

Clinical Practice Guidelines & CDST *Projects & endorsement strategy (WP-7)*

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Work package members

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

Topics



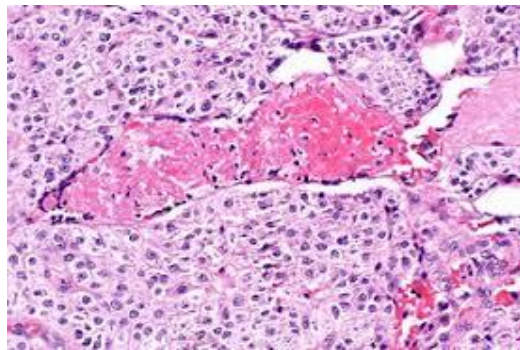
- New guideline project has started
- Second guideline topic is to be established
- Cross-ERN collaboration on guideline methodology
- Endorsement on position statement Cushing
- Endorsement strategy: first results of survey
- Discussion

New guideline project: Congenital hypopituitarism



- Strong link with Transition of care
- Choice of clinical topics is to be decided during the summer
- Diagnostics will be main focus
- SRs to be done in November-December

Second guideline topic



- Survey will be sent around for choice of second and third topic by WP-7, after the GA



Cross-ERN collaboration on CPG methodology

- 10 ERNs and Eurordis are represented
- Mix of methodologists and Project Managers
- Endorsement strategy: minimal criteria for methodological quality? Delphi study
- CPGs versus consensus documents
- Connection with the GRADE project group on rare diseases



Endorsement: position statement

European Journal of Endocrinology, 2025, 192, R17–R27
<https://doi.org/10.1093/ejendo/lvaf017>
Advance access publication 20 February 2025
Invited Review



Delphi panel consensus on recommendations for thromboprophylaxis of venous thromboembolism in endogenous Cushing's syndrome: a position statement

Kristina Isand,^{1,2,3,*} Hiroshi Arima,⁴ Jerome Bertherat,⁵ Olaf M. Dekkers,^{6,7} Richard A. Feelders,^{8,9} Maria Fleseriu,^{10,11} Monica R. Gadelha,¹² Jose Miguel Hinojosa-Amaya,¹³ Niki Karavitaki,^{14,15,16} Frederikus A. Klok,¹⁷ Ann McCormack,¹⁸ John Newell-Price,¹⁹ Sue Pavord,²⁰ Martin Reincke,²¹ Saurabh Sinha,²² Elena Valassi,^{23,24,25} John Wass,² and Alberto M. Pereira Arias²⁶

- Publication was made with a group of international experts
- Experts represent multiple disciplines
- Recommendations focus on both pediatric and adult endocrinology;
- Patient representatives were involved

- Evaluation by WP-7
- Evaluation by MTG6 chairs

- *Endorsement: what is that?*

Endorsement strategy: Survey



- Already many responses – thank you!
- Link is still open
- Meaning of endorsement
- Criteria for endorsement of documents (CPGs, position statements)
- Criteria for endorsement of meetings
- Preliminary results...

