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# EpiCARE – a network for rare and complex epilepsies

*HP-ERN-2016 European Reference Networks / Framework Partnership Agreement*

## D13.1 Timeline for systematic reviews yr2-5

Work Package: WPII: E-Guidelines

Due date of deliverable: 28 February 2018

Actual submission date: 27 February 2018

Start date of project: 1<sup>st</sup> March 2017                      Duration: 12 months

Lead beneficiary for this deliverable: *28 EpiCARE centres*  
 Contributors: Prof, Trinkka Eugen, Dr Nicola Specchio, Dr. Federico Vigevano, Dr Teia Kobulashvili

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<b>Dissemination Level</b>		
<b>PU</b>	Public	x

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## 1. Version log

Version	Date	Released by	Nature of Change
First version	27/02/2018	Prof, Trink Eugen, Dr Nicola Specchio, Dr. Federico Vigevano, Dr Teia Kobulashvili	First draft
Version 2	08/03/2018	Prof, Trink Eugen, Dr Nicola Specchio, Dr. Federico Vigevano, Dr Teia Kobulashvili	Detailed update on year 2 to 5 plan – see table.

## 2. Definition and acronyms

Acronyms	Definitions
GRADE	Grading of Recommendations Assessment, Development and Evaluation
Delphi	Collaborative estimating technique that combines independent analysis with maximum use of feedback, for building consensus among experts who interact anonymously.
AGREE	Appraisal of guidelines for research and evaluation
ILAE	International League Against Epilepsy
EPNS	European Pediatric Neurology Society
EAN	European Academy of Neurology
ILAE-CEA	International League Against Epilepsy – Commission of European Affairs

### 3. Introduction

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The transversal WP II on E-Guidelines of ERN EpiCARE has the mission of collecting and evaluating the existing guidelines currently being used across ERN centres and to develop specific new guidelines to be disseminated in EU countries in order to improve the level of care in patients with rare and complex epilepsies.

In order to accomplish this goal, the dedicated Work Package has been identified within the EpiCARE project.

As a first step we assessed the availability of guidelines and recommendations across different countries of the ERN network. For this purpose, we performed the standardized survey and collected guidelines and recommendations from participating centres.

Official endorsements will be sought from scientific societies including ILAE, EPNS, EAN.

We created guideline development group (GDG) currently comprising members whose areas of expertise include rare and complex epilepsies, guideline development, critical appraisal (e.g. experience in GRADE, AGREE, etc.), research synthesis and statistical analysis. We aim to further expand the GDG to ensure that all relevant parties (e.g., stakeholders, patients representatives, etc.) gain representation.

Main objectives of the first year:

1. Identification of all relevant (national and international) guidelines in the field of rare and complex epilepsies. Ask Epi-CARE members if there are guidelines available in local languages.
2. Evaluation of the appropriateness (GRADE, Delphi etc). Appraisal of the guidelines will be performed by using AGREE method
3. Selection of topics for different age groups
4. To be included neurological diseases with epilepsy
5. List of already published papers
6. List of topics: to be discussed in a second stage (after the survey has been completed)
7. Involvement of patients' advocacy groups
8. Establish a survey to be sent to all centres.

### 4. Activities carried out and results

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***(1) Constitution of a core group for guidance and development of WP II activities:***

A Task force has been identified including epileptologists and also experts from patient's advocacy groups.

Duties of the Task force will be:

- Analyse collected documents
- Appraisal of collected documents according to AGREE method
- Evaluate if collected documents are validated by a scientific society, health authorities, patients' advocacy groups
- Identify the unmet needs in order to define the future development.
- Identify topics to be included (for different age groups)

Members of the Task Force

- Federico Vigeveno Co-Coordinator (IT, Rome)
- Eugen Trinka Co-Coordinator (AU, Salzburg)
- Nicola Specchio (IT, Rome)
- Francesco Brigo (IT, Liaison with ILAE Commission on Guidelines)
- Teia Kobulashvili (AU, Salzburg)
- Georg Zimmermann (AU, expert in statistics)
- Isabella Brambilla (IT, patients advocacy group - Dravet Foundation)

Other members to be defined, possible candidates

- Philippe Ryvlin (FR) and Kees Braun (NL) (liaison with E-pilepsy)
- Nathalie Jette (CND) (ILAE Commission on Guidelines)
- Member from IBE
- Members from the EAN
- Members from the EPNS

***(2) Development of a survey to be distributed to all ERN centres in order to begin WP II activities:***

With the purpose of defining a clear-cut picture of the state of the art of the existing guidelines in the EpiCare consortium, we started collection of already available documents across different countries of the EpiCare network.

