

2018 Annual Report - Epidemiology Commission

Chair

Charles Newton (Kenya)

Members

Jakob Christianson (Denmark)

Jie Mu (China)

David Thurman (USA)

Ryan Wagner (South Africa)

MC Liaison

Sam Wiebe (Canada)

September 2018 to February 2019

The Commission has had two Skype meetings in the last six months.

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

Psychiatric Co-morbidity Task Force

Chairs: Dale Hesdorffer (USA) and Ruth Otterman (USA)

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

Injuries Task Force

Chair: Jie Mu (China)

The aims of this task force are to conduct a systematic review of injuries in people with epilepsy. The initial searches have been conducted. Several 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 (e.g., injury is not directly related to epilepsy, suicide, and SUDEP).
- c. Differentiation between external/internal injuries.

This task force has been delayed whilst the chair is on maternity leave.

Epilepsy Registries Task Force

Chair: Jakob Christensen (Denmark)

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

- a. Database of Registries based upon work done by Nathalie Jetté has been created.
- b. Use data from the European Study of the Burden and Care of Epilepsy (ESBACE) (<https://www.epilepsyallianceeurope.org/programmes/esbace/>).
- c. Work on definitions of epilepsy to be used in registries:

- I. Number of contacts with hospital (inpatient and/or outpatient), either one or two, or more admission.
- II. 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 two 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

Global Cost of Epilepsy Task Force

Chairs: Chuck Begley (USA) and Ryan Wagner (South Africa)

The aim of this task force is three-fold:

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

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

This task force has had three Skype meetings in the last six months and has applied for a budget to hold a meeting in Thailand.

Treatment Gap Task Force

Chairs: Natalie Jetté 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 Jetté 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.

Global Burden of Disease Task Force

Chairs: Charles Newton (Kenya) and Natalie Jetté (Canada)

The aim of this task force 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's attendance at the meeting in Washington.

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

A budget for the IEC meeting in Thailand has been accepted.

Charles Newton

Chair, Epidemiology Commission