SHORT COMMUNICATION



Brain health and national neurological societies: Results of the European Academy of Neurology survey on brain health awareness and areas of implementation for European countries

| Matilde Leonardi ¹ Isabella Colonna ² David Garcia-Azorin ³ Daniel Bereczki ⁴ |
|---|
| Benedetta Bodini ^{5,6} 🕟 Noa Bregman ⁷ 🕟 Reetta K. Kälviäinen ⁸ 🕟 |
| Aida Kondybayeva ⁹ Viktoria Papp ¹⁰ David B. Vodušek ¹¹ Tim von Oertzen ¹² |
| Robertina Danova ¹³ Michael Crean ¹³ Raphael Wurm ^{14,15} Claudio Bassetti ¹⁶ |
| Thomas Berger ^{14,15} Paul Boon ¹⁷ Ulf Kallweit ^{18,19} Anthony Marson ²⁰ |
| Elena Moro ²¹ Irena Rektorova ^{22,23} Antonio Toscano ²⁴ Letizia Leocani ^{25,26} |

Correspondence

Isabella Colonna, Complex Operative Unit of Neurology, "F. Ferrari" Hospital, ASL, Lecce, Italy.

Email: isabellacolonna@hotmail.it

Abstract

Background and purpose: The European Academy of Neurology (EAN) has adhered to the global plan for reducing the burden of neurological disorders and promoting brain health launched by the World Health Organisation (WHO), the WHO Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders. This study reports the results of an EAN survey among national neurological societies (NNSs) on their awareness of brain health policies.

Methods: The EAN survey on the current state of national brain health policies was conducted among the 47 presidents of the NNSs affiliated with the EAN, with the aim of developing the best strategy for close collaboration among stakeholders.

Results: From June 2023 to February 2024, 36/47 responses (77%) were collected. Among respondents, 67% were in contact with their Ministry of Health and 78% were aware of and in contact with one or more national neurological patient organisation, while 17% had no contacts with any association. Ninety-two percent declared a high to medium degree of awareness of the need to support brain health and of brain health plans and strategies in their country.

Conclusions: Our findings suggest good awareness of the importance of brain health and of the strategies implemented at the national level among the EAN-affiliated NNSs and representatives. Efforts towards improvement may be directed towards cooperation between NNSs and political institutions, as well as patient organisations, to optimise brain and global public health and neurological care in each country.

KEYWORDS

brain health, health policies, neurological societies, patients' organization, prevention and care

For affiliations refer to page 4.

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited and is not used for commercial purposes.

© 2024 The Author(s). European Journal of Neurology published by John Wiley & Sons Ltd on behalf of European Academy of Neurology.

2 of 5 LEONARDI ET AL.

INTRODUCTION

The World Health Organisation's Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders (WHO IGAP) provides a global strategy for improving brain health worldwide [1]. It has five strategic objectives: to raise policy prioritisation and strengthen governance; to provide effective, timely and responsive diagnosis, treatment and care; to implement promotion and prevention strategies; to foster research and innovation and strengthen information systems; and to strengthen the public health approach. Ten global targets with measurable indicators will track achievements by 2031. The plan emphasises collaboration between stakeholders in the health sector and beyond, supporting the participation and empowerment of people with neurological disorders, their carers, and their families [2].

The EAN has been at the forefront of this global neurology revolution, promoting awareness and advocacy for neurological issues and brain health. The EAN has championed the Brain Health Mission with the slogan: 'One Brain. One Life. One Mission' to increase understanding and collaboration toward the goals of prevention and burden reduction of neurological disorders and brain health promotion [3]. The EAN adopts the WHO brain health definition: 'a state of brain functioning across cognitive, sensory, socio-emotional behavioural, and motor domains, allowing a person to realise their full potential over the life course, irrespective of the presence or absence of disorders', operationalised as 'a state of optimal cerebral, mental, and social function in a safe, healthy, and supportive environment'. This definition is based on the WHO's five determinants of brain health: physical health, health environment, safety and security, lifelong learning and social connection, and access to quality services [4].

