



Global survey on disruption and mitigation of neurological services during COVID-19: the perspective of global international neurological patients and scientific associations

Chahnez Charfi Triki¹ · Matilde Leonardi² · Salma Zouari Mallouli¹ · Martina Cacciatore² · Kimberly Coard Karlshoej³ · Francesca Giulia Magnani² · Charles R. Newton⁴ · Andrea Pilotto⁵ · Deanna Saylor⁶ · Erica Westenberg⁷ · Donna Walsh⁸ · Andrea Sylvia Winkler^{7,9} · Kiran T. Thakur¹⁰ · Njideka U. Okubadejo¹¹ · David Garcia-Azorin¹²

Received: 28 May 2021 / Accepted: 2 June 2021 / Published online: 11 June 2021
© Springer-Verlag GmbH Germany, part of Springer Nature 2021

Abstract

Background The COVID-19 pandemic outbreak has dramatically disrupted healthcare systems. Two rapid WHO pulse surveys studied disruptions in mental health services, but did not particularly focus on neurology. Here, a global survey was conducted and addresses the impact of the pandemic on neurology services.

Methods A cross-sectional study was carried out in which 34 international neurological associations were asked to distribute the survey to national associations. The responses represented the national situation, in November–December 2020, with regard to the main disrupted neurological services, reasons and the mitigation strategies implemented as well as the disruption on training of residents and on neurological research. A comparison with the situation in February–April 2020, first pandemic wave, was also requested.

Findings 54 completed surveys came from 43 countries covering all the 6 WHO regions. Overall, neurological services disruption was reported as mild by 26%, moderate by 30%, complete by 13% of associations. The most affected services were cross-sectoral neurological services (57%) and neurorehabilitation (56%). The second wave of the pandemic, however, was associated with the improvement of service provision for diagnostics services (44%) and for neurorehabilitation (41%). Governmental directives were the major cause of services' disruption (56%). Mitigation strategies were mostly established through telemedicine (48%). Almost half of respondents reported a significant impact on neurological research (48%) and educational activities (60%). Most associations (67%) were not involved in decision making for neurological patients' issues by their national government.

Interpretation The COVID-19 pandemic affects neurological services and raises the universal need for the development of neurological health care at the policy, systems and services levels. A global national plan on mitigation strategies for disruption of neurological services during pandemic situations should be established and neurological scientific and patients associations should get involved in decision making.

Keywords Neurological services · COVID-19 · Neurology · Health services administration · Policies

Shared co-authorship: Chahnez Charfi Triki and Matilde Leonardi contributed equally to this work.

Chahnez Charfi Triki and Matilde Leonardi are the Co-chairs of the Essential Health Services Group-WHO Neuro COVID19 Forum.

✉ Matilde Leonardi
Matilde.leonardi@istituto-besta.it

Extended author information available on the last page of the article

Background

The severe acute respiratory syndrome Coronavirus 2 (SARS-CoV-2) has been responsible for a 2019 Coronavirus disease (COVID-19) pandemic with a global burden of up to 163,869,893 confirmed cases of COVID-19 and 3,398,302 deaths as of May 2021 [3]. These large numbers, however, reflect only a small perceptible part of the total impact of COVID-19 on healthcare systems and services. COVID-19 presents all countries with an agonizing trade-off between

lives and livelihoods. Since the World Health Organization (WHO)'s declaration of a pandemic in March 2020, billions of citizens and millions of healthcare staff across the world have seen their services and lives disrupted.

In countries around the world, SARS CoV-2 dramatically disrupted healthcare systems that often failed to find a balance between maintaining safe routine healthcare for patients with non-COVID-19 disorders and the sudden need for resources to take in the increasing number of patients with COVID-19 [4]. This competition for resources led to additional COVID-19-related damages, due to complications resulting from uncontrolled disease with increased levels of disability and mortality in non-COVID-19 populations [5]. Health systems have had little time to prepare and to rapidly reorganize services to meet the acute needs of patients with COVID-19, whilst also maintaining routine and emergency care for people requiring new or ongoing support, and at the same time managing physical distancing and reducing face-to-face appointments and attendance at healthcare establishments.

As the varied effects of the virus on patients who required hospitalization began to emerge, hospitals had to double or even triple their intensive care unit (ICU) capacity, and determine how best to monitor patients and patient-flows more closely and over a long period of time. The need to work more collaboratively with other parts of the healthcare system became apparent, including monitoring people with long-term conditions discharged early to their own homes.

According to the first WHO's Pulse Survey on Continuity of Essential Health Services during the COVID-19 pandemic (August, 2020), 48% of 105 responding countries reported at least partial disruptions in all services for non-communicable diseases and mental health. Of these, 64% reported partial disruption of non-communicable disease diagnosis and treatment, while 5% reported severe disruption [6]. The potential for disruption of the weaker healthcare systems in the low and middle income countries (LMIC) was and is higher [7]. In October 2020, WHO released the findings of a rapid assessment of services for mental, neurological, and substance use (MNS) disorders during COVID-19 [1]. While not specific to neurological disorders, the survey included a few indicators relevant to the field of neurology. For example, one in three countries closed down neurology inpatient units at least partially during the pandemic, with surgeries for neurological disorders being disrupted in two-thirds of the countries surveyed and management of emergency neurological conditions, such as status epilepticus, being at least partially disrupted in 35% of countries. While the WHO report lists a range of reasons for disruptions and mitigation mechanisms, these are not specific to services for neurological disorders. The second WHO's Pulse Survey on Continuity of Essential Health Services during the COVID-19 pandemic (April 2021) confirmed that disruption

of health services all over the world became worse after the initial WHO pulse survey, and that the most affected services have been those for individuals with mental health and neurological disorders [2].

Disruptions to neurological services and worsening of pre-existing neurological conditions during the COVID-19 pandemic have also been reported in the scientific literature, and a recent review commissioned by WHO on neurological services confirms this disruption [8]. For example, in some countries, there have been significant reductions in stroke/transient ischemic attack (TIA) admissions and emergency department stroke alerts during COVID-19 compared to the same period the previous year, because they were unable to access medical care. This most likely has led to increased morbidity and mortality in patients with stroke [9]. Also, SARS-CoV-2 infection has been associated with specific neurological manifestations and increased the incidence of central and peripheral nervous system syndromes [10]. There is also emerging evidence for deterioration of pre-existing neurological conditions such as headache, epilepsy and dementia in those who become infected with SARS-CoV-2 [11], as well as the presence of neurological manifestations in patients presenting the Post-COVID-19 syndrome.