We did not only search for rare and complex epilepsy in this first stage, but also considered guidelines and recommendations, and procedures that have been drawn for specific diseases (es. Tuberous Sclerosis, Glut-1 deficiency, Progressive myoclonic epilepsies). We are evaluating also guidelines on both medical and surgical treatment of epilepsies.

The following survey has been designed by the Task Force and sent to all ERN centres:

*Institution name*

.....

*Contact person details*

.....

*Does your centre/hospital serve the paediatric population, adult population or both?*

- Only children*
- Only adults*
- Both, children and adults*

1. Do you follow international guidelines for the diagnosis or treatment of rare and complex epilepsies?

NO  YES

If yes, can you list the guidelines you use? (alternatively, you may send us a copy of them)

2. Do you have national/local guidelines for the diagnosis or treatment of rare and complex epilepsies?

NO  YES

If yes, please send a copy of the national/local guidelines (in English if available, otherwise in your own language)

**(3) Evaluation of the results of the survey:**

*Purpose*

A review of the state of the art of the existing guidelines in the EpiCare consortium regarding: Procedures, Recommendations, Guidelines (if available), Any type of approach to diagnosis and management of epilepsies

*Survey instrument*

Standardized questionnaire circulated to consortium members via email

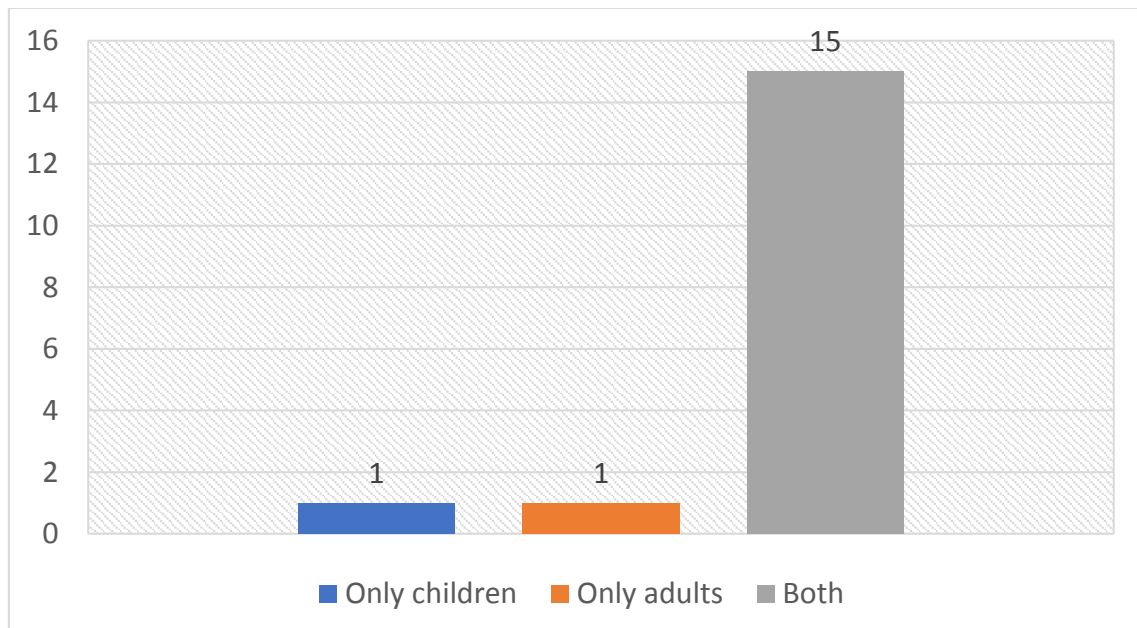
*Survey administration period*

From January to February, 2018

*Response rate*

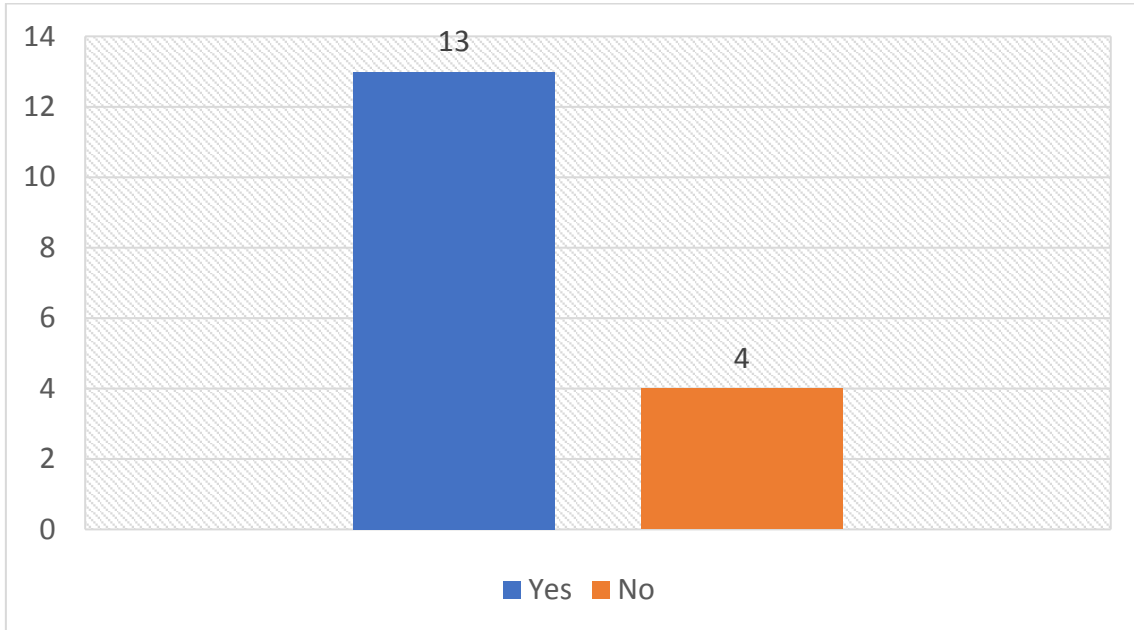
60.1% (17/28) of centres across 10 European countries

Q.1 Does your centre serve the paediatric population, adult population or both?