The EAN has established a leadership programme, a forum with the national neurological societies (NNSs), the Brain Health School Challenge, and the Advocacy Training Programme, which has already certified the first class of 'Brain Health Ambassadors', to ensure an understanding of how to make optimal brain health available to the public through all stages of life. It has also established a Task Force on Environmental Influences in Neurology. The EAN actively supports the implementation of WHOiGAP, especially in less developed regions of Europe. Collaboration with the WHO, regional societies, and global and European patient organisations is essential for the EAN to address the universal challenges of the increasing burden of neurological diseases, as highlighted by the Global Burden of Diseases Collaborator Network [5].

In May and November 2023, and in May 2024, the EAN convened all NNS presidents in NNS forums to unite stakeholders representing 44,000 neurologists to face the burden and promote brain health together. The EAN Communication Committee decided to explore how the concept of brain health is understood and whether the 47 countries have any specific national plans, or interactions with politicians and neurological patient associations, which are pillars of developing a national brain health campaign. The EAN aims to support neurologists in advocating for brain health at local and national levels, in coordination with patient organisations, politicians,

and administrators. This survey provides a starting point for planning at European and national levels to create synergistic actions to improve brain health for human development and to promote the so called 'neurology revolution' [6–8]. The outcomes of this survey have also informed the formulation of the EAN's Roadmap for Brain Health, which sets out concrete steps for implementation in the coming years [9].

METHODS

In Spring 2023, the EAN Communication Committee developed a short survey which, following EAN Board approval, was sent to all NNS presidents. The Communication Committee has met every month online since February 2023 to (i) define the aim of the survey; (ii) identify the main topics to be addressed; (iii) formulate questions related to the information needed for the EAN Brain Health Mission (Box 1); and (iv) draft, discuss, and finalise the paper. In May 2023,

Box 1 The EAN National Neurological Societies Brain Health questionnaire

National Neurological Societies Brain Health Questionnaire

- Q1. Does your national neurological society have a communications officer/international delegate?
- Q2 If you are aware of any brain health plans or strategies in your country, please enter the title of the plan or strategy or a link to website with information about the brain plan.
- Q3. If you know about any activities regarding advocacy for neurology in your country, please write a short description or a link to the website with more information.
- Q4. Have you been or are you/the national neurological society in direct connection with the Ministry of Health?
- Q5. On a scale of 1–5, how well do you think the people in your country are aware of what brain health is and the importance of brain health?
- Q6. On a scale of 1–5, how well equipped are neurologists and other medical professionals in your country to understand and promote brain health?
- Q7. What immediate and long-term actions do you think are possible in order to start promoting brain health within your country (following the WHO IGAP targets and the EAN brain health strategy)?
- Q8. Are you aware of/in contact with patient organisations? If yes, please write the name of the patient organisations with whom you are in contact.
- Q9. In case you have any questions or comments, please post them below.

the questionnaire was finalised, and, in June and October 2023, it was sent to all 47 NNS presidents to increase the response rate. Replies were collected until February 2024.

RESULTS

Of the 47 NNSs, 36 responded to the survey, resulting in a response rate of 77%. In terms of communication for each NNS, in nine countries the President was also responsible for communication (not separate roles) (Albania, Bulgaria, Iceland, Latvia, Macedonia, Norway, Poland, Romania, Slovenia). Twenty-one societies had a communications officer or an international delegate, while six NNSs did not have any designated person in charge of communication.

With the exception of two societies, all the other participants in the survey responded that they were aware of one or more neurological patient organisations in their country; among these, only 28 presidents were in contact with one or more of them (Figure 1a). The most frequently cited patient associations were related to multiple sclerosis, followed by Parkinson's disease, epilepsy, headache, and stroke.

Twenty-four presidents were in direct connection with their Ministry of Health in their role as leader of the NNS, while 12 had no contact (Figure 1b).

At the time of the survey, on a scale of 1–5 (zero awareness to full awareness) 19 presidents (19/36; 53%) declared themselves to be fully aware of brain health plans and strategies in their country

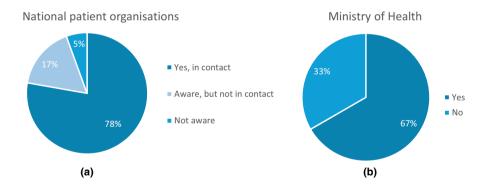
(score 5), while moderate (scores 3–4) and low awareness (scores 1–2) were revealed by 14 (14/36; 39%) and 3 responders (3/36; 8%), respectively. Furthermore, awareness about advocacy activities for neurology in each country was rated to be high (score 5), moderate (scores 3–4) and low (score 1) by 15, 13 and 8 responders, respectively (Figure 2).