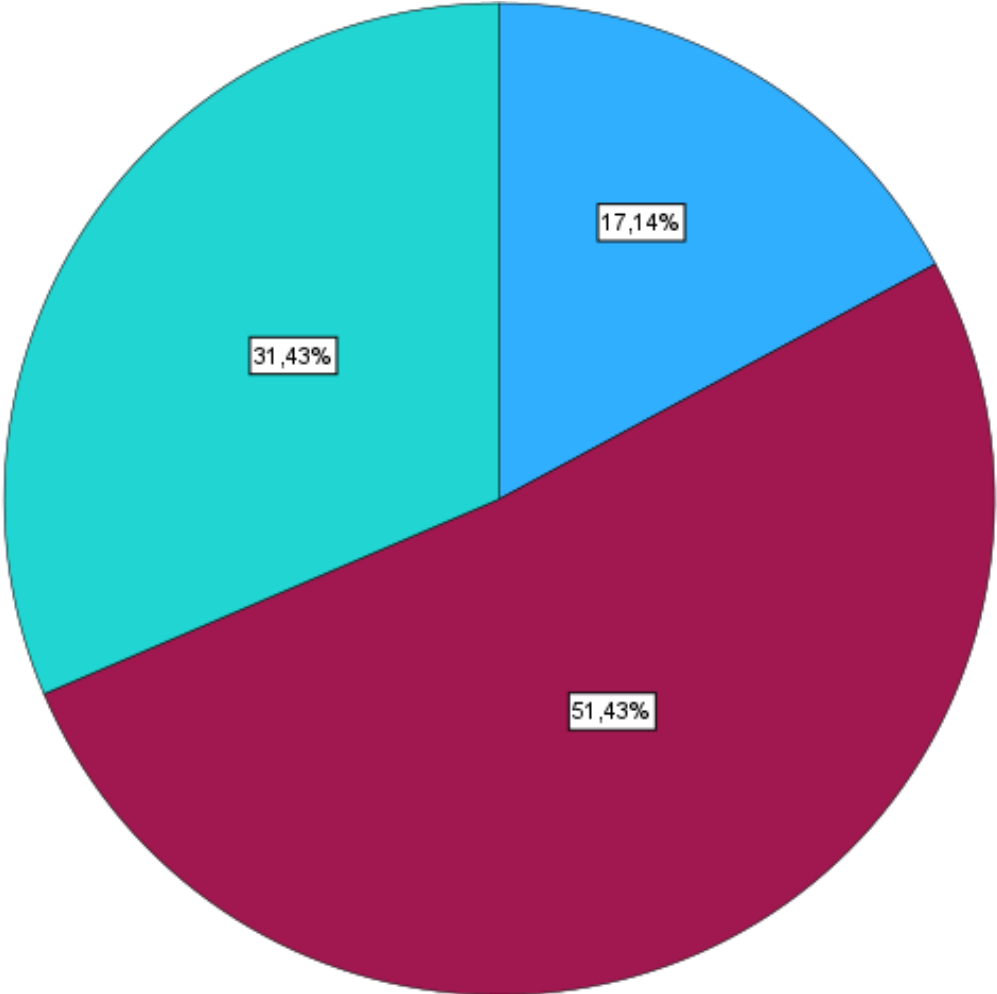
Preliminary results

May 2nd:

36 responses



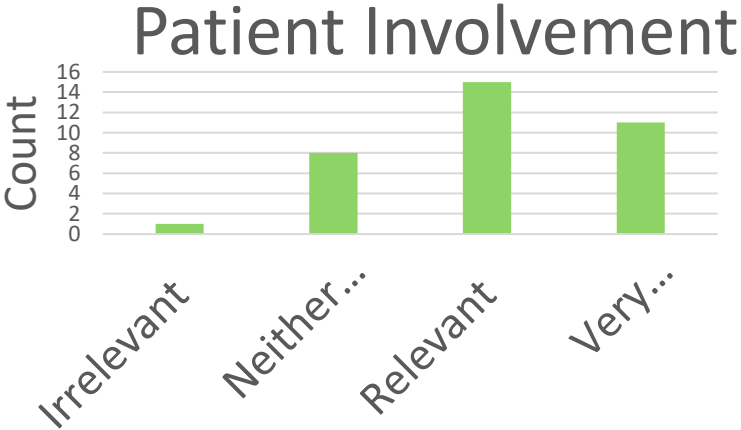
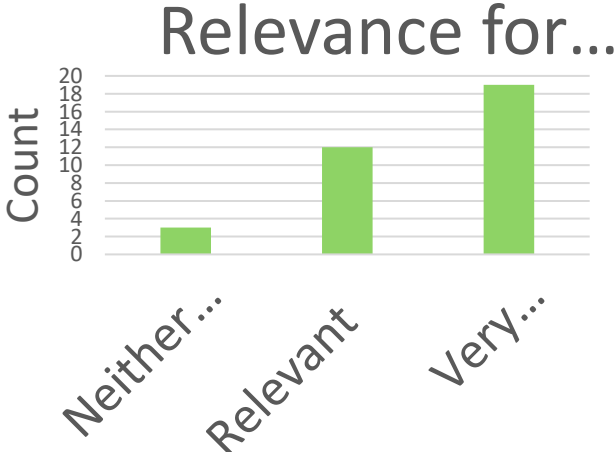
What do you think endorsement means/should mean?



