

See discussions, stats, and author profiles for this publication at: <https://www.researchgate.net/publication/325668207>

Vancouver Declaration on Global Headache Patient Advocacy 2018

Article in *Cephalalgia* · June 2018

DOI: 10.1177/0333102418781644

CITATIONS

9

READS

54

11 authors, including:



David W Dodick

Mayo Foundation for Medical Education and Research

337 PUBLICATIONS 14,224 CITATIONS

[SEE PROFILE](#)



Wolfgang Grisold

Medical University of Vienna

458 PUBLICATIONS 10,200 CITATIONS

[SEE PROFILE](#)



Elena Ruiz de la Torre

EHA European Headache Alliance

32 PUBLICATIONS 831 CITATIONS

[SEE PROFILE](#)

Some of the authors of this publication are also working on these related projects:



Eurolight [View project](#)



Neuropathic pain [View project](#)

Vancouver Declaration on Global Headache Patient Advocacy 2018

Cephalalgia
0(0) 1–11
© International Headache Society 2018
Reprints and permissions:
sagepub.co.uk/journalsPermissions.nav
DOI: 10.1177/0333102418781644
journals.sagepub.com/home/cep



David Dodick¹, Lars Edvinsson², Tomohiko Makino³,
Wolfgang Grisold⁴, Fumihiko Sakai⁵, Rigmor Jensen⁶,
Alan Balch⁷, Elena Ruiz de la Torre⁸,
Deborah Henscheid-Lorenz⁹, Audrey Craven¹⁰ and
Messoud Ashina⁶; on behalf of the International Headache
Society Global Patient Advocacy Coalition

Abstract

Background: Headache disorders comprise the three most prevalent medical disorders globally and contribute almost 20% to the total burden of neurologic illness. Although the experience of a recurrent headache disorder tends to be highly individualized, patient preferences tend to be a low priority in guidelines for the management of patients with headache.

Methods: In September 2017, the first Global Patient Advocacy Summit was convened, bringing together patients, patient advocates, patient advocacy organizations, healthcare professionals, pharmaceutical manufacturers, scientists, and regulatory agencies to advance issues of importance to patients affected by headache worldwide.

Results: Presentations and discussion covered multiple issues, such as improving access to appropriate medical care; incorporating the insights of independent patient advocates and advocacy organizations; leveraging the insights, experience and influence of leading health and neurological organizations; and raising awareness of the role of regulatory agencies in disease advocacy. Attendees agreed that it is important to understand and promote the global, regional, and local interests of people with headache disorders, as well as challenge the pervasive stigma associated with headache. They also agreed that those with severe, recurrent, or disabling headache disorders should have reliable access to competent medical care; healthcare professionals should have access to adequate training in Headache Medicine; global benchmarks should be established for accurate diagnosis and the use of evidence-based treatments in patients with headache; and that information is needed about consultation, diagnosis, and treatment of headache, particularly in regard to patient preferences.

Conclusion: Based on the group's consensus around these issues, a series of statements was developed, and they are collectively presented herein as the Vancouver Declaration on Global Headache Patient Advocacy 2018.

Keywords

Headache patient advocacy, headache disorders, global headache

Date received: 31 March 2018; accepted: 2 April 2018

Introduction

The World Health Organization estimates that the three most prevalent neurologic disorders worldwide are tension-type headache (1.5 billion), migraine (958.8 million), and medication overuse headache (58.5 million) (1). Collectively, these three disorders contribute approximately 17% to the global burden of neurologic diseases, with migraine the second most disabling disease overall (1,2). Cluster headache, often considered the

¹Mayo Clinic, Phoenix, AZ, USA

²University Hospital of Lund, Lund, Sweden

³World Health Organization, Regional Office for the Western Pacific, Manila, Philippines

⁴World Federation of Neurology, London, UK

⁵Saitama International Headache Center, Saitama, Japan

⁶Danish Headache Center, University of Copenhagen, Rigshospitalet, Glostrup, Denmark

⁷Patient Advocate Foundation, Hampton, VA, USA

⁸European Headache Alliance, Brussels, Belgium

⁹American Migraine Foundation, Mount Royal, NJ, USA

¹⁰Migraine Association of Ireland, Dublin, Ireland

Corresponding author:

David W Dodick, Department of Neurology, Mayo Clinic Arizona, 13400 East Shea Boulevard, Scottsdale, AZ 85259, USA.

