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Background: Congenital adrenal hyperplasia (CAH) is one of the commonest forms of primary adrenal insufficiency with an incidence of about 1 in 15,000. Previous studies have highlighted the suboptimal health status and care provision in adults with CAH and these were associated with significant co-morbidities. In 2023, we implemented CaHASE2 (https://www.endocrinology.org/clinical-practice/research-projects/cahase-2/) to develop a strategy for prospective collection of longitudinal data. Our recent CAH service evaluation suggested significant differences in the approach to CAH patients. **Aim:** To identify specific unmet needs in the care of people living with CAH, through standardised phenotyping across all participating centres. **Methods:** In September 2023, PIs agreed a minimal dataset for the collection of real-world data for participating centres. The data is collected using the international CAH

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First Insights into the Health Status of Adults with CAH in the UK and Ireland - CaHASE2

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registry (I-CAH; https://sdmregistries.org/). CaHASE2 was launched in November 2023. **Results:** To date, 351 adults (213 females, 138 males) with CAH have been recruited and 1213 clinic visits were available for analysis. There is a preponderance of younger to middle-aged adults in the currently available datasets (median age 42 years, range 23-88). Preliminary analysis suggests a temporal change in glucocorticoid choice over time with an increased use of hydrocortisone and a decreased use of prednisolone. Analysis of 17OHP concentrations shows that a significant proportion of patients are overtreated. A significant proportion of patients are overweight or obese. Currently 18 centres are actively recruiting and 5 are awaiting local approval to use the I-CAH registry. The data will be analysed in 12-month cycles, to assess the current level of care provision and inform the development of CAH standards. In addition, we will establish a report that will provide centres with information about their local care provision in relation to other centres. **Conclusions:** The CaHASE2 project will provide important information about the health status of adults with CAH and how this might be related to differences in health care provision. Ultimately, such data should lead to a higher degree of equality of service provision in all parts of the UK and Ireland.

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