

NEW ESE POSITION STATEMENT

Self-management and support services for Adult Patients with Adrenal Insufficiency (AI)

This two-year project aims to:

- Evaluate factors that influence self-management for adult patients with AI (international cross-sectional survey adapted & translated in several languages);
- Explore current patient education approaches and support services across Europe;
- Develop an evidence-based European Position Statement using Delphi research methodology.

We invite you to participate as a:

- Principle Investigator to recruit patients with AI from your Centre or country;
- Patient Advocacy Group representative to disseminate the survey to your members;
- Member of the Expert Panel in the Delphi Study to develop the ESE Position Statement.

Please contact Dr SOFIA LLAHANA on adrenal.study@city.ac.uk for further details or for a copy of the study protocol.

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**CITY UNIVERSITY
LONDON**



Frequently asked questions: Expert Panel involvement and expectations

Study title: A mixed methods study to evaluate barriers and enablers to self-management and to develop a European Position Statement on patient education and support services for Adults Patients with Adrenal Insufficiency

Chief Investigator: Dr Sofia Llahana

What are the study aims and objectives?

This study, conducted under the auspices of the Rare Disease Committee of the European Society for Endocrinology (ESE) and the European Reference Network on Rare Endocrine Conditions (EndoERN), is led by the ESE Position Statement Working Group. It is funded by grants from the Addison's Disease Self-Help Group and City, University of London. This study is an extension of a larger UK-based study aiming to develop a digital self-management programme for patients with Adrenal Insufficiency (AI), funded by the UK National Institute for Health and Care Research (NIHR). The survey in the UK has received almost 2,000 responses.

Study aims:

- Evaluate factors influencing self-management for patients with AI through an international cross-sectional survey, adapted and translated into several languages.
- Explore current patient education approaches and support services across different countries.
- Develop an evidence-based European Position Statement using Delphi research methodology.

What are the study stages?

This study will be conducted over two years in two main stages:

1. International Survey: Adapted and translated for each country, involving patients with adrenal insufficiency.
2. Delphi Study: To develop and test the statements for the ESE Position Statement.

How can I get involved in this project?

We invite you to participate as a:

- Member of the Expert Panel contributing to the questionnaire adaptations and translations;
- Principle Investigator to identify patients with AI from your Centre or country;
- Patient Advocacy Group representative to disseminate the survey to your members;
- Member of the Expert Panel in the Delphi Study to develop the ESE Position Statement.

Please contact us on adrenal.study@city.ac.uk to find out how you can collaborate in this study; details on the larger NIHR Self-Management Intervention can be found [here](#)

How was the questionnaire for this study developed and tested?

The questionnaire is based on literature and findings from 13 focus group interviews with patients with AI from the UK, USA, and Canada. It focuses on three self-management areas:

- 1) Daily management of AI and its treatment;
- 2) Management of "sick days" and glucocorticoid treatment adjustment;
- 3) Prevention and management of adrenal crisis.

Disseminated in the UK, the survey received responses from nearly 2,000 patients with AI recruited via PAGs and 28 endocrine centres.

Information on how you can contribute to adapting the survey for international dissemination are included with the questionnaire for your review.

What are the timelines for the Project?

- Survey Translation and Dissemination: May 2024 - March 2025
- Delphi Study: September 2024 - July 2025
- Final ESE Position Statement: By December 2025

How will the results be disseminated?

We plan two potential publications: one on the survey findings and another on the ESE Position Statement, both in the European Journal of Endocrinology. Results will also be presented at various scientific and patient advocacy group meetings.

Will I have an involvement as a co-author in this project?

In accordance with the [ICMJE Recommendations](#), collaborators who contribute to adapting and translating the questionnaire, and identifying patients and disseminating the survey, will be collectively acknowledged as a Group of "*International Adrenal Insufficiency Self-management Consortium*". This includes the Consortium's name being featured in the authors list, citation, and copyright sections of any resulting publications, which ensures proper indexing in PubMed or MEDLINE databases. As acknowledgment implies endorsement, the Chief Investigator (CI) will obtain written permission from all collaborators to be acknowledged in potential publications resulting from this study.

Thank you for your contribution to this study!

Dr Sofia Llahana, Chief Investigator

ESE Position Statement Working Group

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