Email: Dodick.David@mayo.edu

most painful of the primary headache disorders (3–6), is associated with disability in 80% of patients (7), yet patients with this condition often wait several years and consult multiple healthcare professionals before receiving an accurate diagnosis (8,9). There are multiple therapeutic options with proven efficacy for most patients with any of the primary headache disorders, but access to practitioners with training in Headache Medicine is limited, diagnostic accuracy is inconsistent, and the use of evidence-based treatments is suboptimal (8–11).

In clinical practice, the management of chronic diseases such as migraine and cluster headache is challenging because of the highly variable acceptance, adherence, preferences, and response to treatment among patients (12). Moreover, the assessment of outcomes, processes, and other dimensions of care that matter most to patients remains limited (13). Thus, while the patient experience of a recurrent headache condition tends to be highly individualized and dynamic over time (14), evidence-based approaches are impersonal, rely on probabilities that are based on population responses, have static goals that may not align with patient preferences, and may underestimate the value patients place on nonmedical interventions, such as access to patient support groups (12,15). A review of clinical practice guidelines from a variety of disciplines found that less than 5% of the text and references dealt with patient preferences (16); the proportions are similarly low (<5%) in multiple guidelines for the treatment of primary headache disorders (17–23). The lack of prominence given to patient concerns in headache guidelines may help to explain why medical professionals tend to underestimate the high value patients place on nonpharmacologic aspects of therapy, such as answering questions about their condition, educating them about their illness, and teaching them how to treat and prevent attacks (24). What matters most to patients often is missed. The low priority assigned to patient preferences may also contribute to the sizeable proportion (~33%) of patients with headache who report dissatisfaction with treatment (25,26). Despite the limited attention they are given in guidelines, understanding the factors that influence patients' preferences increases the ability to choose appropriate therapy (27), and patients can help to identify and rank outcomes not previously deemed clinically relevant by researchers, clinicians, pharmaceutical manufacturers, and regulatory agencies (12).

In September 2017, as a formal recognition that patient perspectives on stigma, disease awareness, and the management of headache disorders should be obtained directly from patients and their advocates, the first Global Patient Advocacy Summit was convened in Vancouver, Canada. Hosted and organized by the International Headache Society and moderated

by its then-President, David Dodick, the Global Patient Advocacy Summit brought together patient leaders, patient advocacy organizations, leading health, neurological and pain organizations, healthcare professionals, pharmaceutical manufacturers, scientists, and regulatory agency representatives from around the world with the goal of understanding and advancing issues that are important to headache patients. The topics presented and discussed included improving access to appropriate medical care; incorporating the insights of independent patient advocates and advocacy organizations from around the world; leveraging the experience and influence of leading health and neurological organizations; and raising awareness of the role of regulatory agencies in disease advocacy. The main outcomes of the Summit included general agreement that:

- It is important to understand and promote the global, regional, and local interests of people with headache disorders, as well as challenge their pervasive stigma
- All patients affected by headache should have reliable access to competent medical care
- All healthcare professionals should have access to adequate training in Headache Medicine
- A global benchmark should be established to ensure that all patients affected by headache receive an accurate diagnosis and evidence-based treatments
- Information is needed about consultation, diagnosis, treatment of headache, and patient-reported outcomes (e.g. quality of life, satisfaction with treatment).

In addition, it was agreed that the group would develop and promote a series of consensus statements (Table 1) that reflect the priorities of Summit participants and set advocacy goals for the future. These consensus statements, and brief discussions of each, are presented below.

I. A new entity – the International Headache Society Global Patient Advocacy Coalition (IHS-GPAC) – should be formed to understand and promote the global, regional, and local interests of people with recurrent headache disorders

In other disease states, such as stroke (28–30), the establishment and periodic revision of global benchmarks has been helpful in improving the level of care and focusing attention on the priorities of patients. Participants at the Summit agreed to emulate this approach and form a Global Patient Advocacy Coalition (IHS-GPAC) that involves a wide range of

Table 1. Vancouver Declaration 2018 consensus statements and advocacy needs.