In 2017, the WHO Atlas of Country Resources for Neurological Disorders concluded that in 90% of the world "... the available resources for neurological disorders within most countries remain insufficient. In addition, there are large inequalities across regions and different income levels with extremely scanty resources in lower income countries illustrating the need for substantial increase in neurology services and training" [12]. All of the aforementioned factors add to the large pre-existing global burden of neurological disorders. Neurological diseases are in fact the main cause of morbidity and disability worldwide, and the second leading cause of death worldwide as reported in the Global Burden of Diseases 2019. One in three people will suffer from a neurological disease in their lifetime. Finally neurological diseases are a global public health issue, far from being confined to high income countries; in fact, 80% of the disease burden is in LMIC and resources to cater for patients are distributed unequally [7, 13–15].

Based on the aforementioned, a global assessment was warranted to investigate the extent to which specific services for neurological disorders are being disrupted by the ongoing COVID-19 pandemic and which measures countries are undertaking to mitigate the impact of these disruptions. Therefore, the Essential Services Working Group of the WHO Neurology and COVID-19 Global Forum developed a Global survey on national disruption of neurological services related to COVID-19 and resultant mitigation strategies. The overall goal of the survey was to illustrate the impact of the COVID-19 pandemic on delivery of a variety of neurological services and understand reasons for their

disruption, as well as identify mitigation strategies carried out to restore care for neurological disorders at a country level.

Materials and methods

A cross-sectional survey study was conducted. Participants were national representatives from international neurological patient and scientific associations.

Study participants

A call for participation in the Global Neuro Survey was sent to international and global scientific and patients' organizations that were either selected due to their official relationships with WHO or that were identified from a search of global neurology organizations. Associations represented both children and/or adult populations. A variety of neurology subspecialties were also represented, including general neurology, pediatric neurology, neurosurgery, clinical neurophysiology, neuroradiology, neurorehabilitation as well as other rehabilitation subspecialties, neuropsychology, and clinical and neuroscience research. A virtual meeting, with the heads of 34 global international scientific and lay neurological organizations and associations (Supplement 1) who expressed their willingness to participate in the study, was held in December 2020 to inform about the rationale, objectives, components, and dissemination strategy of the survey.

Data sources

The online survey was prepared by the Essential Health Services working Group—WHO Neuro COVID19 Forum of the Brain Health Unit, and it was sent out by the European Federation of Neurological Associations (EFNA) on January 15th, 2021 to all participating international and global organizations. These organizations were then asked to disseminate the survey to leaders of all affiliated national organizations. The survey closed on 31st January 2021.

Organizations' representatives were asked to complete the survey to the best of their knowledge with answers that reflected the situation for their entire country and were encouraged to reach out to other relevant sources of information in their country if necessary and feasible. Respondents were asked to complete the survey using November and December 2020 as the reference period for their answers.

The global survey questionnaire

Survey questions were developed based on existing WHO Pulse Surveys and Rapid Assessments of Services for Mental, Neurological and Substance Use Disorders and

Non-Communicable Disorders (NCDs) [1]. Questions cover all areas of policies, systems, services including education and research. Neurological services of interest were identified, and the questions were grouped into themes to illustrate: (1) the extent to which neurological services had been disrupted in the public and private health sectors during the months of November and December 2020; (2) if the level of disruption had changed since the beginning of the pandemic; (3) the main reasons for service disruptions; and (4) which mitigation strategies had been developed, utilized and to what extent.

The survey also investigated the role of governmental policies and indications on changes or restrictions to neuroservices in an attempt to contain the virus, as well as disruptions of neurology pre- and post-graduate training and of neurological and brain research as a consequence of the pandemic. Questions were then reviewed by the WHO Neurology & COVID-19 Global Forum and by members of the global COVID-19 Neuro Research Coalition [16] before being pilot-tested with a selected group of representatives from national neurology associations.

The *Degree of service disruption* was graded into No disruption, Mild/Slight (less than 50% of all activities affected), Moderate (50% or more of activities affected), and Complete (i.e., closed services).

Causes of reported service disruptions and mitigation strategies were aggregated by those presenting similar features and identified, respectively, into four and five major groups (Table 1).

Analysis

Descriptive statistics including frequencies, means and standard deviations, and medians and interquartile ranges, were calculated as appropriate from survey responses. Where multiple organizations from the same country responded, their responses were considered together and reported as a range to reflect associated variability in responses. Overall (global) results were determined, and then results were further stratified by WHO World Regions (AFRO, AMRO, EMRO, EURO, SEARO, WPRO), and by country income level using World Bank classification: High Income (HIC), Upper Middle Income (UMIC), Lower Middle Income (LMIC), Low Income Countries (LIC) [17]. As we had only one country from LIC, we aggregated both LMIC and LIC in the same group as Lower Middle and Low Income Countries (LMLIC). Data were analyzed using Statistical Package for Social Science (SPSS).

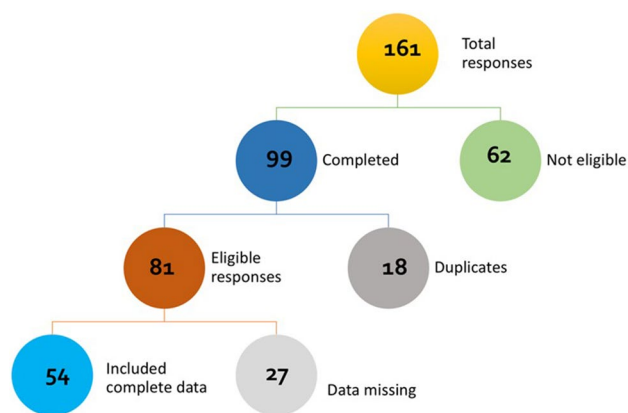
Table 1 The table summarizes the main items of **A** service disruption, **B** the causes of disruption, and **C** the mitigation strategies of the survey questionnaire

