



I-CAH Registry

2026 Benchmarking Report

I-CAH Registry

2026 Benchmarking Report

Report prepared by

Salma R. Ali, Malika Alimussina, Joseph McElvaney, Eunice Jia Lin Tang

With assistance from

Jillian Bryce, Sanhita Koley, Minglu Chen, Martin McMillan

Office for Rare Conditions (ORC) Registries

School of Medicine, Dentistry & Nursing, University of Glasgow, UK

Acknowledgements

The ORC Registries team would like to thank the *SDMregistries* Care Quality Improvement Committee (CQIC) and the participating centres for their continued involvement in the I-CAH Registry.

Contact information

For more information about the *SDMregistries* platform, please visit <https://sdmregistries.org/> or contact us at info@sdmregistries.org

Contents

Report prepared by	2
With assistance from	
Acknowledgements	
Contact information	
Introduction	4
CAH	
The I-CAH Registry (purpose, development)	
Where can I find more information	
Section 1: Summary of the I-CAH Registry	5
Section 2: I-CAH benchmarks	7
Acute adrenal insufficiency-related adverse events	
Anthropometric benchmarks of care	
Section 3: Centre-level data	9
Centre details	
Cases	
Data quality	
Acute adrenal insufficiency-related adverse events in CAH	
Anthropometric benchmarks of care in CAH	

Introduction

This report has been provided to users of the International Congenital Adrenal Hyperplasia (I-CAH) Registry which is part of *SDMregistries*, an international registry platform and network that aims to improve clinical practice, research and understanding of a wide range of conditions affecting sex development and maturation.

An online version of this report can be found at:

<https://sdmregistries.org/benchmarking-reports/>

CAH

Congenital adrenal hyperplasia (CAH) is a group of autosomal recessive disorders with an incidence of 1 in 15,000. In the commonest form of CAH due to 21-hydroxylase deficiency (21-OHD), cortisol deficiency is accompanied by a variable extent of mineralocorticoid deficiency and androgen excess. 21-OHD CAH is the commonest cause of primary adrenal insufficiency in children and patients have a life-long, variable requirement for glucocorticoid and mineralocorticoid replacement. In addition to adrenal insufficiency, children can also be exposed to excess androgens. Optimisation of growth and an avoidance of acute adrenal insufficiency related adverse events form the cornerstones of the clinical management of 21-OHD CAH in childhood.

The I-CAH Registry

The I-CAH Registry is a dedicated module for CAH on the *SDMregistries* platform which also includes a module for DSD (I-DSD), Turner syndrome (I-TS) and hypogonadotrophic hypogonadism (I-HH). Since its development in 2014, the number of cases of CAH in I-CAH has increased from around 200 to over 3,500 in 2026. The *SDMregistries* platform is managed by the Office for Rare Conditions (ORC) Registries team at the University of Glasgow and receives funding from a wide range of sources that includes fees incurred by investigators for obtaining data for research, other ORC Registries project grants and income from the biennial symposium. *SDMregistries* has a Steering Committee which includes representation of the Data Access Committee, the Care Quality Improvement Committee and the Learning and Training Committee. The Steering Committee also guides the Project Management Group which is based at the ORC Registries in Glasgow.

Where can I find more information

Find out more information about I-CAH and *SDMregistries* at <https://sdmregistries.org/>

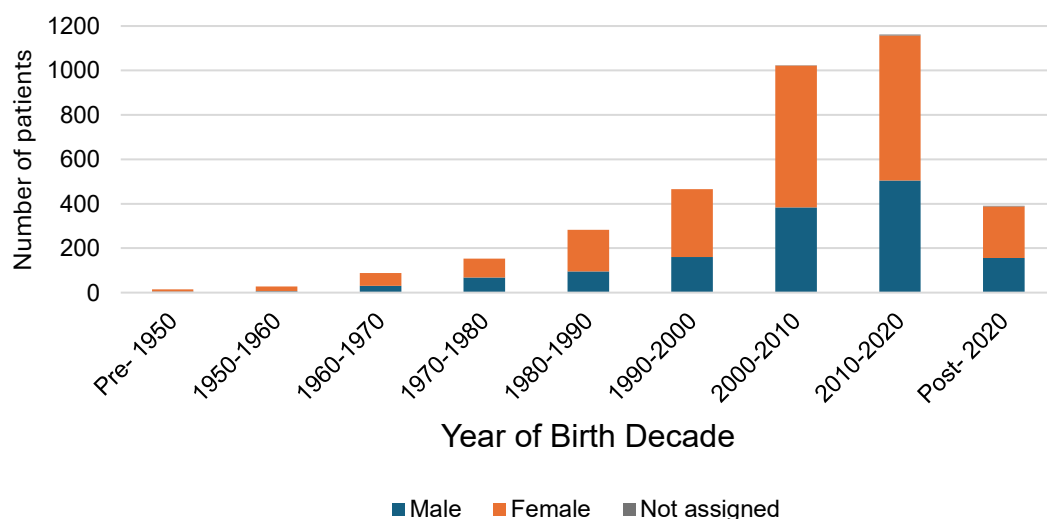
Section 1: Summary of the I-CAH Registry