	Statement	Key advocacy needs
1	A new entity – the IHS Global Patient Advocacy Coalition (IHS-GPAC) – should be formed to understand and promote the global, regional, and local interests of people with recurrent headache disorders	<ul style="list-style-type: none"> • Form IHS-GPAC Steering Committee • Develop global blueprint • Identify countries for beta programs
2	A major purpose of the IHS-GPAC is to destigmatize headache conditions among policy-makers and the general public, and this goal should be universally promoted in IHS-GPAC programs	<ul style="list-style-type: none"> • Have patients and their families in highly visible leadership positions • Promote research that seeks to understand stigma and informs strategies to mitigate stigma • Identify and support individuals and groups prepared to establish local, regional, and national activist political advocacy organizations
3	Individuals with headache disorders should have access to competent medical care, which involves consultation with a local healthcare provider educated or trained in Headache Medicine who can provide an accurate diagnosis and evidence-based treatment	<ul style="list-style-type: none"> • Expand access to adequately trained primary care providers and specialists, especially through the use of new technology • Educate patients and train healthcare professionals, social and community health workers, healers, and spiritual leaders about appropriate care • Regulate treatments lacking evidence to support their use
4	Training in Headache Medicine should be integrated into all medical school and postgraduate medical education curricula	<ul style="list-style-type: none"> • Conduct a global survey of existing programs • Determine how to adapt for regional and national needs
5	Regional and local partners should work to establish a system for the routine and standardized collection of data pertaining to consultation, diagnosis, and treatment of headache, with emphasis on patient-reported measures of efficacy, disease-specific quality of life, and satisfaction	<ul style="list-style-type: none"> • Identify research partners • Engage patients in shaping research agendas • Identify and link with existing databases • Prepare study protocol

stakeholders, including patient organizations and advocates, national and global health, neurological, pain and headache societies, regulatory agencies, and pharmaceutical manufacturers present at the Summit, as well as Health Technology Assessors and payers. It was proposed that the overall approach for the IHS-GPAC should be to create a centralized strategy that provides the vision and advocacy tools to country affiliates; develop impactful country specific strategies and tactics; measure progress and share best practices; and adapt success stories from global collaborators to local environments and needs. The initial objectives of the IHS-GPAC should be to establish an administrative structure and work to develop a global strategic blueprint for headache advocacy that can be implemented by regional and national partners. Summit participants agreed that IHS-GPAC messaging should be simple and relatable, perhaps drawing inspiration from previously successful advocacy initiatives (e.g. AIDS = rights; breast cancer = women; autism = family).

Initiatives administered under the auspices of the IHS-GPAC should adopt the best practices of advocacy initiatives developed by the American Academy of Neurology, the World Health Organization, the World Federation of Neurology, and the Alliance for Headache Disorders Advocacy, as well as the successful efforts of patient organizations (e.g. Migraine Association of Ireland, European Headache Alliance, American Migraine Foundation) and individual advocates. The organizational and operating strategies of the World Health Organization – in which global efforts are directed at providing normative guidance, regional initiatives focus on the delivery of services and public goods, and supporting countries tailor the guidance and services within the relevant context of respective Member States to create actual changes – may be a useful model. As the World Health Organization is endeavoring whole-of-system, whole-of-government, whole-of-society approaches so as to fit in the new context of the Sustainable Development Goals, engagement of stakeholders is critical, including

partnership with local patient groups that gather and share information, provide day-to-day interaction, and support and serve as “laboratories” for pilot programs and ideas. Whenever possible, work at the regional and national levels should include collaborations with representatives from ministries of health, regulatory agencies, manufacturers, and payers, who should be viewed as partners in promoting patient interests in the policy-making process, in clinical research, and in unsupervised settings.

2. A major purpose of the IHS-GPAC is to destigmatize headache conditions among policymakers and the general public, and this goal should be universally promoted in IHS-GPAC programs

The stigma of headache is directly responsible for needless suffering among patients and caregivers, as well as for the perennial lack of resources that shortchanges headache research and restricts access to optimal care worldwide. Evidence suggests that patients with headache have been stigmatized by healthcare professionals who view them as drug seekers with a nonserious disease; family and friends who fail to appreciate their suffering; educators, employers, and insurers who believe headache should not lead to performance decrements or absence; and policymakers who consistently underfund research into treatments that might benefit them (31). As a result, the IHS-GPAC should work to educate and reassure patients that having a headache condition is not a cause for shame or isolation, but an important connection with others in a similar situation, as well as with a powerful global network of advocates that consistently promotes their long-term interests while meeting their immediate needs by helping them manage their illness successfully. People with recurrent headache disorders, especially those from underserved communities, should feel adequately empowered not only to acknowledge their illness publicly, but also to demand equitable access to the best therapies available. At the same time, policymakers should be consistently reminded that the effects of headache disorders are widespread, profound, and worthy of consistent and meaningful support.