Global Survey Questionnaire items	
A. Services types	
A.1. Emergency and acute care for neurological disorders	Inpatient services Acute surgery Emergency Neuroimaging Neurophysiology Lab diagnostics Planned surgery Access to medicines Interventions Primary care Physiotherapy Speech therapy Occupational therapy Cognitive rehabilitation Psychology/counselling
A.2. Investigations and diagnostics	Community-based services Residential long-term care Adult/child day care Special/inclusive school educational programs for children Interventions for caregivers Services/programs delivered by non-governmental organizations
A.3. Treatment and care for neurological disorders	
A.4. Neurorehabilitation	
A.5. Cross-sectoral service delivery for neurological disorders	
A.6. Promotion of brain health and prevention of neurological disorders, in addition to implementation activities of national prevention plan and neurology advocacy	
A.7. Training of pre- and post-graduate students, residents, PhD students or other educational activities	
A.8. Neurological and Brain Research	
B. Causes of services disruption	
B.1. Government directives	<ol style="list-style-type: none"> 1. Closure of inpatient or outpatient services or consultations as per health authority directive 2. Decreased volume of patients due to cancellation of elective care 3. Inpatient services/hospital beds not available due to saturation 4. Clinical staff shifted to provide COVID-19 clinical management or emergency support 5. Disruption of supply chains resulting in unavailability or stock out of essential medicines, medical diagnostics or other health products at health facilities
B.2. Fear: decrease in outpatient volume due to patients not presenting for care	
B.3. Travel restriction hindering access to the health facilities for patients	
B.4. Health personnel and PPE availability	<ol style="list-style-type: none"> 1. Insufficient staff to provide services (e.g., due to quarantine/self-isolation of health-care providers due to COVID-19, but also due to insufficient personnel working in neurology area even before the pandemics) 2. Insufficient Personal Protective Equipment (PPE) available for health-care professionals to provide services
B.5. Others: Government rules on restriction of travel including sending out specimens to other laboratories in cities, different law and rules of each city regarding movement. Fear of nurses to go on duty in COVID wards	
C. Mitigations strategies	
C.1. Remote care and innovations in service delivery	<ol style="list-style-type: none"> 1. Telemedicine deployment to replace in-person consults or other teleconsultation formats (televisit, tele-neurorehabilitation, teleconsultation) 2. Catch-up campaigns for missed appointments 3. Novel dispensing approaches for medicines, novel prescribing approaches (e.g., tele-prescription, extended drug prescriptions) 4. Community communications (e.g., informing on changes to service delivery, addressing misinformation and community fears) to ensure that all citizens are aware and informed of continuity of services and that routine care can always be sought

Table 1 (continued)

Global Survey Questionnaire items

C.2. Systems, services, neurological personnel's reorganization	<ol style="list-style-type: none"> 1. Triaging of neurological patients to identify priorities so as to keep continuity of care for the most fragile and vulnerable ones 2. Redirection of patients to alternate care sites (e.g., primary care), reorientation of referral pathways or integration of several services into a single hub 3. Task-shifting or role delegation
C.3. Government decisions and implications	<ol style="list-style-type: none"> 1. Recruitment of additional staff, novel supply chain management and logistics approaches 2. Government removal of user fees
C.4. Neurological patients reorganization: self-care interventions and provision of home-based care	
C.5. Neurological patients' associations reorganization: helplines for patients and caregivers	

**Fig. 1** PRISMA flow diagram of included/excluded data

Results

We received 161 responses to the online Global Survey, only 99 were totally or partially filled and could be included. Of these, 18 survey questionnaires that came from the same country were collated, thus leaving 81 responses, of which only 54 had complete data and thus were considered for final analysis (Fig. 1). These 54 completed surveys came from 43 countries covering all the 6 WHO regions (Fig. 2). About 57% of patients and scientific neurological associations were from HIC (Supplement 2).

Among the associations that participated, 48% are professional organization and 37% are patients' associations; 15% are related to adults, 33% to children, and 52% to both. The specialty areas represented are global adult neurology (26%), pediatric neurology (29%), neurorehabilitation (15%), and one specific neurological disease subspecialty (30%) (Supplement 3).

Overall, service disruption was reported as not disrupted by 16%, mild by 26%, moderate by 30%, and complete by 13% of associations. There was less disruption in the European region (EURO) and in HIC among all services types. Indeed, services were considered as slightly to completely disrupted, respectively, by 25% of respondents from the EURO region and 24% of respondents from HIC.

Service disruption

The most affected services fell in the areas of *cross-sectoral neurological services* including services provided by non-government organizations (NGOs) for neurological patients or caregivers. Adult or child daycare services were reported as having moderate to complete disruption by 57% respondents. Among these daycare services, inclusive schooling for children with disabilities and special needs and the interventions with and for caregivers were the most affected



Fig. 2 Number of completed survey per country

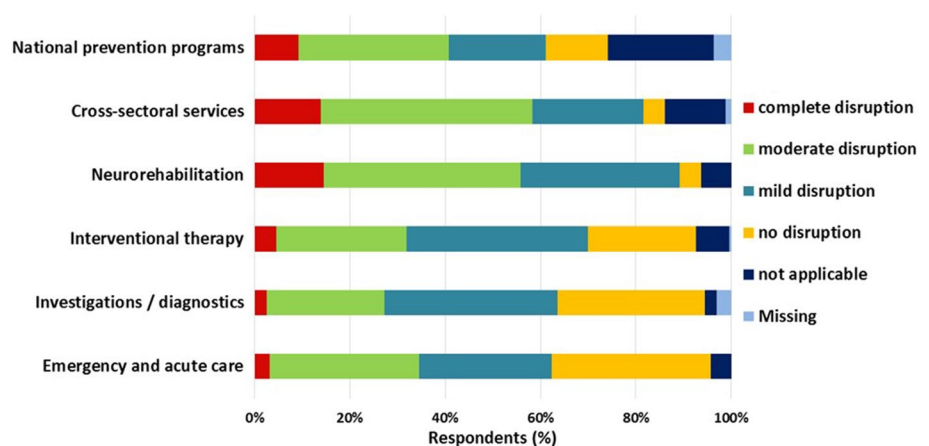
(each completely to moderately disrupted for approximately two-thirds of all respondents). The second most common disrupted service globally is neurorehabilitation including speech therapy and physiotherapy, where the majority of respondents (56%) reported moderate to complete service disruption. Other services including emergency and acute care, interventional therapy, and diagnostic investigations were reported as less disrupted (Fig. 3).

This trend was found in all WHO world regions. However, EUR and SEAR overall showed less disruptions in

emergency and acute care and investigations and intervention services. Likewise, cross-sectoral services and neurorehabilitation were reported as the most affected by all scientific and lay associations in all WHO regions. All types of health neurological interventions, acute/emergency and diagnostic services were reported as those most disrupted by the disease-specific associations (Supplement 4).

Significant national variability within a given country was reported by more than half of the respondents (56%). Most respondents (54%) emphasized that there had been critical

Fig. 3 The figure shows the percentages of respondents (x-axis) reporting the extent of services disruption with respect to services types



disruptions in health-care provision in remote areas due either to already poor health systems (47%) or to the shifting of personnel or of resource allocation from neurological care to the management of COVID-19 (53%).