The public awareness of the importance of brain health in their countries was rated to be moderate (scores 3–4) and low (score 2) by 23 and 13 responders, respectively (Figure 2). The ability of neurologists and other medical professionals to understand and promote brain health in their country was considered to be excellent (score 5 on a scale of 1–5), moderate (scores 3–4 on a scale of 1–5), and low (scores 1–2 on a scale of 1–5) by 3, 24, and 9 responders, respectively. The responders indicated possible immediate and long-term actions in order to start promoting brain health within their country, as shown in the supplementary materials (available on request).

DISCUSSION

These findings indicate that most NNS presidents are considerably aware of brain health strategies and advocacy activities in their countries. However, direct connections with the Ministry of Health vary, with some lacking such connections. While awareness of local patient organisations is generally high, regular contact is less common, with many presidents in touch with only one or few patient organisations. Most presidents believe public awareness of brain health in their

FIGURE 1 Percentage of national neurological societies in contact with national neurological patient organisations (a) and with the Ministry of Health (b) of their respective countries.



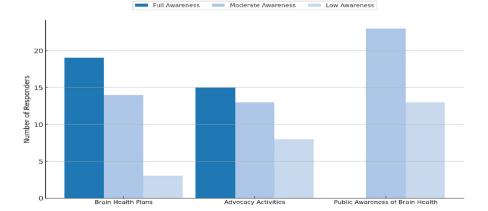


FIGURE 2 Awareness of brain health plans, advocacy activities, and public awareness at a national level.

4 of 5 LEONARDI ET AL.

countries is moderate to low, with neurologists' ability to promote it rated as moderate. There is consensus on the need to promote brain research based also on the recently published EAN strategic research agenda, which highlights important clinically relevant and patient-centred research gaps and priorities [10]. Improving awareness about brain health within the general population is considered relevant by almost all interviewed presidents. Many agreed that organising campaigns on social media and educational events in schools would be a good starting point to create national awareness of brain health.

In response to Question 5 about barriers to or facilitators of brain health plan implementation, some respondents highlighted the need for political stability, a more organised healthcare system, and increased collaboration with national and international institutions such as the EAN and WHO. This work underscores the need to increase brain health awareness in many European countries, as national advocacy and awareness campaigns can significantly enhance health behaviours and lead to tangible improvements [6, 11]. Since 2018, countries such as Norway, Finland, Germany, Italy and Switzerland have launched national brain health plans that have increased national awareness and promoted advocacy, translating public health needs into political action [6, 9].

A significant gap exists between current actions and necessary steps, requiring bold, global, multi-level solutions to foster brain health throughout life, as advocated by the WHO. Our findings highlight the need for increased cooperation between neurological national societies, health ministers, and patient organisations to develop public health strategies. Effective implementation of public health agendas relies on well-defined national action plans and governance structures, as demonstrated in fields such as human immunodeficiency virus/acquired immunodeficiency syndrome, antimicrobial resistance, cancer, and dementia [6]. A dedicated national plan is essential to secure policy commitment and funding [6]. The framework for such national brain action plans is provided in the Roadmap toward Promoting Brain Health in Europe and Closing the Awareness and Funding Gap, currently in process for publication [9].

The 47 European NNSs* are integral components of the 'home of neurology', and EAN connections with them are pivotal. The EAN aims to assist neurologists in enhancing their capacity, reducing the burden of neurological disorders, and advocating for brain health alongside their patients, both locally and nationally. EAN efforts will continue to focus on cooperation with NNSs, political institutions, patient organisations, and all relevant stakeholders to optimise brain health, public health and neurological care in each country.