The concept of stigma should be incorporated into IHS-GPAC programming whenever possible, with the understanding that the manifestations, magnitude, and deleterious consequences of stigmatizing attitudes towards individuals with disabling headache disorders may differ markedly between societies. To maximize the chances of success, IHS-GPAC initiatives should have patients and their families in highly visible leadership positions, with the precise roles for healthcare

professionals, regulators, payers, government officials, healthcare technology assessment organizations, professional societies, advocacy organizations, and industry determined by the dynamics of local situations and the goals of individual programs. Further, IHS-GPAC should promote research that seeks to understand and define cultural differences in stigmatization of people with headache disorders, inform strategies that will successfully mitigate stigma, and, ultimately, lead to improved delivery of care. IHS-GPAC must also recognize that structural stigma towards individuals with headache disorders is often manifest in governmental and institutional policies, and in business practices that codify and formalize discrimination, deny appropriate health care, limit research, and restrict opportunities that lead to fulfilling careers and lives. Accordingly, the IHS-GPAC should identify and support individuals and groups prepared to establish local, regional, and national activist political advocacy organizations working to counter structural stigma towards individuals with headache disorders.

3. Individuals with headache disorders should have access to competent medical care, which involves consultation with a local healthcare provider educated or trained in Headache Medicine who can provide an accurate diagnosis and evidence-based treatment

A shortage of neurologists in general, and of specialists in Headache Medicine in particular, is a serious and growing problem in the United States (32), in Europe (33–36), and in the vast majority of developing nations (37,38), leaving many people with primary headache disorders underdiagnosed and receiving suboptimal care (39,40). A survey done by the European Headache Alliance showed that patients affected by headache in France, Germany, Ireland, Italy, Netherlands, Spain, Sweden, and the United Kingdom commonly encounter delays of several years before being correctly diagnosed, confirming other research (8,9), and many remain dissatisfied with the management of their condition, citing poor response to treatment and the difficulty of accessing and communicating with healthcare professionals as the main reasons (41). In the United States, there are more than 80,000 persons with migraine for each headache specialist, and the number of headache specialists certified by the United Council of Neurologic Subspecialties is inadequate to meet patient demand in the United States (32) – a substantial barrier to care that is projected to worsen through 2025 (42). Among 17 countries in sub-Saharan Africa, for example, there is an estimated average of 0.6 neurologists per

million people (38). Migraine and other primary headache disorders are low priority and are under-recognized, and the majority of those with migraine resort to herbal or traditional healers (43).

The global objectives of IHS-GPAC advocacy should be to promote access to adequately trained healthcare providers; early and accurate diagnosis of headache disorders; prescribing of evidence-based acute and preventive treatments; integration of nonpharmacologic therapies (e.g. cognitive, behavioral, and relaxation treatments, as well as complementary, integrative, and traditional medicine); attention to factors, including diet, exercise, and sleep, that influence the health outcomes of various diseases, including headache disorders; and meaningful awareness of patient preferences. Specific recommendations for expanding access to appropriate medical care for people with headache disorders include providing patients and healthcare professionals with more information and education to help them understand the scope of the problem; defining and widely disseminating simple and shared models of care; increasing the availability of specialized headache centers and specialists regardless of geographic, financial, and time barriers to care, particularly through the use of technology (i.e. electronic consultation, secure text messaging, telemedicine) (44); and making awareness and consideration of headache disorders and patients high priority among policymakers (41). Health policy initiatives should be launched and aimed at facilitating integrated service delivery through disease awareness, surveillance, initial and ongoing care, and establishing social support through patient peer-groups that promote health literacy and disease management through mutual learning. In developing nations, it has been suggested that improvements in early headache management at the community level, training and research at the facility level, and healthy lifestyle modification among urban residents may help to reduce the burden of illness and improve productivity in what are often young, thriving populations (45); this may require training social and community health workers, healers, and spiritual leaders, as well as regulating treatments lacking evidence to support their use. While these benchmarks may be aspirational in many parts of the world (even in developed nations with access to specialized care), patient advocates should urge policymakers to adopt and meaningfully work towards achieving them.

4. Training in Headache Medicine should be integrated into all medical school and postgraduate medical education curricula

Headache Medicine electives are rarely offered at medical schools, and academic neurologists with interest in

Headache Medicine spend most of their time in clinic – less than 25% of time is spent conducting research or teaching (46). As a result, medical students receive an average of 1 hour of preclinical and 2 hours of clinical teaching in headache. The extent of preparation is nearly the same for neurology residents; they receive an average of 3 hours of didactic instruction in headache (46). Among professionals working in Headache Medicine, only 1.3% were exposed to a headache center during medical school (32). Since the clinical consequences of suboptimal training – low rates of evidence-based medical care (10,11) – can be substantial, it is understandable that a large majority (82.4%) of those currently working in Headache Medicine strongly agree that there needs to be improved headache education for physicians of all specialties (32). Topics about which the majority of neurology residents feel unprepared and want more extensive training than they currently receive include procedural approaches and practice management (47). Given the frequent overlap in symptoms, the ability to differentiate between primary and secondary headaches and implement a specific and cost-effective diagnostic evaluation for relevant secondary headache disorders, some of which are potentially life-threatening, is of paramount importance in training programs. In addition, training is required in the basic communication and interpersonal skills that allow for patient preferences to surface in the decision-making and care-planning process. Healthcare professionals need to learn the skill set that empowers patients to talk about what matters most to them so they can translate that content into information to facilitate shared decision-making.

