

Epidemiology Commission

2021 Annual Report

Members

Charles Newton (Kenya), chair
Jakob Christianson (Denmark)
Jie Mu (China)
David Thurman (USA)
Ryan Wagner (South Africa)
Sam Wiebe (Canada), Management Committee liaison

2021 Highlights

- Publication of report from the Epilepsy Treatment Gap Task Force in *Epilepsia* Kwon CS, Wagner RG, Carpio A, Jetté N, Newton CR, Thurman DJ. The worldwide epilepsy treatment gap: A systematic review and recommendations for revised definitions – A report from the ILAE Epidemiology Commission. *Epilepsia*. 2022 January 10.
- Publication of report by the Global Cost of Epilepsy Task Force in *Epilepsia* Begley C, Wagner RG, Abraham A, Beghi E, Newton C, Kwon CS, Labiner D, Winkler AS. The global cost of epilepsy: A systematic review and extrapolation. *Epilepsia*. 2022 February 23.
- Oral Presentation of Global Cost of Epilepsy Task Force results by Chuck Begley, co-chair of Global Cost of Epilepsy Task Force, at the International Epilepsy Congress, 30 August 2021.

The Commission convened for two Zoom calls during 2021 in March and September, with updates given by each of the Task Force chairs.

Psychiatric Co-morbidity Task Force

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

- This Task Force forms part of the previous Commission, with work continuing over this Commission's tenure.
- The two chairs have taken a step back from the work and Churl-su Kwon has picked up the work as part of his DPhil, which he is undertaking with Charles and Nathalie Jetté,
- A manuscript detailing a systematic review was previously drafted and is being currently updated.

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.
- The work of this Task Force has been delayed due to the continuing involvement of the Chair in COVID relief efforts.

Epilepsy Registries Task Force

Chair: Jakob Christianson (Denmark)

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

- The plan now is to use EpiCare, a group currently studying rare disorders, as a template, which can be developed further, with the aim to develop uniform reporting and data collection processes and instruments.
- The Task Force has looked at childhood registries/Nordic country registers in attempt to form registry- seizure frequency/seizure freedom not typically collected due to burden.

Global Cost of Epilepsy Task Force

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

- The aims of this Task Force were three-fold:
 1. To undertake a systematic review of the current literature on the global cost of epilepsy;
 2. To develop methods for estimating the cost of epilepsy for all countries;
 3. To generate global and regional estimates of the cost of epilepsy.
- These objectives have been achieved through regular meetings, with the results published recently in *Epilepsia*
Begley C, Wagner RG, Abraham A, Beghi E, Newton C, Kwon CS, Labiner D, Winkler A. The global cost of epilepsy: A systematic review and extrapolation. *Epilepsia*. 2022 February 23.
- Future projects and ideas that extend the work of this Task Force have been discussed.

Treatment Gap Task Force

Chairs: Natalie Jetté (USA) and Arturo Carpio (Ecuador)

- The initial aims of this Task Force were to conduct:
 1. A systematic review of the treatment gap;
 2. A Delphi process for an agreement of the definition of the treatment gap.
- These objectives were achieved, the results were recently published in *Epilepsia*
Kwon CS, Wagner RG, Carpio A, Jetté N, Newton CR, Thurman DJ. The worldwide epilepsy treatment gap: A systematic review and recommendations for revised definitions—A report from the ILAE Epidemiology Commission. *Epilepsia*. 2022 January 10.

Global Burden of Disease Task Force

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

- The aim of this Task Force was to update the prevalence and incidence studies.
- Given the somewhat recent publication of the *Global Burden of Disease's* report on epilepsy, it was felt that efforts to update the global epilepsy incidence and mortality figures should be postponed, whilst several other projects of the Commission were completed.

Innovations & Methods

The Commission has continued to rely on [RedCAP](#) databases for data extraction undertaken during systematic reviews. Furthermore, [Covidence](#) was used by the Global Cost of Epilepsy Task Force to manage and screen the systematic review process.

Submitted by Ryan Wagner and Charles Newton