



EpiCARE: a European Reference Network for rare and complex epilepsies

“WP Guidelines”

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Status update on WP II tasks

SUMMARY of TASKS

- To define guideline panel and working groups
- To identify international/national clinical practice guidelines
- To assess the quality of collected guidelines by using AGREE II instrument
- To identify areas where development of guidelines are needed
- To address existing gaps by undertaking systematic reviews

Guideline panel and working groups

Name (alphabetical order)	Institution	Guideline panel	Survey WG	Systematic review WG
Isabella Brambilla	Dravet Italia ONLUS			
Francesco Brigo	Department of Neuroscience, Biomedicine, and Movement Science, University of Verona, Verona, Italy			
Anezka Belohlavkova	Motol University Hospital, Czech Republic			
Pilar Bosque	Christian-Doppler-Klinik, Paracelsus Medical University of Salzburg			
Laura Canafoglia	Fondazione Istituto Neurologico Carlo Besta Milano Italy			
Dana Craiu	"Carola Davila" University of Medicine Bucharest and Pediatric Neurology Clinic, Bucharest, Romania			
Birgitta Esser	Department of Epileptology, University Hospital Bonn			
Petr Fabera	Motol University Hospital, Czech Republic			
Silvana Franceschetti	Fondazione Istituto Neurologico Carlo Besta Milano Italy			
Ana Franco	Hospital de Santa Maria, Departamento de Neurociências			
Tove Hallböök	Sahlgrenska University Hospital, Gothenburg, Sweden			
Teia Kobulashvili	Christian-Doppler-Klinik, Paracelsus Medical University of Salzburg			
Magdalena Kaczorowska-Frontczak	The Children's Memorial Health Institute, Warsaw, Poland			
Katarzyna Kotulska-Jóźwiak	The Children's Memorial Health Institute, Warsaw, Poland			

Guideline panel and working groups

Name (alphabetical order)	Institution	Guideline panel	Survey WG	Systematic review WG
Simona Lattanzi	Department of Experimental and Clinical Medicine, Marche Polytechnic University, Ancona, Italy.			
Tony Marson	Institute of Translational Medicine, University of Liverpool, Liverpool, UK.			
Sara Matricardi	Child Neurology and Psychiatry Unit, Children's Hospital G. Salesi, Ancona, Italy			
Kristina Malmgren	Sahlgrenska University Hospital, Gothenburg, Sweden			
Barbara Mostacci	IRCCS Institute of Neurological Sciences of Bologna, Bologna, Italy.			
Daniel Nass	Department of Epileptology, University Hospital Bonn			
Luca De Palma	Ospedale pediatrico Bambino Gesù, Roma, Italy			
Claudia Rinaldi	Department of Experimental and Clinical Medicine, Marche Polytechnic University, Ancona, Italy.			
Johann Sebastian Ortiz De la Rosa	Universidade Estadual de Campinas			
Nicola Specchio	Ospedale pediatrico Bambino Gesù, Roma, Italy			
Paolo Tinuper	IRCCS Institute of Neurological Sciences of Bologna, Bologna, Italy.			
Eugen Trinkla (WP leader)	Christian-Doppler-Klinik, Paracelsus Medical University of Salzburg			
Federico Vigeveno (WP leader)	Ospedale pediatrico Bambino Gesù, Roma, Italy			
Georg Zimmermann	Christian-Doppler-Klinik, Paracelsus Medical University of Salzburg			

Survey evaluating the state of the art of existing guidelines - Results

Survey response rate is 84% (27/32 centers across 17 European countries).

Collected documents (n=80)

- Guidelines (n= 38)/Recommendations (n= 12) - 63% (50/80)
- Protocols - 25% (20/80)
- Consensus papers - 3 % (3/80)
- Position papers - 1% (1/80)
- Clinical policies - 1% (1/80)
- Reviews - 3% (3/80)
- Glossary of terms - 1% (1/80)
- Practical clinical definition of epilepsy - 1% (1/80)

Documents available in English (n= 37)

Documents available in different languages (n= 43)

Survey evaluating the state of the art of existing guidelines – results

Screening of collected guidelines

Language	Collected documents (n=80)	Number of guidelines screened	Number of eligible guidelines	Number of excluded guidelines	Comment
English	37	37	15	22	Completed
German	4	4	0	4	Ongoing ¹
Italian	5	5	2	3	Completed
Spanish	2	2	0	0	Ongoing
French	2	2	1	1	Ongoing
Swedish	1	1	1	0	Ongoing
Finnish	4	0	0	0	WG members to be identified
Dutch	5	0	0	0	WG members to be identified
Polish	2	2	0	2	Ongoing
Czech	1	1	0	1	Completed
Portuguese	17	0	0	0	Ongoing

1. Ongoing: evaluated only by one reviewer, disagreements were identified that is under discussion, etc.

Survey administration period

- From September to December, 2018.

Response rate

- **66 % (21/32)** of centers across 13 European countries.

Topic	Authors	Status
Treatment of infantile spasms	Ellie Hancock Stuart Osborne	Updated, under review by the Cochrane Editorial Board.
Lennox Gastaut syndrome	Ellie Hancock Helen Cross	The last update was published in 2013.
Severe myoclonic epilepsy in infants (Dravet syndrome)	Francesco Brigo	The last review update was published in May 2017.

Topics:

- Treatment of Dravet syndrome
- Treatment of Lennox-Gastaut syndrome
- Treatment of infantile spasms

Tasks:

- **To register the title of a systematic review**
 - SR on Dravet syndrome: by end of February 2019.
 - SR on Lennox-Gastaut syndrome
 - SR on Infantile spasms
- **To prepare SR protocols in the review manager**
 - SR on Dravet syndrome: currently being prepared by members of the WG by using Review manager 5
 - SR on Lennox-Gastaut syndrome
 - SR on Infantile spasms
- **To conduct literature searches**
- **To submit protocols to ILAE for three selected guidelines to be developed**
 - Ongoing

Survey - next steps:

- To complete AGREE II quality assessment of all eligible guidelines
- To present results at the 33rd IEC congress in Bangkok in June 2019 and at the 5th congress of the European Academy of Neurology in Oslo in July 2019.
- To publish results of the surveys

Systematic reviews – next steps:

- To register the title systematic reviews
- To submit the protocols to Cochrane Review Group
- To conduct the systematic reviews
- To conduct the systematic review evaluating current evidence of existing guidelines for rare and complex epilepsies

Guidelines – next steps:

- To submit the guideline protocols to ILAE
- Together with the Epi-Care Network coordination endorsements from scientific societies (i.e. ILAE, EPNS, EAN), Public institutions, Health authorities, etc. will be asked
- Actions in the second stage: dissemination, implementation, and auditing; updating and retiring .

Thank you