When comparing the extent of service disruption among the public versus the private sector, most respondents did not find any differences in service delivery between the two health sectors. However, where available, in the private sector, greater disruption of emergency services, neurorehabilitation, and investigations/diagnostics was reported by 17%, 13%, and 11% of respondents.

Regarding the trend of neurological service disruption over the period between two waves of COVID-19 (considering the first wave as the beginning of the pandemic, which for each country varied from February to April 2020, and second waves occurring November to December 2020), most participants mentioned equal disruption of prevention programs (54%) and neuro-interventions (49%) during this time period. Other services, however, showed recovery and improvement of service provision mainly for neurological investigations and diagnostics services (44%) and, to a lesser degree, for neurorehabilitation (41%) (Fig. 4).

Respondents from different association types and from countries with different income levels reported different levels of disruption over time in 2020 as presented in Supplement 5a,b. It is to be noted that respondents belonging to UMIC stated more improvements from the first to second COVID-19 wave among neurorehabilitation services. Analysis obtained from countries with different transmission stages showed worsening of services disruption over time in countries with sporadic cases (Supplement 5c).

Causes of disruption

The most frequently reported cause of service disruption was related to governmental directives that, due to emergency situations, gave priority in service use to individuals

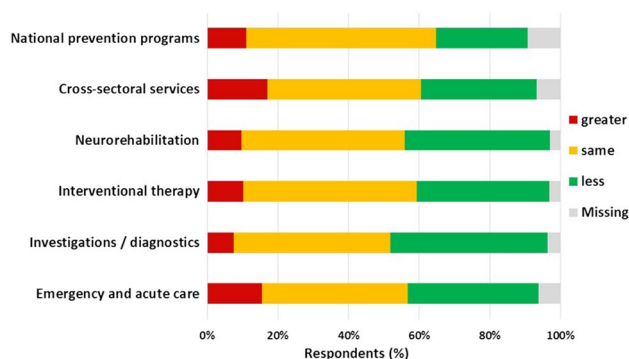


Fig. 4 Percentages of respondents reporting the changes in services disruption level in Nov/Dec 2020 compared to the beginning of the pandemic (February–April 2020)

with acute COVID-19 in almost all 43 countries included in the analysis. This caused the closing of disease-specific consultation clinics, thus affecting neurological services, and a change in allocation of clinical units/beds/services to care for individuals hospitalized with COVID-19 (56%). The second, third, and fourth reasons of service disruption were fear of becoming infected with COVID-19 in health facilities (19%), travel restrictions, and finally the lack of personal protective equipment (PPE) available for neurological health-care providers (12%) (Fig. 5). These findings were similarly reported in all WHO regions, by countries with different income levels, and by both patient and scientific associations. However, the AFR region and LICs suffered more severely from lack of PPE than others (Supplementary 6).

Mitigation strategies

The evaluation of mitigation strategies revealed that telemedicine was the primary means of maintaining continuity of care for adults and children with neurological disorders (48%). Also, 28% of respondents reported reorganization done by regional or local authorities or by individual physicians with neurological patients redirected to nearby alternative care sites according to priorities such as disease severity, need of assistance and/or provision of essential drugs. Only a minority of respondents (10%) reported that the government was trying to guarantee continuity of care for people with neurological disorders (i.e., recruitment of additional staff). Other mitigation strategies were adopted both by the patients themselves (8%) and by some patient associations (6%).

However, the reported mitigation strategies were insufficient to maintain basic provision of neurological care, mostly for outpatients. Indeed, 56% of respondents said that healthcare providers were unable to monitor treatment results and patients' satisfaction in their country during the pandemic period.

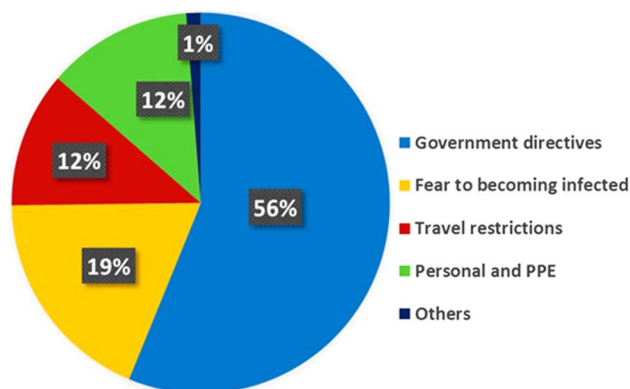


Fig. 5 The figure shows the percentages of different causes of service disruption

Regarding the knowledge of the existence of national or international guidelines for the management of individuals with neurological diseases during the pandemic or the management of individuals with neurological manifestations of COVID-19, 50% reported that they were aware of their existence, 37% of respondents indicated they were not aware of the existence of national or international guidelines, while 13% of associations did not answer the question.

Neurological training activities and brain research

Most respondents indicated that educational activities (60%), and the residency and PhD study programs in all related areas of neurology (39%) had been interrupted or reorganized due to the pandemic and the changes were still present in the period considered by the survey (Supplement 7). Moreover, 44% of the respondents reported that neurology residents had been involved from the first wave in the management of patients with COVID-19 in general COVID wards or in Neuro-Covid Units.

When these results were stratified by WHO regions, only respondents from WPR and EUR reported little or no alteration for neurology, child neurology, neurosurgery, neurorehabilitation residency or PhD programs, whilst the undergraduate medical educational activities were more interrupted in these regions (Supplement 8).

Nearly half of patients' associations that provided training and educational services to caregivers, patients and health professionals before the start of the pandemic continued to provide these services (46%).

Respondents also reported that neurological and brain research was affected by the pandemic both in terms of funding allocation and research activities. Specifically, 37% of the respondents reported a decrease in funding allocation for brain research, as COVID-19 research had been prioritized; this result is evident for countries of all income strata (Supplement 9) and for all WHO regions, except for the SEAR from which no data were reported (Supplement 10). Nearly half (48%) of the respondents declared that COVID-19 had a significant impact on overall neurological research activities, and in particular 38% of respondents reported an interruption of clinical trials.

A minority of the respondents (11%) declared that COVID-19 did not affect funding allocation for research, responses that primarily derived from UMICs. Finally, only 6% of the respondents reported an increase of funding for research; this result was driven by LMICs.

Policies and emergency decision making for neurological services and patients

Most of the scientific and patients' associations participating in the survey (67%) reported that they were not involved

by their national government in any phase of the decision making related to the pandemic and its consequences. Only a smaller percentage of respondents were involved in an advisory capacity (9%) or as an observer (7%). Associations from EUR (11%), AMR (14%), and AFR (14%) reported their involvement as advisors and a minority of associations from EUR (7%) and AMR (29%) reported their involvement as observers (Fig. 6).