Sanctioned educational programs should be developed and offered in partnership with accredited providers, and they should be tailored to the needs of medical students as well as those seeking postgraduate and continuing medical education. Migraine programming should also be aimed at primary care providers, including pediatricians and pharmacists, as migraine alone affects up to 10% of all school-aged children and adolescents, and these healthcare professionals frequently interface with young patients and parents (48,49). Educational curricula should encourage integrated service delivery, including the use of traditional medicine (with appropriate regulation of effectiveness and safety), lifestyle modification, and cognitive, behavioral, and mindfulness-based approaches. In cluster headache, educational programs should target general neurologists, primary care physicians, otorhinolaryngologists, and dentists (9). Content for new programming should complement existing programs, such as those presently offered by the International Headache Society and its country affiliate members, leading neurological organizations, academic headache

programs, and whenever possible take advantage of ascendant platforms (e.g. online, social media, smart phones) (38).

5. Regional and local partners should work to establish a system for the routine and standardized collection of data pertaining to consultation, diagnosis, and treatment of headache, with emphasis on patient-reported measures of efficacy, disease-specific quality of life, and satisfaction

Patient registries – organized systems using observational methods to collect uniform data (clinical and other) about patients with a particular disease or condition for predetermined scientific, clinical, or policy purposes – produce highly valuable evidence-based outcomes and patient-preference data that offer a range of important benefits, mainly because they involve large, heterogeneous study populations that provide “real world” information. Registries have been shown to improve patient care in a range of disease states, including cystic fibrosis, diabetes, heart disease, and cancer (50–53). For headache disorders, by engaging patients

in shaping research agendas and protocols, and linking results with existing databases (e.g. national health insurance and patient health record systems), the resulting analyses can serve as important tools in helping researchers, policymakers, and medical professionals work with patients in the improvement of patient care.

The American Registry for Migraine Research is a state-of-the-art, large-scale, prospective longitudinal study designed to collect real-world data, including biological samples, electronic health records, daily diaries, patient-reported outcomes, diagnostic test results, imaging studies, and patient questionnaires. To heighten global awareness of migraine, better understand patient needs, and drive targeted research, the IHS-GPAC should work with the American Migraine Foundation and International Headache Society to expand the current initiative into an International Registry for Migraine Research. Suggested endpoints for the registry are shown in Table 2. The leadership and steering committees of these and other research initiatives should engage patients at every level.

Patient registries that generate real-world evidence from a variety of sources, including patient-generated data and electronic health records, can complement traditional evidence generation strategies regarding the usage, potential benefits or risks, as well as the

Table 2. Data for collection by the International Registry for Migraine Research.

Consultation	<ul style="list-style-type: none"> • Proportion of total cases presenting with a primary headache disorder (migraine, cluster, tension-type) • Proportion of total cases presenting with secondary headache disorders • Type of healthcare professional initially consulted
Diagnosis	<ul style="list-style-type: none"> • Total patients and total headache diagnoses, with breakdowns by age, sex, and headache type and subtype • Proportion of patients with a family member with recurrent headache • Use of diagnostic classifications and validated diagnostic tools • Current prescription and nonprescription medication usage
Treatment	<ul style="list-style-type: none"> • Proportion of patients receiving evidence-based drug therapy <ul style="list-style-type: none"> • Acute • Preventive • Use of nonpharmacologic approaches and devices
Efficacy	<ul style="list-style-type: none"> • Proportion of patients with relief/freedom from pain and associated symptoms • Proportion of patients with disease progression and remission over time • Change in headache frequency, duration, and severity over time • Change in functional impairment over time
Disease-specific quality of life	<ul style="list-style-type: none"> • Proportion of patients with functional disability • Proportion of patients who are employed (at least part-time) • Proportion of patients who can/cannot perform daily activities at home, school, or work
Satisfaction	<ul style="list-style-type: none"> • Proportion of patients and caregivers satisfied with medical care and outcomes of treatment • Proportion of patients and caregivers satisfied with education, training, and support

comparative effectiveness of various treatment and management approaches. They can facilitate shared decision-making amongst clinicians and patients – an integral component of patient-centered care. Shared decision-making is the process by which patients and clinicians work collaboratively to develop a care plan that is based on the best available evidence, clinical experience that balances anticipated outcomes and potential risks with the preferences, values, and goals of the patient. Shared decision-making builds trust and can enhance patient compliance, adherence, and outcomes.

