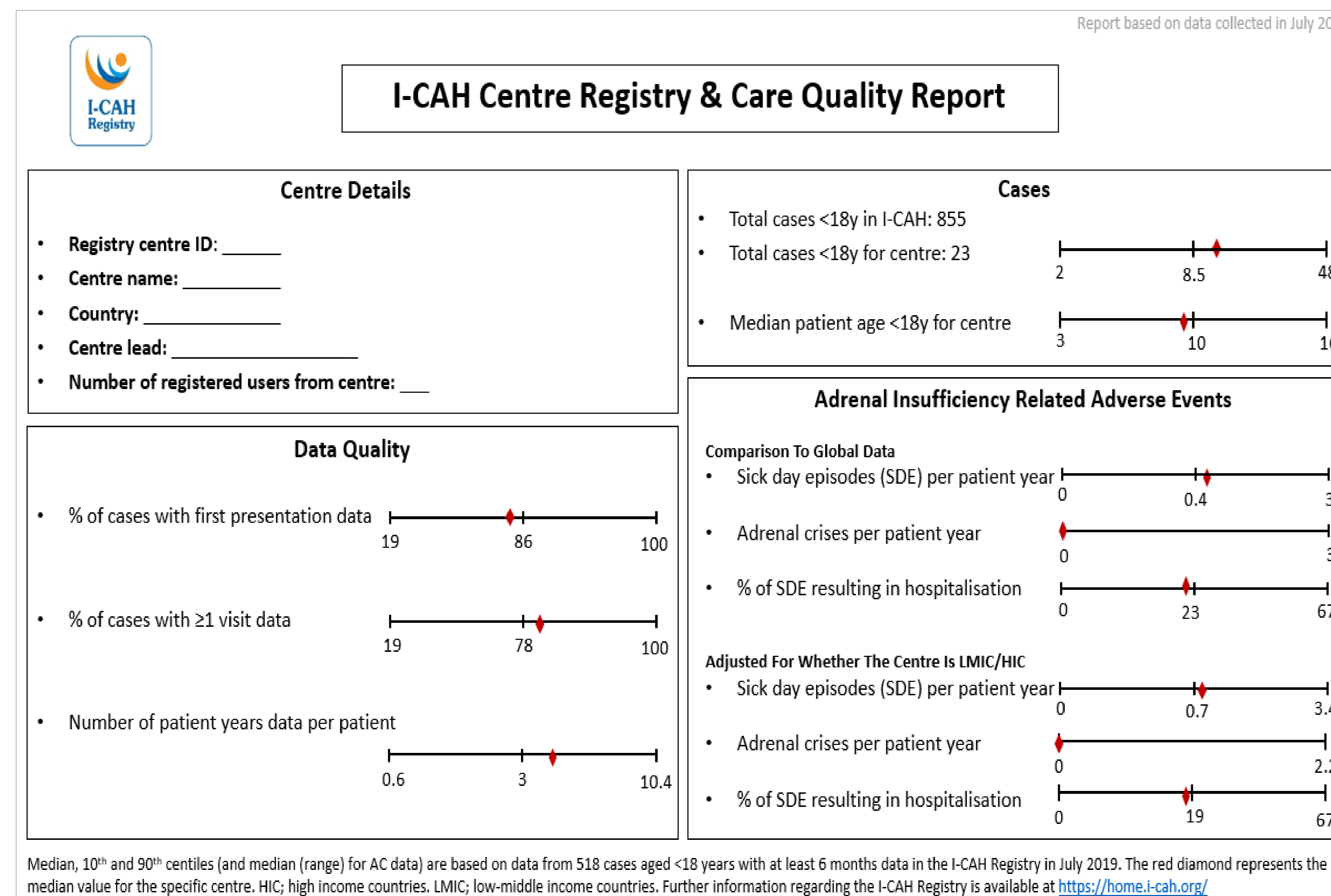
## METHOD

- Individualised care quality reports created for 32 centres who participated in a previous I-CAH study that evaluated real world estimates of AI-related adverse events in children with CAH (1)
- Care quality reports provided information on:
  - Quality of data in the I-CAH Registry
  - Quality of CAH care, as reflected by sick day episodes (SDE) and adrenal crises (AC), incorporating clinical benchmarks for SDE and AC from a previous study (1)
- An online survey was circulated to centre leads to obtain feedback regarding the content and structure of the care quality reports