As of 1 June 2026, 3,619 cases of 21-OHD CAH had been reported in I-CAH from 133 centres across 36 countries. The median number of patients per centre was 13 (1, 67)¹. Of the 3,619 patients, 10 were deceased. Among the remaining 3,609 patients, the median current age was 19 years (6, 43) with 1,732 (48%) aged <18 years and 1,877 (52%) aged ≥18 years.

1.1 World map showing countries with centres reporting cases of 21-OHD CAH

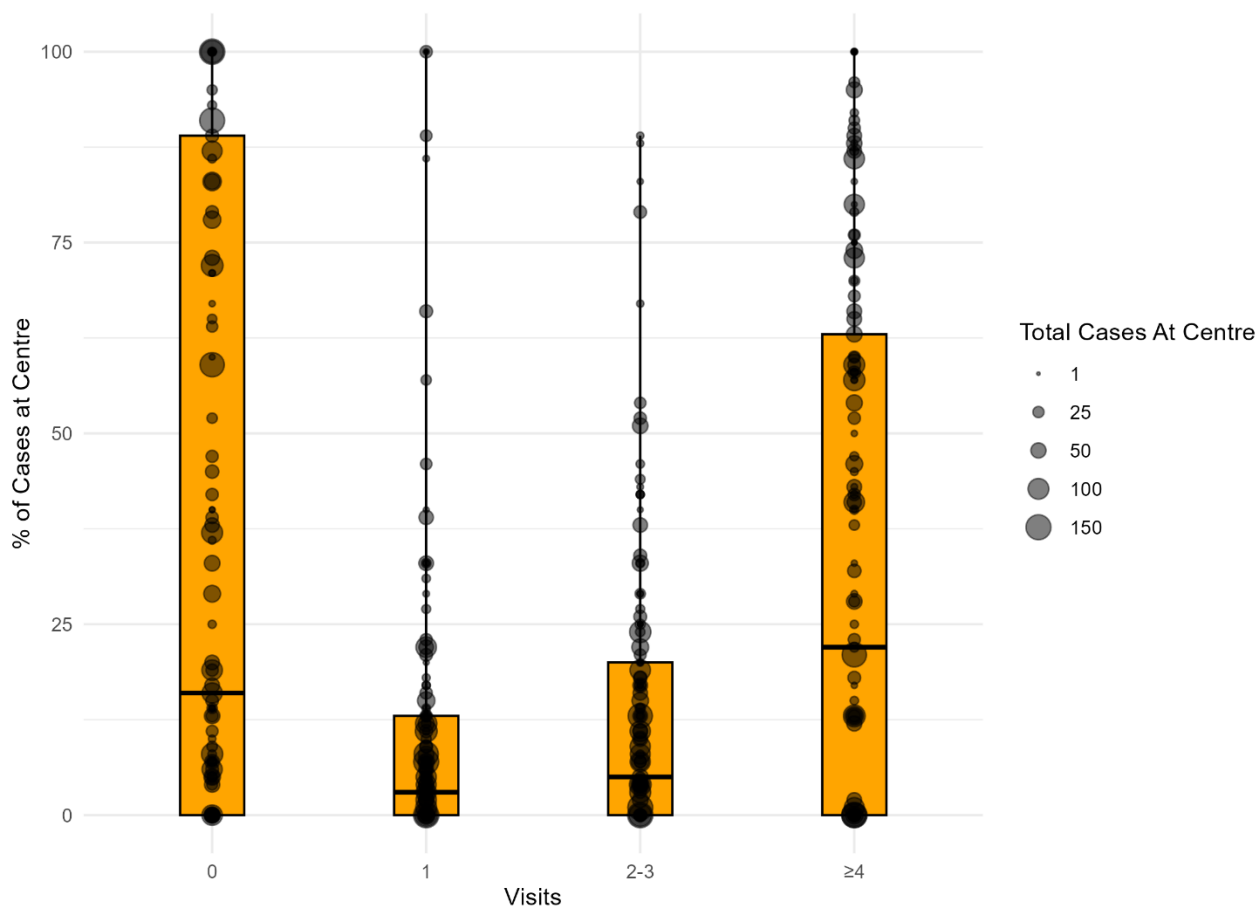


1.2 Proportion of male and female cases according to year of birth

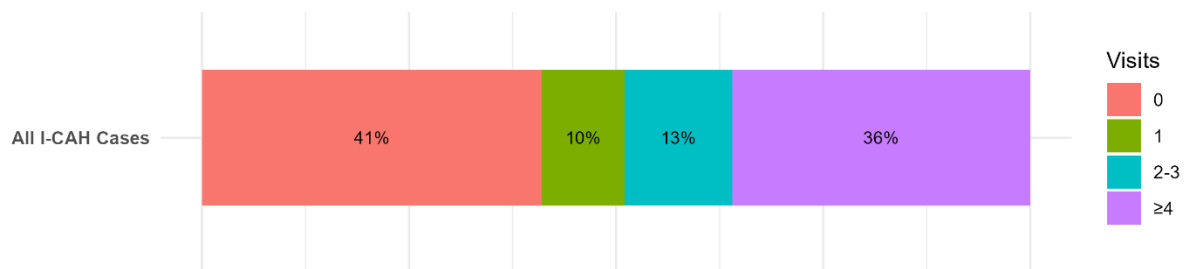


¹ Values are presented as median (10th, 90th centiles) throughout report, unless otherwise stated.

1.3 Annualised number of visits²