Conclusion

By bringing together patients, leaders, and diverse stakeholders, the Global Patient Advocacy Summit galvanized the establishment of a global movement in headache advocacy. The formation of the IHS-GPAC and the pursuit of the expressed goals outlined in this Vancouver Declaration establish benchmarks, and will facilitate awareness and policy development toward improvements in the diagnosis and care for those with headache disorders across the globe.

Clinical implications

- The Vancouver Declaration on Global Patient Advocacy establishes the benchmarks, priorities and an advocacy blueprint for the International Headache Society's Global Patient Advocacy Coalition (IHS-GPAC).
- The IHS-GPAC will promote the global, regional, and local interests of people with headache disorders.

Acknowledgement

The International Headache Society would like to thank the sponsors of the Global Patient Advocacy Summit: Amgen, Eli Lilly, Novartis, Allergan, Teva and electroCore.

Declaration of conflicting interests

The authors declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this article: DWD has provided consultation, within the past 5 years, to Acorda, Allergan, Amgen, Alder, Promius, eNeura, Eli Lilly & Company, Insys Therapeutics, Autonomic Technologies, Teva, Xenon, Tonix, Trigemina, Boston Scientific, Nocira, Zosano, Biocentric, Biohaven, Magellan, Theranica, Charleston Laboratories, Supernus, Gore and Electrocore. Royalties: Oxford University Press and Cambridge University Press (book royalty); he receives editorial/honoraria from UpToDate, MedNet LLC, Peer View Institute for Medical Education, Medicom, Chameleon Communications, Medscape, WebMD, Academy for Continued Healthcare Learning, Haymarket Medical Education, Global Scientific Communications, HealthLogix, Miller Medical, Academy for Continued Healthcare Learning, MeetingLogiX, Wiley Blackwell, Medicom; stock/options: Nocira, Epien, Healint, Theranica, and Mobile Health; he has a consulting use agreement with NAS and Myndshft; he has a board position at King-Devick Technologies, Inc. and Epien Inc. LE has given lectures and received unrestricted grants from AMGEN/Novartis and TEVA. RJ has given lectures and conducted trials for ATI, Merck, and Allergan, is a Director in LTB and Trustee in IHS. MA discloses he is a consultant, speaker or scientific advisor for Allergan, Amgen, Alder, ATI, Eli Lilly, Novartis, and Teva, primary investigator for Amgen 20120178 (Phase 2), 20120295 (Phase 2), 20130255 (OLE), 20120297 (Phase 3), Alder ALD403-CLIN-001 (Phase 3), Amgen PAC1 20150308 (Phase 2a), and GM-11 gamma-Core-R trials. The other authors have no conflicting interests.

Funding

The authors received no financial support for the research, authorship, and/or publication of this article.

References

1. Global, regional, and national burden of neurological disorders during 1990–2015: A systematic analysis for the Global Burden of Disease Study 2015. *Lancet Neurol* 2017; 16: 877–897.
2. World Health Organization. Global Health Estimates 2015: disease burden by cause, age, sex, by country and by region, 2000–2015. Geneva, 2016. Available at: http://www.who.int/healthinfo/global_burden_disease/estimates/en/index2.html. (2016, accessed 30 March, 2018).
3. Rozen TD. Cluster headache as the result of secondhand cigarette smoke exposure during childhood. *Headache* 2010; 50: 130–132.
4. Bahra A, May A and Goadsby PJ. Cluster headache: A prospective clinical study with diagnostic implications. *Neurology* 2002; 58: 354–361.
5. Halker R, Vargas B and Dodick DW. Cluster headache: Diagnosis and treatment. *Semin Neurol* 2010; 30: 175–185.
6. Ashkenazi A and Schwedt T. Cluster headache – acute and prophylactic therapy. *Headache* 2011; 51: 272–286.
7. van Kleef M, Lataster A, Narouze S, et al. Evidence-based interventional pain medicine according to clinical diagnoses. 2. Cluster headache. *Pain Pract* 2009; 9: 435–442.
8. Bahra A and Goadsby PJ. Diagnostic delays and mismanagement in cluster headache. *Acta Neurol Scand* 2004; 109: 175–179.
9. Voiticovschi-Iosob C, Allena M, De Cillis I, et al. Diagnostic and therapeutic errors in cluster headache: A hospital-based study. *J Headache Pain* 2014; 15: 56.
10. Lipton RB, Serrano D, Holland S, et al. Barriers to the diagnosis and treatment of migraine: Effects of sex, income, and headache features. *Headache* 2013; 53: 81–92.

