

## **Report of the Epidemiology Commission from October 2017 to September 2018.**

**Members of the Committee:** Charles Newton; David Thurman; Jakob Christianson; Mu Jie; Ryan Wagner.

The Commission has met on 6 occasions in the last 12 months:

13<sup>th</sup> October 2017 Skype call

3<sup>rd</sup> December 2017 Meeting at American Society of Epilepsy in Washington DC, USA

6<sup>th</sup> February 2018 Skype call

17<sup>th</sup> April 2018 Skype call

15<sup>th</sup> August 2018 Skype call

26<sup>th</sup> August 2018 Skype call at European Epilepsy meeting in Vienna, Austria.

The work of the Commission is divided into the following task forces:

### **1. Psychiatric Co-morbidity**

*Chairs: Dale Hesdorffer and Ruth Otterman*

This is a follow up from the previous commission. The data has been extracted for the systematic review and the paper is currently been drafted by Dale Hesdorffer and Ruth Otterman.

### **2. Injuries Task Force**

*Chair: Jie Mu*

The aims of this task force are to conduct a systematic review of injuries in people with epilepsy. The initial searches have been conducted. A number of issues are being discussed:

- a. Distinguish between injury 'due' to epilepsy and injury 'related' to epilepsy (e.g. if a patient has a skin rash due to taking AEDs, is this an injury?)
- b. Limiting the co-morbidities to be included (eg injury is not directly related to epilepsy, suicide and SUDEP)
- c. Differentiation between external/internal injuries

### **3. Registries**

*Chair Jakob Christensen*

The aim is to develop a database of registries of epilepsy throughout the world. This would be a database for researchers

- a. Database of Registries based upon work done by Nathalie Jette has been created
- b. Use data from the European Study of the Burden and Care of Epilepsy (ESBACE) (<https://www.epilepsyallianceeurope.org/programmes/esbace/>) work,
- c. Work on definitions of epilepsy to be used in registries:
  - a. Number of contacts with hospital (inpatient and/or outpatient), either 1 or 2 or more admission.
  - b. Prescriptions of anti-seizure medication
- d. The Danish national hospital record was explored; the diagnosis of epilepsy (clinically) was used as the definition of epilepsy. Using 2 diagnoses increased the validity of the ICD 10 G40 diagnosis for epilepsy. Combination with information on reimbursement for anti-seizure drugs increased the validity further. Estimates were based on various definitions which will have implication for estimates of burden of epilepsy

#### **4. Global Cost of Epilepsy**

*Chairs Chuck Begley and Ryan Wagner*

The aim of this task force is three-fold:

- I. to undertake a systematic review of the current literature on the global cost of epilepsy
  - a. A lot of work has been conducted as part of the Chapter for the ILAE/WHO/IBE Global report for Epilepsy
  - b. This work is underway and databases and terms have been selected.
- II. to develop methods for estimating the cost of epilepsy for all countries
- III. to generate global and regional estimates of the cost of epilepsy

Objectives 2 and 3 will be developed from the completion of the first objective, which is anticipated to be completed by the end of 2019

#### **5. Treatment Gap**

*Chairs Natalie Jette and Arturo Carpio*

The initial aims of this Task Force are to conduct

- a. a systematic review of the Treatment Gap.
- b. Delphi process for an agreement of the definition of the Treatment Gap

Discussions involving Nathalie Jette and Charles Newton have suggested that the terminology of the Treatment Gap needs to re-defined. In particular, expand the definition to include coverage.

The Search strategy for articles addressing the treatment gap has been defined and implemented. Titles and abstracts derived from the search have been reviewed for relevance, and current definitions used in the selected articles have been extracted.

#### **6. Global Burden of Disease**

*Chairs Charles Newton and Natalie Jette*

The aim of this commission is to

- a. update the prevalence and incidence studies
- b. determine the global burden measured as Disability Adjusted Life Years (DALYs)

A paper has been submitted on the global burden using the DALYs. The plan is to update the prevalence and incidence studies.

#### **Databases**

The commission has adopted the use of REDCap (<https://www.project-redcap.org/>) for the review of studies within the commission. All the systematic reviews will be conducted with the same format of assessing the quality of the studies, and extracting the data into REDCap proformas.

#### **Budget**

The 2017 budget was used to support Ryan Wagner and Charles Newton attendance to the meeting in Washington.

The 2018 budget will be used to support David Thurman and Ryan Wagner's travel to the meeting in Vienna.

David Thurman (Treasurer) will prepare a budget for the Thailand meeting

- This will need include air travel for all members of the commission
- The Cost Task Force asked to have separate, one-day meeting in Thailand