

Clinical Practice Guidelines & Clinical Decision Support Tools (WP7)

Olaf Dekkers – adult chair, Anna Nordenström - Paediatric chair,
Jette Kristensen - ePAG, Alessandro Lazzerini e-PAG, Diana Vitali-ePAG



Work package members

Olaf Dekkers **Adult chair**

Leiden University Medical Center (Leiden , Netherlands)



Anna Nordenström **Paediatric chair**

Karolinska University Hospital (Stockholm, Sweden)



Jette Kristensen **ePAG representative**

Addison Foreningen Danmark (Denmark)



Alessandro Lazzerini **ePAG representative**

Spanish Association of Congenital Adrenal Hyperplasia (CAH) (Spain)



Diana Vitali **ePAG representative**

SOD ITALIA – Italian organization for septo optic dysplasia and other neuroendocrine disorders (Roma, Italy)

Main goal of WP 7



Main goal:

- ☐ To develop EndoERN clinical practice guidelines and decision-making tools for identified subject areas. Focus on knowledge gaps and guideline needs.

- ☐ Key considerations include:
 - Covering the transition from pediatric to adult endocrinology
 - Ensuring alignment with EndoERN's core objectives
 - Patient perspectives and needs will be central to the guideline development process,
 - Patients have an active involvement.

- ☐ The impact of the guidelines will be assessed, and methodological support provided.

- ☐ Review and update endorsed / appraised guidelines (MTG's will be asked to provide info)

**Clinical Practice
Guideline**

A Nordenström and others

Pubertal induction: a clinical
guideline

186:6

G9–G49

Pubertal induction and transition to adult sex hormone replacement in patients with congenital pituitary or gonadal reproductive hormone deficiency: an Endo-ERN clinical practice guideline

A Nordenström¹, S F Ahmed², E van den Akker³, J Blair⁴, M Bonomi^{5,6}, C Brachet⁷, L H A Broersen⁸, H L Claahsen-van der Grinten⁹, A B Dessens^{10,11}, A Gawlik¹², C H Gravholt^{13,14}, A Juul^{15,16}, C Krausz¹⁷, T Raivio¹⁸, A Smyth¹⁹, P Touraine^{20,21}, D Vitali²² and O M Dekkers^{23,24}

Pubertal induction and transition to adult sex hormone replacement in patients with congenital pituitary or gonadal reproductive hormone deficiency: an Endo-ERN clinical practice guideline

A Nordenström¹, S F Ahmed², E van den Akker³, J Blair⁴, M Bonomi^{5,6}, C Brachet⁷, L H A Broersen⁸, H L Claahsen-van der Grinten⁹, A B Dessens^{10,11}, A Gawlik¹², C H Gravholt^{13,14}, A Juul^{15,16}, C Krausz¹⁷, T Raivio¹⁸, A Smyth¹⁹, P Touraine^{20,21}, D Vitali²² and O M Dekkers^{23,24}