11. Dodick DW, Loder EW, Manack Adams A, et al. Assessing barriers to chronic migraine consultation, diagnosis, and treatment: Results from the Chronic Migraine Epidemiology and Outcomes (CaMEO) study. *Headache* 2016; 56: 821–834.
12. Addario BJ, Fadich A, Fox J, et al. Patient value: Perspectives from the advocacy community. *Health Expect* 2018; 21: 57–63.
13. Porter ME, Larsson S and Lee TH. Standardizing patient outcomes measurement. *N Engl J Med* 2016; 374: 504–506.
14. Serrano D, Lipton RB, Scher AI, et al. Fluctuations in episodic and chronic migraine status over the course of 1 year: Implications for diagnosis, treatment and clinical trial design. *J Headache Pain* 2017; 18: 101.
15. Lee YK, Low WY and Ng CJ. Exploring patient values in medical decision making: A qualitative study. *PLoS One* 2013; 8: e80051.
16. Chong CA, Chen IJ, Naglie G, et al. How well do guidelines incorporate evidence on patient preferences? *J Gen Intern Med* 2009; 24: 977–982.
17. Tfelt-Hansen P, Pascual J, Ramadan N, et al. Guidelines for controlled trials of drugs in migraine: Third edition. A guide for investigators. *Cephalalgia* 2012; 32: 6–38.
18. Pringsheim T, Davenport W, Mackie G, et al. Canadian Headache Society guideline for migraine prophylaxis. *Can J Neurol Sci* 2012; 39: S1–S59.
19. Silberstein SD, Holland S, Freitag F, et al. Evidence-based guideline update: Pharmacologic treatment for episodic migraine prevention in adults: Report of the Quality Standards Subcommittee of the American Academy of Neurology and the American Headache Society. *Neurology* 2012; 78: 1337–1345.
20. Lanteri-Minet M, Valade D, Geraud G, et al. Revised French guidelines for the diagnosis and management of migraine in adults and children. *J Headache Pain* 2014; 15: 2.
21. National Institute for Health and Care Excellence. Headaches in over 12s: Diagnosis and management (CG150). Available at: <https://www.nice.org.uk/guidance/cg150>. (published 2012, updated 2015, accessed March 30, 2018).
22. Robbins MS, Starling AJ, Pringsheim TM, et al. Treatment of cluster headache: The American Headache Society evidence-based guidelines. *Headache* 2016; 56: 1093–1106.
23. May A, Leone M, Afra J, et al. EFNS guidelines on the treatment of cluster headache and other trigeminal-autonomic cephalalgias. *Eur J Neurol* 2006; 13: 1066–1077.
24. Lipton RB and Stewart WF. Acute migraine therapy: Do doctors understand what patients with migraine want from therapy? *Headache* 1999; 39: S20–S26.
25. Lipton RB, Buse DC, Serrano D, et al. Examination of unmet treatment needs among persons with episodic migraine: Results of the American Migraine Prevalence and Prevention (AMPP) Study. *Headache* 2013; 53: 1300–1311.
26. Malik SN, Hopkins M, Young WB, et al. Acute migraine treatment: Patterns of use and satisfaction in a clinical population. *Headache* 2006; 46: 773–780.
27. Peres MF, Silberstein S, Moreira F, et al. Patients' preference for migraine preventive therapy. *Headache* 2007; 47: 540–545.
28. Aboderin I and Venables G. Stroke management in Europe. Pan European consensus meeting on stroke management. *J Intern Med* 1996; 240: 173–180.
29. Norrving B. The 2006 Helsingborg Consensus Conference on European Stroke Strategies: Summary of conference proceedings and background to the 2nd Helsingborg Declaration. *Int J Stroke* 2007; 2: 139–143.
30. Kjellstrom T, Norrving B and Shatchkute A. Helsingborg Declaration 2006 on European Stroke Strategies. *Cerebrovasc Dis* 2007; 23: 231–241.
31. Young WB. The stigma of migraine. *Pract Neurol* 2018; February: 23–26.
32. Minen MT, Monteith T, Strauss LD, et al. New investigator and trainee task force survey on the recruitment and retention of headache specialists. *Headache* 2015; 55: 1092–1101.
33. Martelletti P, Haimanot RT, Lainez MJ, et al. The Global Campaign (GC) to Reduce the Burden of Headache Worldwide. The International Team for Specialist Education (ITSE). *J Headache Pain* 2005; 6: 261–263.
34. Martelletti P. Headache medicine: Academic teaching in Europe. The Sapienza University Master's Degree. *Headache* 2007; 47: 1224–1225. (author reply 1225–1227).
35. Jensen R, Mitsikostas DD, Valade D, et al. Guidelines for the organization of headache education in Europe: The headache school II. *J Headache Pain* 2010; 11: 161–165.
36. Martelletti P, Birbeck GL, Katsarava Z, et al. The Global Burden of Disease survey 2010, Lifting The Burden and thinking outside-the-box on headache disorders. *J Headache Pain* 2013; 14: 13.
37. Woldeamanuel YW. Headache in resource-limited settings. *Curr Pain Headache Rep* 2017; 21: 51.
38. Mateen FJ, Clark SJ, Borzello M, et al. Neurology training in sub-Saharan Africa: A survey of people in training from 19 countries. *Ann Neurol* 2016; 79: 871–881.
39. Steiner TJ, Birbeck GL, Jensen R, et al. The Global Campaign, World Health Organization and Lifting The Burden: Collaboration in action. *J Headache Pain* 2011; 12: 273–274.
40. Steiner TJ, Antonaci F, Jensen R, et al. Recommendations for headache service organisation and delivery in Europe. *J Headache Pain* 2011; 12: 419–426.
41. Tassorelli C, Farm I, Kettinen H, et al. Access to care – an unmet need in headache management? *J Headache Pain* 2014; 15: 20.
42. Bradley WG. Neurology in the next two decades: Report of the Workforce Task Force of the American Academy of Neurology. *Neurology* 2000; 54: 787–789.
43. Haimanot RT. Burden of headache in Africa. *J Headache Pain* 2003; 4: S47–S54.
44. Kirsh SR, Ho PM and Aron DC. Providing specialty consultant expertise to primary care: An expanding spectrum of modalities. *Mayo Clin Proc* 2014; 89: 1416–1426.
45. Woldeamanuel YW, Andreou AP and Cowan RP. Prevalence of migraine headache and its weight on neurological burden in Africa: A 43-year systematic review and