When exploring income-stratified data, the respondents from HICs and UMICs were the only ones that reported their involvement as observers, whilst a small percentage of respondents, independent of income level, reported their associations' involvement in an advisory capacity (Supplement 11).

Concerning governmental policies regulating access to adult or child neurology diagnostics, care or rehabilitation services, most respondents declared these policies were either not provided by governments (41%) or were provided as general guideline including indications and instructions for healthcare facilities in primary, secondary, and tertiary care level altogether with no specific indications for neurological patients (28%).

SEAR was the only region where respondents reported release of governmental policies bundling all three levels of care together that were relevant for individuals with neurological disorders (Fig. 7). Income-stratified data revealed the absence of any governmental policy regulating access to all the levels of care for neurological patients was particularly evident for UMICs (Supplement 12).

Discussion

Data from our survey indicate that, almost a year after the beginning of the pandemic, neurological service disruptions were still present in most countries. Disruptions that occurred at the beginning of the pandemic existed in November–December 2020. A recent WHO commissioned global review of scientific literature clearly highlighted the

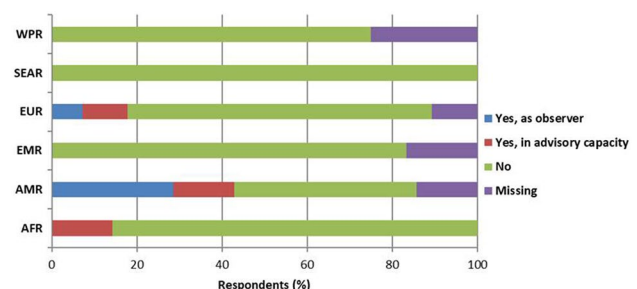


Fig. 6 Percentages of respondents (*x*-axis) reporting their involvement in national decision making. The different WHO regions are depicted on the *y*-axis

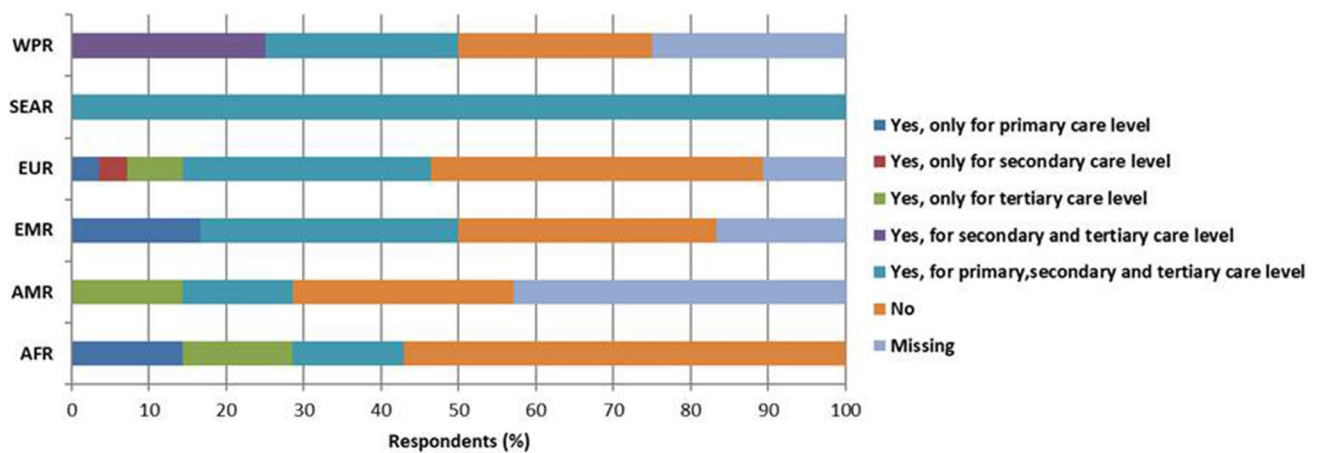


Fig. 7 The figure shows the percentages of respondents (x -axis) reporting the presence of government policies regulating the access to services. The different WHO regions are depicted on the y -axis

disruption of neurological services in all regions of the world. The scientific studies in the review were mostly carried out by researchers and health professionals and referred to the first wave of COVID-19 [18]. Our global survey, by involving 34 global neurological organizations and receiving replies from 54 respondents from 43 countries, focused on the November–December 2020 COVID-19 wave, and demonstrated that almost all scientific and patient associations reported that neurological services were disrupted to some extent.

Cross-sectoral service delivery and neurorehabilitation were the most disrupted services. In the global review, the most frequently reported disruptions occurred for cross-sectoral service delivery for neurological disorders, which was assessed in 151 of 240 studies (63%), followed by emergency and acute care for neurological disorders (47%), and treatment and physical care for neurological disorders ($n = 109$, 45%) [18]. This is in disagreement with data obtained from the WHO survey on mental, neurological and substance abuse services that gathered data from July–August 2020, where prevention programs were most severely affected. However, that WHO survey did not include items related to neurorehabilitation [1].

Disruption of neurological services seemed to affect remote areas more severely, which is in accordance with prior data [7]. Pre-existing disparities in healthcare infrastructures and organizations were only aggravated by the COVID-19 pandemic. Moreover, provision of healthcare through telemedicine was not possible in many remote areas devoid of reliable Internet and telephone access [7, 19–21]. In the same way, the priority given to COVID-19 management also contributed to heterogeneity in provision of medical services. In fact, many healthcare systems were reorganized so that individuals with non-COVID-19 chronic neurological conditions were temporarily referred

to alternative health-care facilities while university/hospital centers were targeted for management of individuals with COVID-19 infections. Other studies have also described the repercussions of such measures on altering equitable distribution of resources [7, 19, 22, 23].

In our global survey, different WHO regions showed greater disruption in neurorehabilitation and cross-sectoral services than others. However, the distribution of services differed from that previously published by WHO in October 2020 (1). According to this report, the AFR region was affected most, followed by the EUR and SEAR regions, while in our Global Survey the EUR and SEAR regions reported the least level of service disturbances among all services types [1]. This difference may be due to the fact that the services studied by the two surveys were not identical. Although the pediatric population were also affected by the peak burden of rehabilitation services disruption, child neurology associations reported less service disruption than adult neurology associations. These results are probably linked to the lower rate of symptomatic carriage of COVID-19 among children [24]. According to our results, a considerable proportion of respondents reported more disruption for emergency and acute care (17%), neurorehabilitation (13%), and investigations and diagnostic tools (11%) in the private sector during the surveyed period. Previous assessments have also demonstrated restrained participation of the private sector in the pandemic response. This has been attributed to large sectors of the population in many countries that rely on the public health system for all of their medical care, but private sector organizations have also reported their exclusion from governmental policy for healthcare organization's plans towards management of COVID-19 patients, including from offering both screening tests and patient care [25].