Bar chart representing % of cases at all centres reporting 21-OHD with 0, 1, 2-3 and ≥ 4 annualised visits as of June 2026. Points represent individual centres with size relative to the total number of cases at the centre.



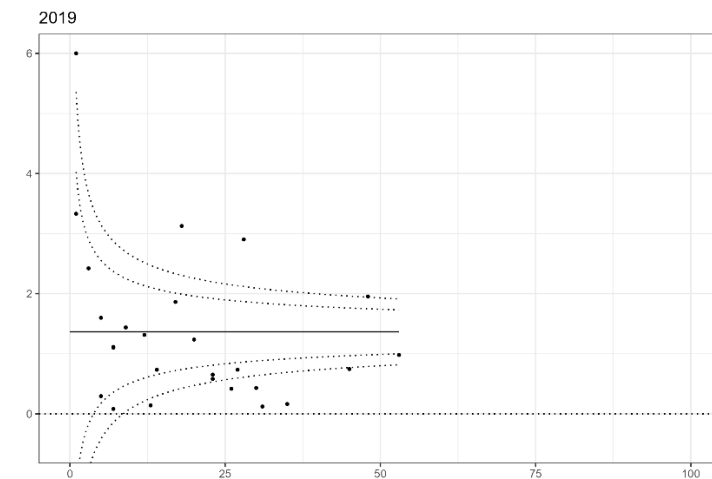
Bar representing proportions of all cases with 21-OHD in I-CAH with 0, 1, 2-3 and ≥ 4 annualised visits as of June 2026.

² Annualised number of visits was defined as the number of distinct follow-up years in which a patient had at least one recorded visit. Follow-up years were calculated relative to the age at first recorded visit, with the first visit assigned to year 0. Thus, multiple visits within the same follow-up year were counted once. A value of 0 indicates that no follow-up visits were recorded.