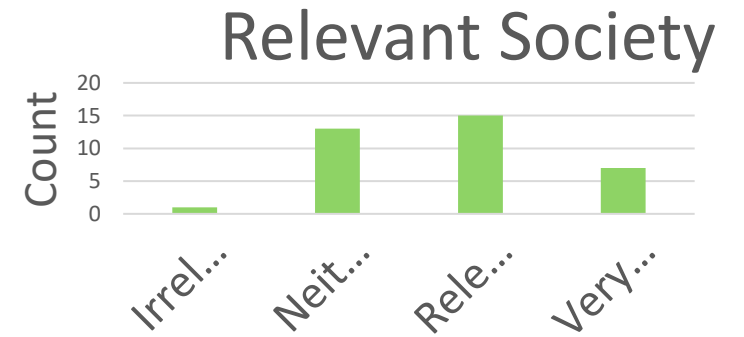
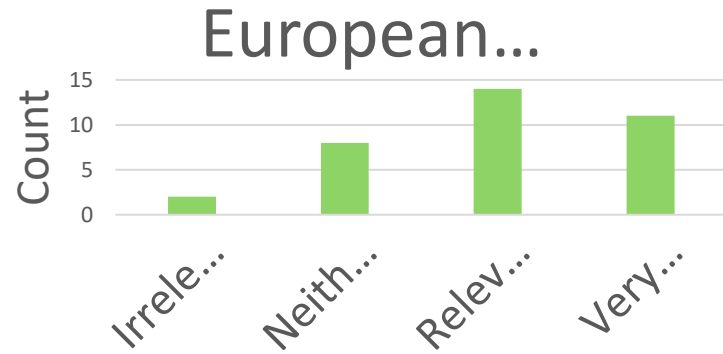
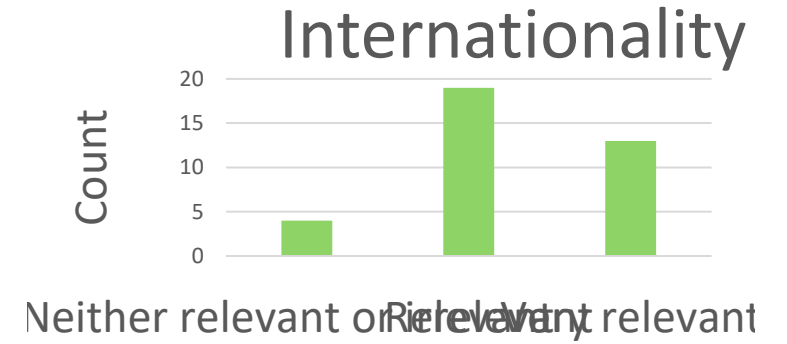
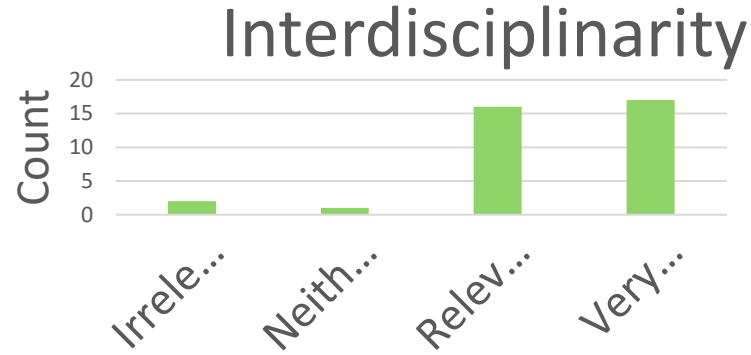
Meaning of Endorsement

- The Endo-ERN members should be aware of the document
- The document's recommendations should be known by Endo-ERN members
- The document's recommendations should be followed by Endo-ERN members