AUTHOR CONTRIBUTIONS

Matilde Leonardi: Conceptualization; investigation; writing – original draft; writing – review and editing; methodology; supervision. Isabella Colonna: Writing – review and editing; writing – original draft; investigation; formal analysis. David García-Azorín: Writing

- review and editing; writing - original draft; investigation. Daniel Bereczki: Writing - review and editing; writing - original draft; investigation. Benedetta Bodini: Writing - review and editing; writing - original draft; investigation. Noa Bregman: Writing - review and editing; writing - original draft; investigation. Reetta K. Kälviäinen: Investigation; writing - original draft; writing - review and editing. Aida Kondybayeva: Investigation; writing - review and editing; writing - original draft. Viktoria Papp: Investigation; writing - original draft; writing - review and editing. David B. Vodusek: Investigation; writing - original draft; writing - review and editing. Tim von Oertzen: Writing - original draft; investigation; writing - review and editing. Robertina Danova: Methodology; investigation; formal analysis. Michael Crean: Methodology; investigation; writing - review and editing. Raphael Wurm: Writing - original draft; investigation; writing - review and editing. Claudio Bassetti: Writing - review and editing. Thomas Berger: Writing - review and editing. Paul Boon: Writing - review and editing. Ulf Kallweit: Writing - review and editing. Anthony Marson: Writing - review and editing. Elena Moro: Writing - review and editing. Irena Rektorova: Writing - review and editing. Antonio Toscano: Writing - review and editing. Letizia Leocani: Writing - review and editing; supervision; investigation.

AFFILIATIONS

France

¹Neurology, Public Health, Disability Unit and Coma Research Centre, Fondazione IRCCS Istituto Neurologico C. Besta, Milan, Italy ²Complex Operative Unit of Neurology, "F. Ferrari" Hospital, ASL, Lecce, Italy

³Department of Neurology, Hospital Universitario Rio Hortega, Valladolid, Spain

⁴Department of Neurology, Semmelweis University, Budapest, Hungary ⁵Neurology Department, St. Antoine Hospital, APHP, Paris, France ⁶Paris Brain Institute, ICM, CNRS, INSERM, Sorbonne Université, Paris,

⁷Cognitive Neurology Unit, Neurological Institute, Tel Aviv Sourasky Medical Center. Tel Aviv. Israel

⁸Epilepsy Center, Neurocenter, School of Medicine, Institute of Clinical Medicine, Kuopio University Hospital and Faculty of Health Sciences, University of Eastern Finland, Kuopio, Finland

⁹Scientific and Educational Center for Neurology and Applied Neuroscience, Asfendiyarov Kazakh National Medical University, Almaty, Kazakhstan ¹⁰Odense University Hospital, Odense, Denmark

¹¹Division of Neurology, University Medical Centre, Ljubljana, Slovenia

¹²Medical Directorate, University Hospital Würzburg, Würzburg, Germany

¹³European Academy of Neurology, Vienna, Austria

 $^{14} \rm Department$ of Neurology, Medical University of Vienna, Vienna, Austria $^{15} \rm Comprehensive$ Center for Clinical Neurosciences, Medical University of

Vienna, Vienna, Austria

¹⁶Neurology Department, Inselspital, University Hospital, University of Bern, Bern, Switzerland

¹⁷Department of Neurology, 4Brain, Institute for Neuroscience, Reference Center for Refractory Epilepsy, Ghent University Hospital, Ghent, Belgium ¹⁸Centre for Narcolepsy and Hypersomnolence Disorders, Professorship for Narcolepsy and Hypersomnolence Research, Department of Medicine, Witten/Herdecke University, Witten, Germany

¹⁹Centre for Biomedical Education and Research, Witten/Herdecke University, Witten, Germany

²⁰Department of Pharmacology and Therapeutics, University of Liverpool, Liverpool, UK

²¹Department of Psychiatry, Neurology and Neurological Rehabilitation, Grenoble Alpes University Hospital, Grenoble, France

²²Brain and Mind Research, Central European Institute of Technology, Masaryk University, Brno, Czechia

 $^{^{\}ast} From\ end\ of\ May\ 2024$ the neurological societies became 48, with the entrance of Malta in the EAN.

CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

ORCID

Matilde Leonardi https://orcid.org/0000-0003-0552-8923 Isabella Colonna 🕩 https://orcid.org/0000-0001-9390-9341 David Garcia-Azorin https://orcid.org/0000-0002-3132-1064 Daniel Bereczki https://orcid.org/0000-0002-3270-9300 Benedetta Bodini https://orcid.org/0000-0001-8010-1220 Noa Bregman https://orcid.org/0000-0002-8778-798X Reetta K. Kälviäinen 🕩 https://orcid.org/0000-0003-2935-5131 Aida Kondybayeva 🕩 https://orcid.org/0000-0003-2213-0263 Tim von Oertzen https://orcid.org/0000-0003-2164-7842 Raphael Wurm (1) https://orcid.org/0000-0003-3027-7775 Claudio Bassetti https://orcid.org/0000-0002-4535-0245 Thomas Berger https://orcid.org/0000-0002-2062-5193 Paul Boon https://orcid.org/0000-0002-4180-8896 Ulf Kallweit https://orcid.org/0000-0003-1975-6919 Anthony Marson https://orcid.org/0000-0002-6861-8806 Elena Moro https://orcid.org/0000-0002-7968-5908 Irena Rektorova https://orcid.org/0000-0002-5455-4573 Antonio Toscano https://orcid.org/0000-0002-3995-4827 Letizia Leocani https://orcid.org/0000-0001-9326-6753

REFERENCES

World Health Organization. Intersectoral global action plan on epilepsy and other neurological disorders 2022-2031. 2023 https://www.who.int/publications/i/item/9789240076624

- Grisold W, Freedman M, Gouider R, et al. The Intersectoral Global Action Plan (IGAP): a unique opportunity for neurology across the globe. J Neurol Sci. 2023;15(449):120645. doi:10.1016/j. jns.2023.120645
- Bassetti CLA, Endres M, Sander A, et al. The European academy of neurology brain health strategy: one brain, one life, one approach. Eur J Neurol. 2022;29(9):2559-2566. doi:10.1111/ene.15391
- Kolappa K, Seeher K, Dua T. Brain health as a global priority. J Neurol Sci. 2022;439:120326. doi:10.1016/j.jns.2022.120326
- GBD 2021 Nervous System Disorders Collaborators. Global, regional, and national burden of disorders affecting the nervous system, 1990–2021: a systematic analysis for the Global Burden of Disease Study 2021. *Lancet Neurol*. 2024;23(5):e9. doi:10.1016/S1474-4422(24)00038-3
- Winter SF, Walsh D, Catsman-Berrevoets C, et al. National plans and awareness campaigns as priorities for achieving global brain health. *Lancet Glob Health*. 2024;12(4):e697-e706. doi:10.1016/ S2214-109X(23)00598-3
- Owolabi MO, Leonardi M, Bassetti C, et al. Global synergistic actions to improve brain health for human development. *Nat Rev Neurol*. 2023;19(6):371-383. doi:10.1038/s41582-023-00808-z
- Owolabi MO, Leonardi M, Bassetti C, et al. The neurology revolution. Lancet Neurol. 2022;21(11):960-961. doi:10.1016/ S1474-4422(22)00394-5
- Boon PAJM, Berger T, Leonardi M, et al. A roadmap towards promoting and improving brain health in Europe and closing the awareness and funding gap. Eur J Neurol. (in press).
- Boon P, Lescrauwaet E, Aleksovska K, et al. A strategic neurological research agenda for Europe: towards clinically relevant and patient-centered neurological research priorities. Eur J Neurol. 2024;31(3):e16171. doi:10.1111/ene.16171
- Bassetti CLA, Heldner MR, Adorjan K, et al. The Swiss Brain Health Plan 2023–2033. Clin Transl Neurosci. 2023;7(4):38. doi:10.3390/ ctn7040038

How to cite this article: Leonardi M, Colonna I, Garcia-Azorin D, et al. Brain health and national neurological societies: Results of the European Academy of Neurology survey on brain health awareness and areas of implementation for European countries. *Eur J Neurol.* 2024;31:e16516. doi:10.1111/ene.16516

²³First Department of Neurology, St. Anne's University Hospital and Faculty of Medicine, Masaryk University, Brno, Czechia

²⁴ERN-NMD Centre for Neuromuscular Disorders of Messina, Department of Clinical and Experimental Medicine, University of Messina, Messina, Italy ²⁵University Vita-Salute San Raffaele, Milan, Italy

²⁶Experimental Neurophysiology Unit, Institute of Experimental Neurology— INSPE, IRCCS San Raffaele Scientific Institute, Milan, Italy