Compared to the beginning of the pandemic, service disruption in November–December 2020 was less severe in delivery of investigations such as neuroimaging, neurophysiology and laboratory tests, in providing neurorehabilitation services, and in providing interventional therapies such as planned surgery and botulinum toxin injections. According to most respondents of the Global Survey, neurological service disruptions were predominantly related to the health emergency governmental measures including lockdowns and transportation restrictions and as second, to patients' fear of COVID-19. Our results differ from the data provided by WHO pulse survey, which reported that service disruptions were mostly due to personal considerations such as fear from COVID-19 disease exposure and to transportation restriction [1]. Studies carried out among patients with epilepsy also found individual factors as the leading cause behind service disruption, such as fear of catching the virus and inability to travel, with loss of employment and financial stressors contributing as well [21]. According to these two last studies, governmental directives during all phases of the emergency were considered to be the second major cause for service disruption [1, 21].

Regarding mitigation strategies adopted and solutions developed to alleviate COVID-19 pandemic consequences, most of our respondents reported primarily use of virtual remote care, the so-called “Tele-neurology”, which included advice, consultations, rehabilitation, and prescriptions provided remotely, as well as videoconferencing and home-based self-monitoring. In spite of some constraints due to technical difficulties, lack of physical contact, and inability to perform diagnostic monitoring and laboratory investigations, telemedicine played a prominent role in maintaining healthcare service delivery for acute and chronic neurological conditions and also to reach neurological patients in remote areas, as reported in several studies [1, 21, 26–28].

Our findings, are consistent with those previously reported by the WHO Pulse survey on the impact of COVID-19 on mental, neurological and substance use services, which revealed the importance of healthcare personnel reorganization in the provision of essential neurological care and apportioned less value to governmental policies and individual patients' or neurological patients associations' reorganization [1].

However, our data also demonstrate that such emergency measures failed to provide adequate follow-up for the outpatients with neurological disorders, findings which have also been previously demonstrated. In fact, most of our respondents (56%) reported that in their country during November–December 2020, there remained an inability to ensure regular continuity of care, or monitoring of treatment outcome and of patients' satisfaction. However, 32% of respondents reported that phone calls have been made by health professionals in their country to follow-up patients.

In a recent paper evaluating neurologists' perceptions of switching from face-to-face clinical work to tele-neurology, over 80% of participants complained of a reduction in work satisfaction but mostly due to logistic difficulties in performing tele-health such as lack of reliable internet networks or telephone access in some areas and inability to perform laboratory testing and other investigations [29]. Therefore, further infrastructural development and countries' digitalization in all countries are required to achieve the full potential of tele-neurology.

Nearly half of survey respondents (43%) said they were not consulted by Governments or by international bodies in the neurological care planning during COVID-19 pandemic, neither in the first nor in the second wave. However, in some countries collaborations between patients and professional organizations have been developed. For example, an alliance between the Italian health-care system, the Italian Neurological Society (SIN) and the Italian Association of Myasthenia (AIM) was developed to evaluate the needs of vulnerable patients with neuromuscular diseases and to maintain essential services by developing new and effective solutions [30].

Finally, the dissemination of new tailored guidelines for disease management and the influx of academic increasing productivity about neurological manifestations associated with COVID-19 [31] are globally still limited. This was demonstrated when 37% of respondents expressed they were unaware of the existence of national or international guidelines, of any type and for neurological patients in particular. Inconsistent with our findings, there are several examples of active involvement in dissemination of information useful for neurological patients, such as for example the WFN, or AAN or EAN or EFNA or WFNR guidelines for management of neurological patients, or for provision of neurorehabilitation, or the development of a website for neurological guidelines created since April 2020 by a task force of 15 neurologists belonging to Boston University Medical Center data. For this last the analyses of web analytics showed a great interest of neurologists to get knowledge about current treatment recommendations as well as about tele neurological examination [32].

Limitations

Out of the 34 lay and scientific international organizations involved, the response rate was low. In addition, presidents of national associations may have not had access to all the country's information, so their responses might be incomplete. Although the international associations of adult and pediatric neurology and related disciplines were invited; very few scientific associations of a specific neurological disease participated in the survey and most of the single

disease organizations that responded to the survey, are patients' associations. In addition, associations of child neurology only and of combined children and adults neurology are more represented in our study. Given the high use of rehabilitation treatments in pediatric age, this might explain the high representation of disruptions in neurorehabilitation, not reported in other studies.

Regional representation was not balanced, as only one country from the SEAR region participated in the survey. The majority of respondents were from Europe with a majority of patients and scientific associations specialized in neurological childcare. Also, only one association was from a low-income country, which is limiting the information on impact of COVID in this group of countries. In addition, we did not study the degree of disruptions, the causes and the mitigation strategies according to the stage of community transmission of COVID-19. Moreover, the estimate of the degree of disruption was subjective and was operator dependent.

Conclusions

To the existing evidence of the magnitude of healthcare systems and healthcare delivery disruptions, this global neuro survey is providing countries' and regions' perspectives, more detailed and specific for a wide range of neurological services. It highlights the threats that pandemics pose to unprepared healthcare systems with specific emphasis on the particularly vulnerable neurological services in LMIC, but also in HIC. Results emphasize the multiple reasons for the disruptions including: the role of previous lack of targeted neurological policies, systems, and services; the effects of governmental policies; the inevitable logistic fall-outs of movement restrictions and of transportation limitations; the lack of health workforce for neurological patients worldwide; the lack of involvement in policy decision of the neurological community in many countries on neurological issues such as organization, care pathways reorganization; ranking of national priorities; involvement of scientific or patients' organization in the political planning; without forgetting the role of fear that many patients had on personal safety. Our survey also confirms the need for most countries to invest in the development of neurological health care at policies, systems, and services levels in primary, secondary, and tertiary care and thus in health personnel, education and research and to support the development of infrastructures to implement the use of telemedicine, which has also proven to make neurologists able to reach most patients, even in remote areas.