Section 2: I-CAH benchmarking

2.1 Acute adrenal insufficiency-related adverse events

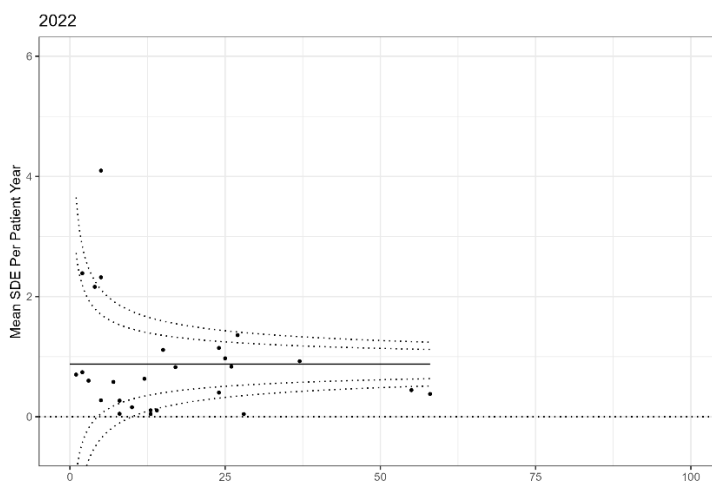
The funnel plots below show the mean sick day episodes (SDEs) per patient-year among participating centres for each benchmarking period. The solid horizontal line indicates the mean SDE rate for that period, the inner and outer dotted lines represent ± 2 and ± 3 standard deviations from the mean. Each point represents an individual centre.



2016–2019:

222 children from 27 centres in 17 countries contributed 256 patient-years of follow-up.

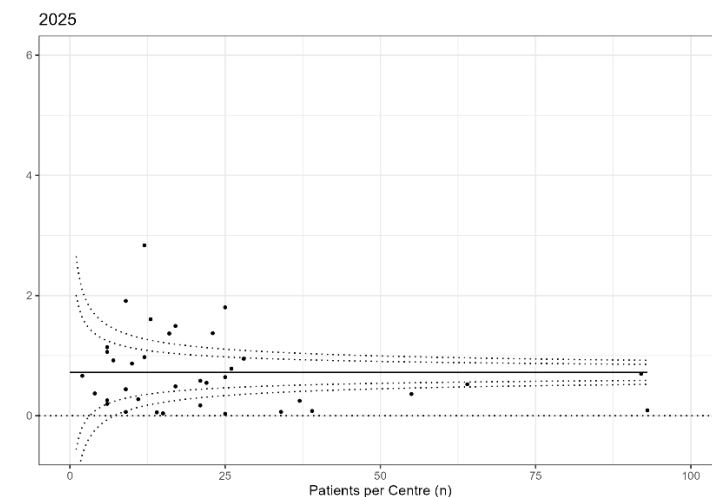
Median cases per centre was 5 (1, 35) and the median SDE rate was 0.6 events per patient-year per centre (0, 8.3).



2019–2022:

513 children from 38 centres in 21 countries contributed 880 patient-years of follow-up.

Median cases per centre increased to 8 (2, 27), while the median SDE rate decreased to 0 events per patient-year per centre (0, 1.7).



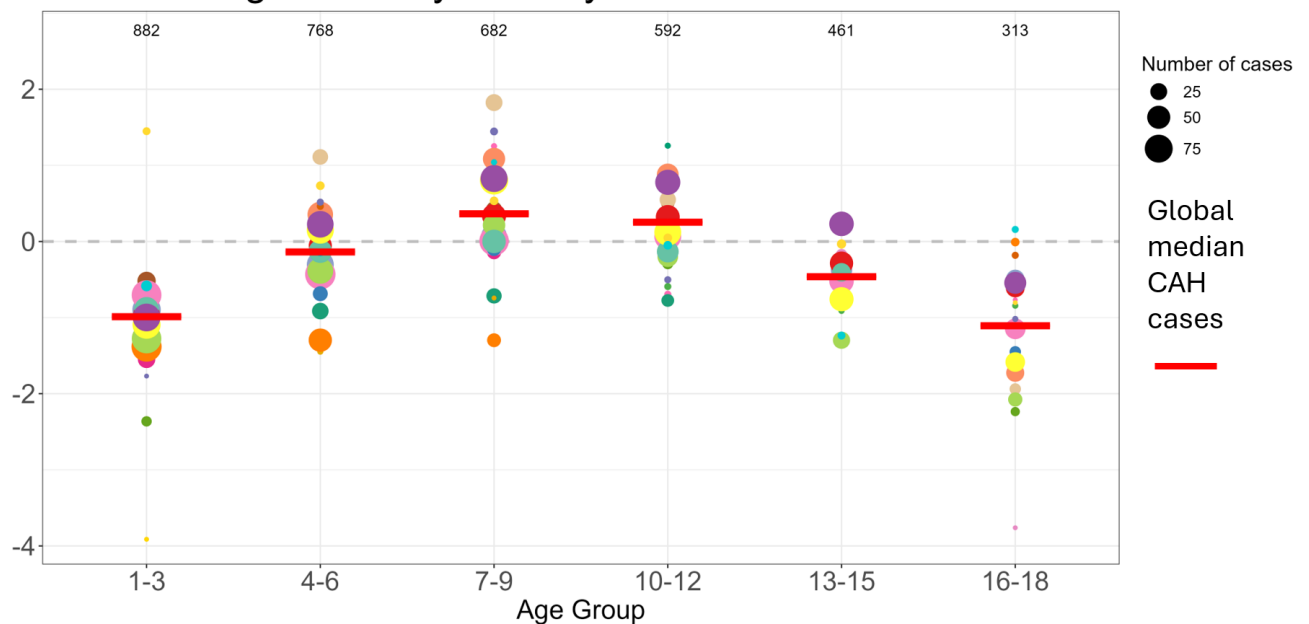
2022–2025:

979 children from 56 centres in 25 countries contributed 1,725 patient-years of follow-up.

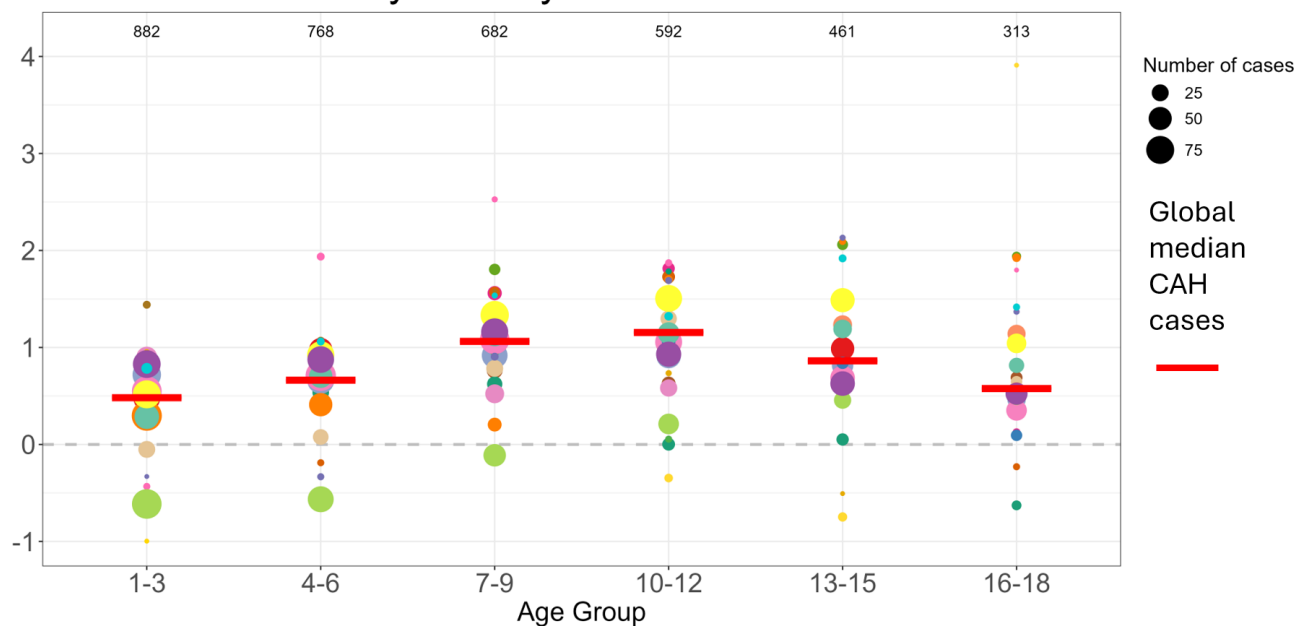
Median cases per centre increased further to 12 (2, 36), and the median SDE rate remained 0 events per patient-year per centre (0, 1.1).

2.2 Anthropometric Benchmarks of Care

Median Height SDS By Country



Median BMI SDS By Country



Height and BMI standard deviation scores (SDS) for 21-OHD cases <18 at clinic visits grouped by age. Points represent the median of cases in each country, with size relative to the total number of cases in that country. Horizontal dotted line shows 0 SDS. Overall number of cases for each age group shown above. Data from 1969 – 2025, total number of cases 1,293. Population-specific height reference data used where available. WHO reference data used for BMI.