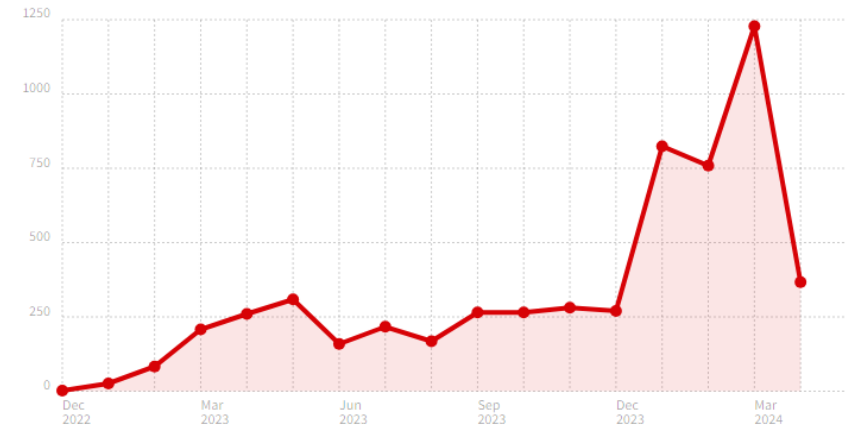
European
Reference
Network



Endo-ERN

Total Views	3,901 Pageviews
5,691	1,790 PDF Downloads

Since 12/1/2022



Citations



27 Total citations
27 Recent citations
26 Field Citation Ratio
6.21 Relative Citation Ratio

Powered by Dimensions

Altmetrics



Posted by 10 X users
49 readers on Mendeley

16 Web of Science

European Journal of Endocrinology, 2024, **190**, G1–G14





<https://doi.org/10.1093/ejendo/lvae041>

Advance access publication 4 April 2024

Clinical Practice Guideline



Familial hyperaldosteronism: an European Reference Network on Rare Endocrine Conditions clinical practice guideline

Paolo Mulatero,^{1,*}  Ute I. Scholl,² Carlos E. Fardella,³ Evangelia Charmandari,^{4,5}
Andrzej Januszewicz,⁶ Martin Reincke,⁷  Celso E. Gomez-Sanchez,^{8,9} Michael Stowasser,¹⁰ 
and Olaf M. Dekkers¹¹ 



Familial hyperaldosteronism: an European Reference Network on Rare Endocrine Conditions clinical practice guideline

Paolo Mulatero,^{1,*} Ute I. Scholl,² Carlos E. Fardella,³ Evangelia Charmandari,^{4,5}
Andrzej Januszewicz,⁶ Martin Reincke,⁷ Celso E. Gomez-Sanchez,^{8,9} Michael Stowasser,¹⁰
and Olaf M. Dekkers¹¹



European
Reference
Network



Endo-ERN

Total Views	5 Pageviews
250	245 PDF Downloads

Since 4/1/2024



Standard Operating Procedure (SOP)



- ❑ Standard Operating Procedure (SOP) to guide:
 - **The process of topic selection**, topics proposed by MTG's and voting procedure
 - **Selection of guideline expert committee**, 9-12 members with specific criteria
minimum: chair, 5 experts, ePAG, methodology experts, incl representation prof society
 - **Guideline Process**, incl literature review and methodology
 - Finalize withing 12-18 months
 - **Dissemination** in collaboration with Work Package 2 and 6.

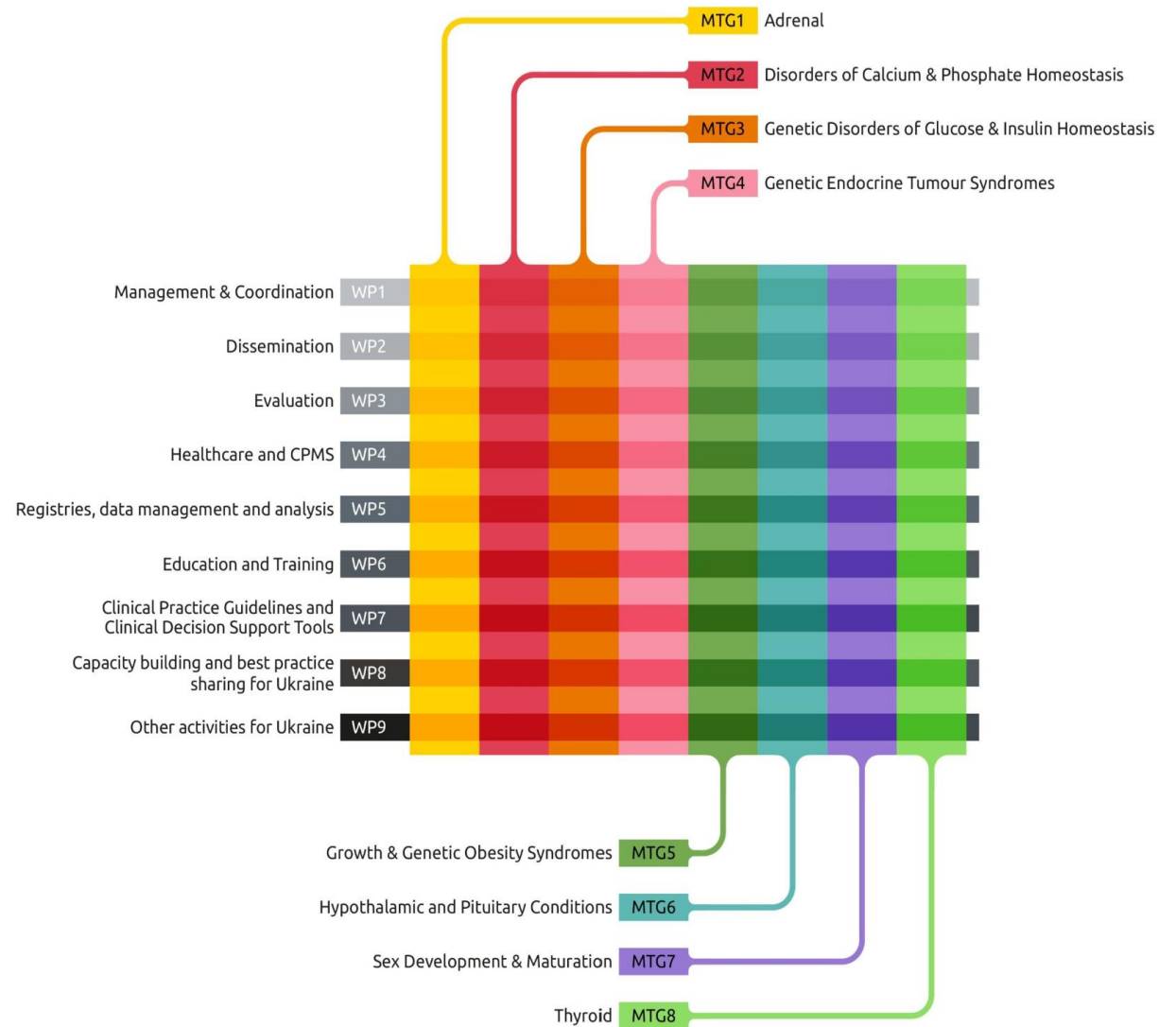
- ❑ Patient involvement in different subject areas is tailored to specific needs and existing European-level structures.