In line with the sentiment of "Building Back better" this survey demonstrates that in every country there is no health without brain health, but in many countries the

COVID-19 pandemic has just highlighted pre-existing problems, both for the scientific and for the patients' organizations. The COVID-19 pandemic has shown that these organizations have to be on the public health forefront in all countries and to contribute to the development of public health decisions supporting adults and children with neurological disorders. The global burden of neurological disorders requires patient and professional organizations to be able to respond to the global neurological challenges in a timely manner. COVID-19 made the world dramatically open the eyes on the needs of all, but in particular of the most vulnerable such as the adults and children with neurological disorders. Our survey provides to decision makers and to the neurological community, pathways for implementing mitigation strategies that can last beyond the end of the pandemic so as to support all in all countries, as no-one is safe until everyone is safe.

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1007/s00415-021-10641-3>.

Acknowledgements We thank the members of the WHO Neurology and COVID-19 Forum and the members of the global COVID-19 Neuro Research Coalition for their valuable feedback and the European Federation of Neurological Associations for their essential collaboration. We are grateful for the contribution of all the 34 international scientific and patients neurological associations and to their national Presidents for collaborating in the survey

Author contributions CCT and ML: conceptualization, data curation, formal analysis, methodology, project administration validation, visualization, and writing of original draft. SZM, MC, KK, FGM, and DW: conceptualization, formal analysis, methodology, project administration, validation, visualization, review, and editing of the manuscript. CN, AP, DS, EW, ASW, KT, NO, and DGA: conceptualization, formal analysis, methodology, project administration, validation, visualization, review, and editing of the manuscript.

Funding None.

Code availability The database is coded in SPSS and can be extracted to Excel.

Declarations

Conflicts of interest DS declares grants or contracts from National Institutes of Neurological Disorders and Stroke; National Multiple Sclerosis Society, National Institutes of Mental Health, and American Academy of Neurology, not related with this work; payment honoraria for lectures for Medlink Neurology and member as Multiple Sclerosis International Federation Global Access Working Group. AP declares payment for lectures honoraria from Abbvie, Biomarin, Chiesi, Nutricia, UCB, and Zambon Pharmaceuticals. TK declares funding from National Institutes of Health, Center for Disease Control and Prevention (COVID related CDC funding). DGA declares grants from the Regional Health Administration and International Headache Society; honoraria for reviewing manuscripts for the review from the World Health Organization; travel support from Teva, Lilly, Novartis and Allergan; participation in advisory board from Allergan; membership of the Spanish Society of Neurology executive board.










Availability of data The full database is available for other researchers upon request to the corresponding author.

Consent for publication All authors approved the final version of the manuscript.

References

- WHO (2021) The impact of COVID-19 on mental, neurological and substance use services. <https://www.who.int/publications-detail-redirect/978924012455>. Accessed 5 Apr 2021
- WHO (2019) Second round of the national pulse survey on continuity of essential health services during the COVID-19 pandemic. <https://www.who.int/publications-detail-redirect/WHO-2019-nCoV-EHS-continuity-survey-2021.1>. Accessed 22 May 2021
- GAVI-The Vaccine Alliance (2021) COVID-19 dashboard. <https://www.gavi.org/covid19/dashboard>. Accessed 10 Apr 2021
- Chen PM, Hemmen TM (2020) Evolving healthcare delivery in neurology during the coronavirus disease 2019 (COVID-19) pandemic. *Front Neurol*. <https://doi.org/10.3389/fneur.2020.00578>
- Santi L, Golinelli D, Tampieri A et al (2021) Non-COVID-19 patients in times of pandemic: emergency department visits, hospitalizations and cause-specific mortality in Northern Italy. *PLoS ONE* 16:e0248995. <https://doi.org/10.1371/journal.pone.0248995>
- WHO (2020) Pulse survey on continuity of essential health services during the COVID-19 pandemic: interim report, 27 August 2020. https://www.who.int/publications-detail-redirect/WHO-2019-nCoV-EHS_continuity-survey-2020.1. Accessed 22 May 2021
- Bhaskar S, Rastogi A, Menon KV et al (2020) Call for Action to Address Equity and Justice Divide During COVID-19. *Front Psychiatry*. <https://doi.org/10.3389/fpsy.2020.559905>
- The Neurological Alliance (2020) The impact of covid-19 on neurological care within the NHS - Briefing paper. https://www.neural.org.uk/wp-content/uploads/2021/01/20201221-Changes-to-NHS-activity_COVID-first-wave.pdf
- Altschul DJ, Haranahalli N, Esenwa C et al (2020) The impact of COVID-19 on emergent large-vessel occlusion: delayed presentation confirmed by ASPECTS. *AJNR Am J Neuroradiol* 41:2271–2273. <https://doi.org/10.3174/ajnr.A6800>
- Werner C, Scullen T, Mathkour M et al (2020) Neurological impact of coronavirus disease of 2019: practical considerations for the neuroscience community. *World Neurosurg* 139:344–354. <https://doi.org/10.1016/j.wneu.2020.04.222>
- Bhaskar S, Bradley S, Israeli-Korn S et al (2020) Chronic neurology in COVID-19 era: clinical considerations and recommendations from the REPROGRAM consortium. *Front Neurol*. <https://doi.org/10.3389/fneur.2020.00664>
- WHO (2017) ATLAS Country Resources for Neurological Disorders. In: WHO. http://www.who.int/mental_health/neurology/atlas_second_edition/en/
- Feigin VL, Vos T (2019) Global burden of neurological disorders: from global burden of disease estimates to actions. *Neuroepidemiology* 52:1–2. <https://doi.org/10.1159/000495197>
- Feigin VL, Vos T, Nichols E et al (2020) The global burden of neurological disorders: translating evidence into policy. *Lancet Neurol* 19:255–265. [https://doi.org/10.1016/S1474-4422\(19\)30411-9](https://doi.org/10.1016/S1474-4422(19)30411-9)
- Knauss S, Stelzle D, Emmrich JV et al (2019) An emphasis on neurology in low and middle-income countries. *Lancet Neurol* 18:1078–1079. [https://doi.org/10.1016/S1474-4422\(19\)30392-8](https://doi.org/10.1016/S1474-4422(19)30392-8)
- Winkler AS, Knauss S, Schmutzhard E et al (2020) A call for a global COVID-19 neuro research coalition. *Lancet Neurol* 19:482–484. [https://doi.org/10.1016/S1474-4422\(20\)30150-2](https://doi.org/10.1016/S1474-4422(20)30150-2)
- World Bank Country and Lending Groups—Country Classification (2021). <https://datahelpdesk.worldbank.org/knowledgebase/articles/906519-world-bank-country-and-lending-groups>. Accessed 22 May 2021
- García-Azorín D, Seeher KM, Newton CR, Okubadejo NU, Pilotto A, Saylor D, Leonardi M (2021) Disruptions of neurological services, its causes and mitigation strategies during COVID-19: a global review. *J Neurol*, pp 1–14
- Basu S (2020) Non-communicable disease management in vulnerable patients during Covid-19. *Indian J Med Ethics* V:103–105. <https://doi.org/10.20529/IJME.2020.041>
- Wirrell EC, Grinspan ZM, Knupp KG et al (2020) Care delivery for children with epilepsy during the COVID-19 pandemic: an international survey of clinicians. *J Child Neurol* 35:924–933. <https://doi.org/10.1177/0883073820940189>
- Albert DVF, Das RR, Acharya JN et al (2020) The impact of COVID-19 on epilepsy care: a survey of the American Epilepsy Society Membership. *Epilepsy Curr*. <https://doi.org/10.1177/1535759720956994>
- Bhaskar S, Sharma D, Walker AH et al (2020) Acute neurological care in the COVID-19 Era: the pandemic health system resilience PROGRAM (REPROGRAM) consortium pathway. *Front Neurol*. <https://doi.org/10.3389/fneur.2020.00579>
- Paliwal PR, Tan BYQ, Leow AST et al (2020) Impact of the COVID-19 pandemic on hyperacute stroke treatment: experience from a comprehensive stroke centre in Singapore. *J Thromb Thrombolysis*. <https://doi.org/10.1007/s11239-020-02225-1>
- Brodin P (2020) Why is COVID-19 so mild in children? *Acta Paediatr* 109:1082–1083. <https://doi.org/10.1111/apa.15271>
- Davalbhakta S, Sharma S, Gupta S et al (2020) Private health sector in India-ready and willing, yet underutilized in the covid-19 pandemic: a cross-sectional study. *Front Public Health*. <https://doi.org/10.3389/fpubh.2020.571419>
- Bhaskar S, Bradley S, Chattu VK et al (2020) Telemedicine as the new outpatient clinic gone digital: position paper from the pandemic health system RESilience PROGRAM (REPROGRAM) international consortium (Part 2). *Front Public Health*. <https://doi.org/10.3389/fpubh.2020.00410>
- Surya N, Srivastava A, Nagda T et al (2021) Education, training, and practices of neurorehabilitation in India during the COVID-19 pandemic. *Front Neurol*. <https://doi.org/10.3389/fneur.2021.626399>
- Pareyson D, Pantaleoni C, Eleopra R et al (2021) Neuro-telehealth for fragile patients in a tertiary referral neurological institute during the COVID pandemic in Milan, Lombardy. *Neurol Sci*. <https://doi.org/10.1007/s10072-021-05252-9>
- Courtney E, Blackburn D, Reuber M (2021) Neurologists' perceptions of utilising tele-neurology to practice remotely during the COVID-19 pandemic. *Patient Educ Couns* 104:452–459. <https://doi.org/10.1016/j.pec.2020.12.027>
- Mauri E, Abati E, Musumeci O et al (2020) Estimating the impact of COVID-19 pandemic on services provided by Italian Neuromuscular Centers: an Italian Association of Myology survey of the acute phase. *Acta Myol* 39:57–66. <https://doi.org/10.36185/2532-1900-008>
- Lee JE, Mohanty A, Albuquerque FC et al (2020) Trends in academic productivity in the COVID-19 era: analysis of neurosurgical, stroke neurology, and neurointerventional literature. *J Neuro-Interventional Surg* 12:1049–1052. <https://doi.org/10.1136/neurintsurg-2020-016710>
- Cervantes-Arslanian A, Lau KHV, Anand P et al (2020) Rapid dissemination of protocols for managing neurology inpatients with COVID-19. *Ann Neurol* 88:211–214. <https://doi.org/10.1002/ana.25774>