## RESULTS

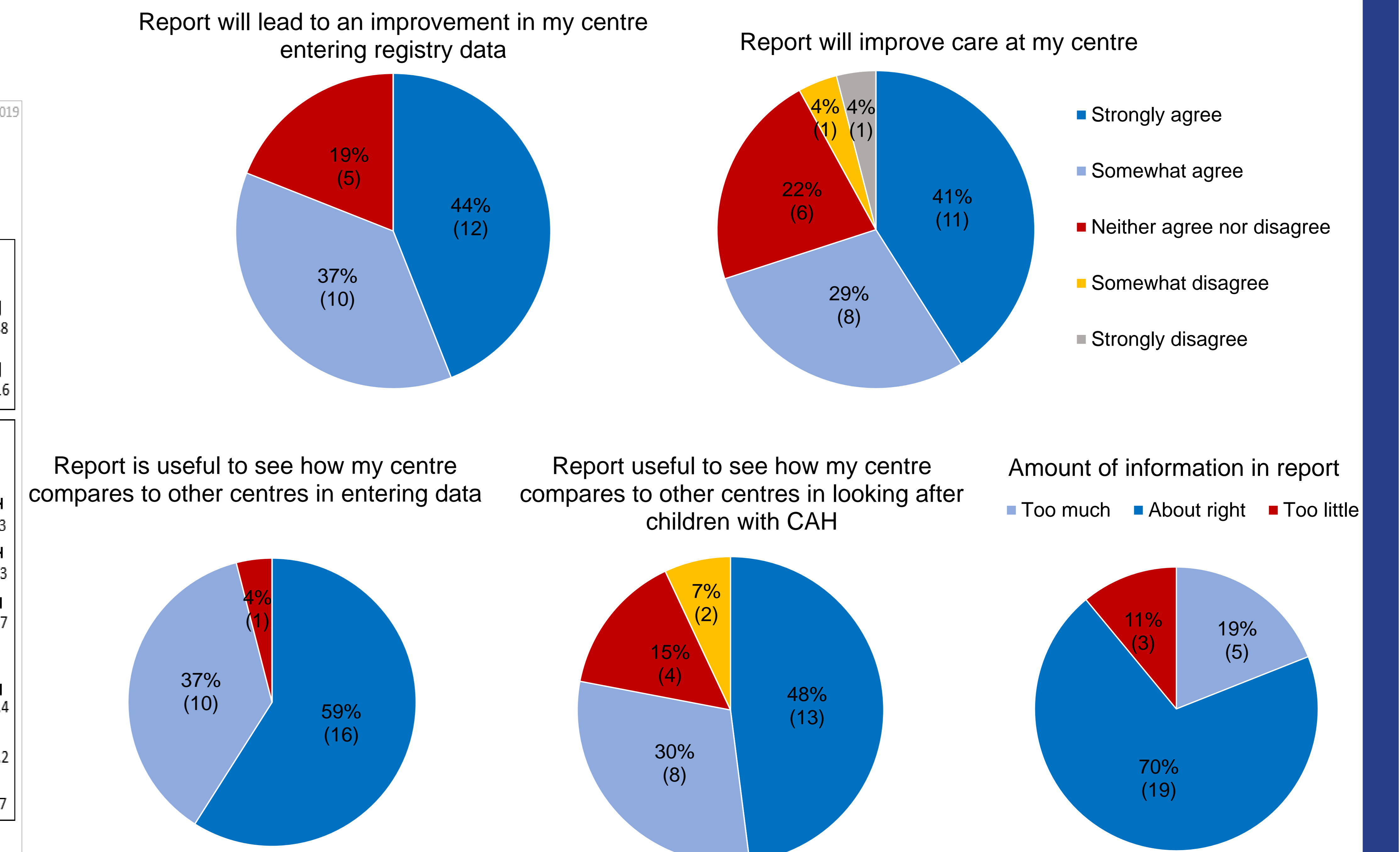
### The I-CAH Centre Report

Sent to 32 I-CAH centres (18 countries) in February 2021  
(diamond symbol in red denotes hypothetical centre)



### The I-CAH Centre Report Feedback Survey

Survey response: 27 (84%) centres



## CONCLUSIONS

- The real-world data within the I-CAH registry are a valuable resource for studying core clinical outcomes that can be used as benchmarks for improving clinical care
- Further work needs to be undertaken to determine whether the exercise of producing regular care quality reports for centres is associated with an improvement in these clinical benchmarks

## REFERENCES

- Ali SR et al. Real-World Estimates of Adrenal Insufficiency-Related Adverse Events in Children with Congenital Adrenal Hyperplasia. J Clin Endocrinol Metab. 2021;106:e192-e203

## ACKNOWLEDGEMENTS

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## CONTACT INFORMATION

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- Visit the I-CAH Registry website: <https://home.i-cah.org/>