Collaboration

Work Packages 2 and 6

Vital for:

- Education & Training
- Guideline dissemination
- ☐ Development of infographics for clear communication of key guideline messages.
- ☐ Standardized presentation of guidelines will be pursued to enhance recognition
- ☐ Publication in EJE



Guideline publications and plan



AIM:

Publish at least one guideline per year in years 2-4

2nd Guideline on Familial Hyperaldosteronism, Published April 2024, presented ECE May 2024

3rd Guideline on Transition in collaboration with MTG 6, initiated

☐ Patient involvement is a priority in the guideline development process.

Efforts will be made to:

- Create lay versions, to facilitate patient access and understanding.
- Translate guidelines into multiple languages and

☐ Dissemination strategies will include:

- CME credits, downloadable slide decks etc

Assessing guideline impact



- ☐ Efforts will be made to assess the impact of the guidelines on clinical practice.
 - ☐ Beyond downloads / citations
- ☐ Feedback from clinicians on the usefulness of the guidelines, focusing on specific aspects of impact.
- ☐ Collaboration with WP5, using the registry along with MTG's, for this assessment.
 - ☐ Measures of impact
 - ☐ Pre-thinking of variables to include

Challenges to discuss



- ☐ Patient representatives
 - ☐ Disease specific knowledge needed
 - ☐ National vs European patient organisations
 - ☐ ('Disappointed that this is not payed for')
- ☐ Guidelines for rare diseases
 - ☐ (next slide)
- ☐ Measuring impact
 - ☐ Upfront thinking
 - ☐ Measure of changing practice / impact
 - ☐ Questionnaires
 - ☐ Assessing changing practice in databases (WP6)
- ☐ New topics

Guidelines for rare diseases



- ☐ Evidence base
 - ☐ Data are limited
 - ☐ FH: disease rare, but many patients covered in the literature
- ☐ Expert opinion vs guidelines
 - ☐ Always relevant to search for evidence
 - ☐ Both guidelines and consensus statements require consensus (Djulbegovic JAMA 2019)
- ☐ Topic related
 - ☐ Transition in puberty: what type of evidence to search for?



European
Reference
Network



Endo-ERN