Authors and Affiliations

Chahnez Charfi Triki¹  · Matilde Leonardi²  · Salma Zouari Mallouli¹ · Martina Cacciatore² · Kimberly Coard Karlshoej³ · Francesca Giulia Magnani² · Charles R. Newton⁴  · Andrea Pilotto⁵  · Deanna Saylor⁶ · Erica Westenberg⁷  · Donna Walsh⁸  · Andrea Sylvia Winkler^{7,9} · Kiran T. Thakur¹⁰  · Njideka U. Okubadejo¹¹  · David Garcia-Azorin¹² 

Chahnez Charfi Triki
Chahnezct@gmail.com

Salma Zouari Mallouli
mallouli.salma26@gmail.com

Martina Cacciatore
martina.cacciatore@istituto-besta.it

Kimberly Coard Karlshoej
kimberly@wfneurology.org

Francesca Giulia Magnani
francesca.magnani@istituto-besta.it

Charles R. Newton
charles.newton@psych.ox.ac.uk

Andrea Pilotto
Andrea.pilotto@unibs.it

Deanna Saylor
Dcettom1@jhmi.edu

Erica Westenberg
erica.westenberg@tum.de

Donna Walsh
executivedirector@efna.net
<https://www.efna.net>

Andrea Sylvia Winkler
andrea.winkler@tum.de

Kiran T. Thakur
ktt2115@cumc.columbia.edu

Njideka U. Okubadejo
nokubadejo@unilag.edu.ng

David Garcia-Azorin
dgazorin@ucm.es

¹ Child Neurology Department, Hédi Chaker Hospital, LR19ES15, Sfax University, Sfax, Tunisia

² Neurology, Public Health, Disability Unit, Fondazione IRCCS Istituto Neurologico Carlo Besta, Milan, Italy

³ World Federation of Neurology, Cqhester House, Fulham Green, 81-83 Fulham High Street, London SW6 3JA, UK

⁴ Department of Psychiatry, University of Oxford, Oxford, UK

⁵ Neurology Unit, Department of Clinical and Experimental Sciences, University of Brescia, Brescia, Italy

⁶ Department of Neurology, Johns Hopkins University School of Medicine, Baltimore, MD, USA

⁷ Department of Neurology, Center for Global Health, Klinikum rechts der Isar, Technical University of Munich, Munich, Germany

⁸ European Federation of Neurological Associations, Brussels, Belgium

⁹ Centre for Global Health, Institute of Health and Society, University of Oslo, Oslo, Norway

¹⁰ Department of Neurology, Columbia-Irving University Medical Center/New York Presbyterian Hospital, New York, USA

¹¹ Neurology Unit, Department of Neurology, College of Medicine, University of Lagos, Lagos, Nigeria

¹² Department of Neurology, Hospital Clínico Universitario de Valladolid, Valladolid, Spain