COVID-19 GLOBAL NEURO SURVEY First global survey on disruptions of and mitigation strategies for restoring and maintaining services for children and adults with neurological disorders

Frequently Asked Questions

Why do we need this global survey?

According to the World Health Organization's (WHO) <u>Pulse survey on continuity of essential health services during the COVID-19 pandemic</u>, 48% of 105 countries reported at least partial disruptions in all services for noncommunicable diseases and mental health. 64% reported partial disruption of noncommunicable disease diagnosis and treatment, while 5% reported severe disruption.

In October 2020, WHO also <u>released the findings</u> of a rapid assessment of services for mental, neurological and substance use (MNS) disorders during COVID-19. While not specific to neurological disorders, the survey included a few indicators relevant to the field of neurology. For example, 1 in 3 countries closed down neurology inpatient units at least partly during the pandemic, with surgeries for neurological disorders being disrupted in two-thirds of the countries and the management of emergency conditions such as status epilepticus being at least partially disrupted in 35% of countries. While the report lists a range of reasons for disruptions and mitigation mechanisms, these are not specific to services for neurological disorders.

Disruptions to neurological services and worsening of pre-existing neurological conditions during the COVID-19 pandemic have also been reported in the scientific literature. For example, there have been significant reductions in stroke/TIA admissions and emergency department stroke alerts during COVID-19 compared to the same period the previous year. There is also emerging evidence for deterioration of pre-existing neurological conditions such as headache, epilepsy and dementia.

WHO provides guidance on how to maintain essential services during the pandemic, with one chapter dedicated to mental, neurological and substance use disorders. However, the global burden of neurological disorders is huge; neurological disorders are the leading cause of disability-adjusted life years and the second-leading cause of death. Therefore, a detailed global assessment of the extent to which specific services for neurological disorders are being impacted by the ongoing COVID-19 pandemic and what countries are undertaking to mitigate the impact of these disruptions is warranted. The survey can also inform the development of WHO's Global Action plan on epilepsy and other neurological disorders, a resolution recently approved by the World Health Assembly.

Who is this survey for?

The online survey is disseminated by the European Federation of Neurological Associations (EFNA) on behalf of the Neurology & COVID-19 Global Forum Working Group on Essential Services. The survey is sent to approximately 40 international associations working in the area of neurology, from different related specialties (such as neurology, pediatric neurology, neurosurgery, clinical neurophysiology, neuroradiology, neuro-rehabilitation, neuropsychology, including research and neuroscience as well as training) as well as global patient associations for children and adults.

International associations are asked to distribute the survey through their networks to obtain national associations' responses.

National association representatives are asked to **complete the survey for the entire country to the best of their knowledge**, reaching out to other relevant sources of information in their country as necessary and feasible.

At this stage, we are not asking individual clinicians to complete the survey for the services that they provide.

Unless otherwise specified, the reporting period for this survey is November – December 2020. Please consider your country as a whole and select the responses that are most representative for your country. If there is significant regional variability, please leave a comment to that effect.

How was the survey developed?

The survey questions have been developed by the essential services working group (the Working Group) of the Neurology & COVID-19 Global Forum (the Global Forum) based on existing WHO Pulse Surveys, Rapid Assessments of Services for mental, neurological and substance use disorders and NCDs.

Survey questions have been reviewed by the Global Forum and members of the COVID-19 Neuro Research Coalition as well as pilot-tested with a selected group of national association representatives.

A virtual meeting under the auspices of WHO was held with the Heads of the international associations on 8 December 2020 to present the rationale, objectives, components and dissemination strategy of the survey. This virtual meeting aimed to ensure associations' overall buy-in and presented the opportunity to clarify any outstanding questions and provide critical input to the survey questions.

How is the survey disseminated?

For dissemination purposes, the Working Group identified a list of approximately 40 international organizations/associations in the field of neurology. The online survey is sent to these associations by EFNA on behalf of the working group with the request to disseminate the survey to regional and national counterparts for completion.

The online survey will be open until 31 January 2021.

How long does it take to complete the survey? Do I have to complete it in one go?

We expect that the completion of the survey will take approximately 30 - 40 minutes of your time. You can complete the survey in multiple sessions, i.e. leave it open on your computer and come back to it later using the same browser.

We are sharing with you a pdf version of the entire survey so that you can familiarize yourself with the questions and obtain any information that you might not have from other sources.

How will the information be used?

Your responses will help us understand the availability, disruptions and mitigation strategies used for services for children and adults with neurological disorders during COVID-19 pandemics and develop better guidance for countries to maintain services for neurological disorders. Specifically, the survey will

- Support a rapid assessment of services for children and adults with neurological disorders, expanding
 existing information and surveys to specific services needed for children and adults with neurological
 disorders.
- Inform the development of guidance and recommendations for countries, assisting their response to the challenges posed by the COVID-19 pandemic.
- Provide examples of mitigation strategies and inform questions for future global surveys.

What do we mean by services?

We define "services" in the broadest sense possible. Services for people with neurological disorders may be provided by a wide range of health professionals/disciplines, are relevant across the life-course (including children, adults and older adults) and cover the whole spectrum of health and social care (i.e. from prevention, diagnosis, treatment/management, support, care and rehabilitation, also including neurosurgery and research).