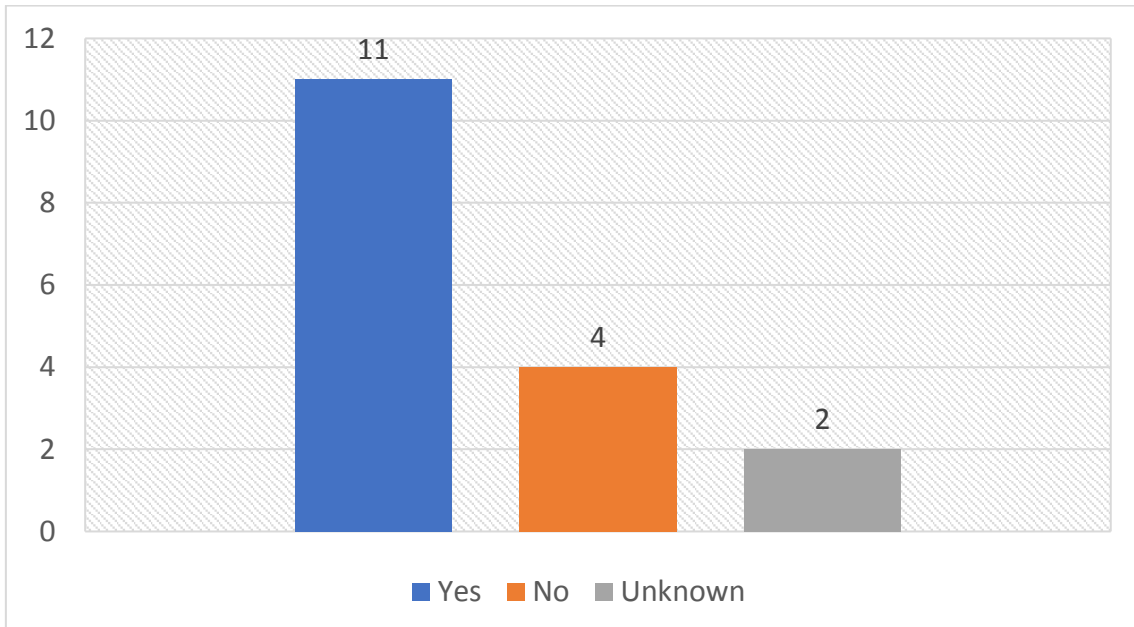




Q.2 Do you follow international guidelines for the diagnosis or treatment of rare and complex epilepsies?



Q.3 Do you have national/local guidelines for the diagnosis or treatment of rare and complex epilepsies?



Collected documents (n=63)

Guidelines/Recommendations (including consensus papers) – 70% (44/63)

Protocols 29% (18/63)

Glossary of terms 2% (n=1/63)

International papers

44% (28/63)

National papers

56% (35/63)

Available in languages: English, German, Italian, Dutch, Portuguese, Spanish, Czech.

In addition to the deliverables of the first year, we provide list of activities to be accomplished within the next 4 years (yr2nd-5th) as outlined in the table below.

During the activities we hypothesis that new deliverables might come up, following the yearly results.

Therefore, we will be providing the progress report and update on the status of systematic reviews annually.

	Year 2	Year 3	Year 4	Year 5
<i>Task force (TF)</i>	Complete the enrollment of experts in the Task Force. Starts collaboration with other WPs.	Teleconferences and meeting with TF members.	Teleconferences and meeting with TF members.	Teleconferences and meeting with TF members.
<i>Collection of guidelines</i>	Review and evaluation of guidelines: scoring following already reported methods (GRADE, DELPHI). - Generate research question(s) for each identified topic - Perform literature searches in order to identify the existing and ongoing guidelines/systematic reviews(SR) relevant to our research questions - If no guidelines/SRs are available or if they do not fully address our research questions, new reviews have to be conducted/new guidelines have to be produced - If there are ongoing SRs/guidelines authors will be contacted to find out when these	Proposal for updates of current guidelines or development of new guidelines on specific topics following unmet needs.	Working on specific topics to update existing guidelines and develop new guidelines. Endorsement from Scientific Societies (ILAE, ILAE-CEA, EPNS, EAN) and patients advocacy groups.	Dissemination of results.

	reviews/guidelines are going to be finalized. - If there are SRs/guidelines which are outdated GDG will explore the possibility to update them - If there are recent reviews/guidelines available GDG will assess whether they meet current (adopted by EpiCare network) methodological standards and decide if we can proceed with using the existing reviews/guidelines.			
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## 5 Conclusions

The survey performed by the EpiCare WP II on E-Guidelines showed that the majority of EpiCare centres do follow guidelines for the diagnosis and treatment of epilepsies. Based on this data our next objective is to look at the contents and decide how to proceed in order to identify the topics which might be included in the future job. We are approaching the analysis of collected documents (Quality appraisal by using Appraisal of Guidelines for Research & Evaluation II - AGREE method), evaluating if collected documents are validated by a scientific society, health authorities, patients' advocacy groups, etc.

After the evaluation of the current available documents and unmet needs the Task Force will propose if:

- Update current documents
- Create ex-novo documents

All the activities will be shared and discussed with respective WP leaders (WP2 to WP10).

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. (WP 11: Dissemination).

## 6 Bibliography / References

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