Criteria for endorsement of documents



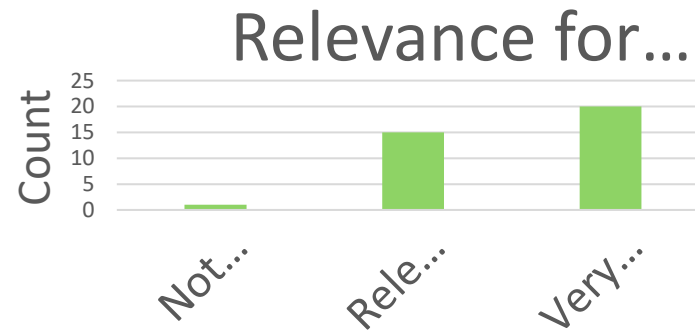
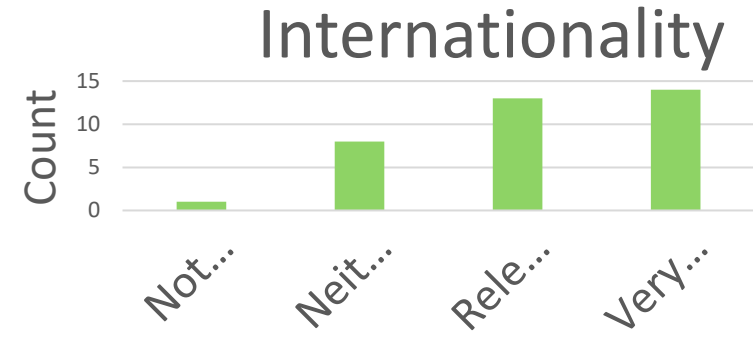
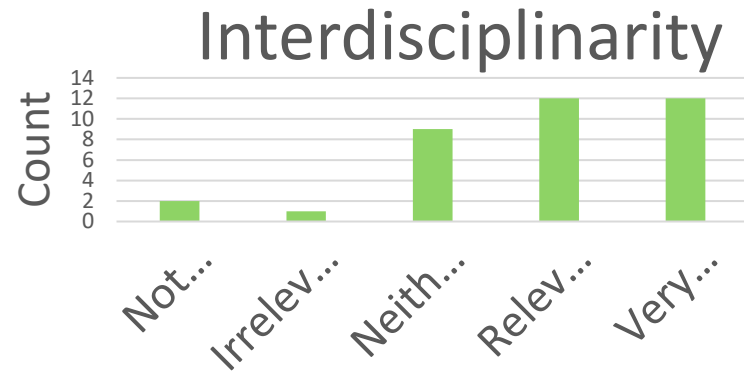
Criteria for endorsement of documents



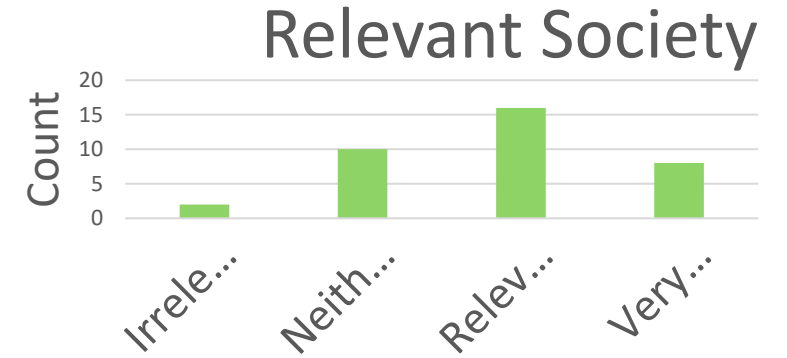
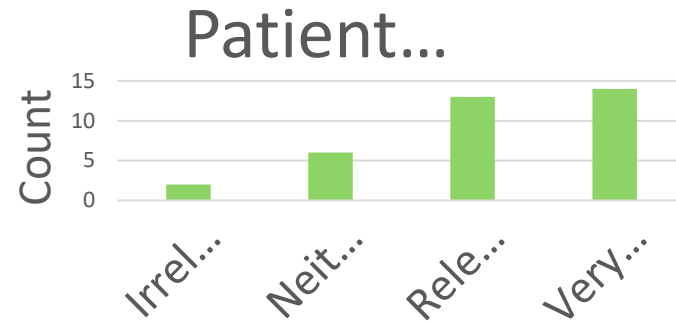
Other items mentioned

- Expert's involvement
- Document availability
- Quality of background data and systematic reviews

Criteria for endorsement of meetings



Criteria for endorsement of meetings



Additional remarks of responders

- Committee should be installed to decide on endorsement
- A structured process should be in place
- It should be clarified what the additional value is of Endo-ERN endorsement



Preliminary conclusions

- Clinical content is considered most relevant for documents
- Methodological quality is also an important criterion
- Relevance for Endo-ERN is considered relevant for both documents and meetings
- Patient involvement is more important for documents than for meetings
- More responses are expected (please fill in if you have not yet done so)!
- Endorsement procedure will be formalized based on the results

**Any comments,
or remarks?**



To conclude...



I will be back by November!