

Details of study ID 201808_SA

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Coinvestigators: Eunice Jia Lin Tang, Jillian Bryce, Faisal Ahmed and the participating centres https://sdmregistries.org/i-cah-adverse-events-in-cah-study-group/
Date of Approval: August 2018
Name of study: Acute Adrenal Insufficiency Related Adverse Events in Children with Congenital Adrenal Hyperplasia (CAH) (2022-2025)
Summary of the proposed work performed with the registry data: Background: CAH is the most common cause of primary adrenal insufficiency (AI) during childhood and patients are at risk of life-threatening adrenal crises. Previous studies have shown that children are at greater risk of illness sequelae. Our previous work in 2019 and 2022 concluded that the real-world data that are collected within the <i>SDMregistries</i> show wide variability in the reported occurrence of adrenal insufficiency-related AE ¹⁻³ . This project is being continued to investigate whether the level of variation has changed over the period of the last 3 years, both across centres who participated in the 2022 exercise but also by accumulating data from new centres. Methodology: Retrospective data collection from the <i>SDMregistries</i> . Centres will be approached to enter/update data in the Registry. Objective: To understand the current international benchmark of AI-related AE and the change in this benchmark. Inclusion criteria: All patients with a diagnosis of classic 21-hydroxylase deficiency CAH in the SDM Registry with age <18 years at the time of clinic visits with a minimum of 2 clinical encounters 6 months apart for the period 01/08/2022 to 31/07/2025 (minimum 6 encounters per patient). Exclusion criteria: • Age>18 years on 31/7/25 • All other forms of CAH The data that will be collected and analysed will be in the following fields: Core Data <i>Centre:</i> Centre name, country <i>Record:</i> Register ID record, country of usual residence CAH Assessment Data <i>CAH Longitudinal data:</i> Date of the assessment, Weight, Height

Current medication: Glucocorticoids, fludrocortisone, fludrocortisone frequency, current GC replacement, salt replacement

Adverse Events: Include details such as use of oral steroids, occurrence of adrenal crisis, number of affected days, hydrocortisone (HC) injections, emergency interventions, and any predisposing conditions. If no adverse events occurred for a patient, please enter "0" in the corresponding field.

Previous Publications:

1. Ali SR, Bryce J, Haghpanahan H et al. Real-world estimates of adrenal insufficiency-related adverse events in children with congenital adrenal hyperplasia. [J Clin Endocrinol Metab 2021 Jan 1;106\(1\):e192-e203.](#)
2. Ali SR, Bryce J, Krone NP et al. Management of acute adrenal insufficiency-related adverse events in children with congenital adrenal hyperplasia: results of an international survey of specialist centres. [Horm Res Paediatr 2022 May 13. doi: 10.1159/000525075.](#)
3. Tseretopoulou X, Ali SR, Bryce J et al. Temporal trends in acute adrenal insufficiency events in children with congenital adrenal hyperplasia during 2019–2022. [J Endocr Soc. 2024 Aug 20;8\(10\):bvae145. doi: 10.1210/jendso/bvae145.](#)

Lay summary for the public (for the *SDMregistries* website and other publicity materials) (maximum 50 words)

CAH is a serious condition and is associated with life-threatening adrenal crises and sick day episodes. We would like to explore the variation of the frequency (incidence) of these episodes among centres that treat children with CAH and see whether this shows any change over time.

Publication Plan for authorship in outputs (refer to [guidance](#))

All contributors who participate in the project shall be included as authors if their participation is in accordance with the *SDMregistries* publication plan.

The project group who will be closely involved in the work (project design, data extraction, data analysis, writing the paper) will be listed first.

The senior authors will be involved in designing the project and data analysis, acting as guarantors and taking responsibility for the work will be listed last authors. All other contributors will be listed in alphabetical order between these two groups of authors. More than two authors from any one contributing centre will need careful justification.

Created: 16 August 2021

Revised: 18 March 2026