- meta-analysis of community-based studies. *J Neurol Sci* 2014; 342: 1–15.
46. Finkel AG. American academic headache specialists in neurology: Practice characteristics and culture. *Cephalalgia* 2004; 24: 522–527.
 47. Jordan JT, Mayans D, Schneider L, et al. Education research: Neurology resident education: Trending skills, confidence, and professional preparation. *Neurology* 2016; 86: e112–e117.
 48. Gibbs TS, Fleischer AB Jr, Feldman SR, et al. Health care utilization in patients with migraine: Demographics and patterns of care in the ambulatory setting. *Headache* 2003; 43: 330–335.
 49. Latinovic R, Gulliford M and Ridsdale L. Headache and migraine in primary care: Consultation, prescription, and referral rates in a large population. *J Neurol Neurosurg Psychiatry* 2006; 77: 385–387.
 50. Pollard C, Bailey KA, Petite T, et al. Electronic patient registries improve diabetes care and clinical outcomes in rural community health centers. *J Rural Health* 2009; 25: 77–84.
 51. Gliklich RE, Dreyer NA and Leavy MB (eds). *Registries for evaluating patient outcomes: A user's guide* (Internet). 3rd edition. Rockville (MD): Agency for Healthcare Research and Quality (US), <http://www.ncbi.nlm.nih.gov/books/NBK208619/> (2014, accessed 30 March 2018).
 52. Adams KF Jr, Fonarow GC, Emerman CL, et al. Characteristics and outcomes of patients hospitalized for heart failure in the United States: Rationale, design, and preliminary observations from the first 100,000 cases in the Acute Decompensated Heart Failure National Registry (ADHERE). *Am Heart J* 2005; 149: 209–216.
 53. National Cancer Institute. National and state cancer registries, <http://epi.grants.cancer.gov/registries.html#nci> (1992, accessed 30 March 2018).

Appendix I. Global Patient Advocacy Summit participants and IHS Global Patient Advocacy Coalition members

Patient organisations/advocates		
Alleanza Cefalalgici	Federica Grossi	Italy
Alliance for Headache Disorders	William Young	USA
	Robert Shapiro	USA
Alliance for Patient Access	David Charles	USA
	Christopher Fink	USA
American Headache and Migraine Association	Jill Dehlin	USA
American Migraine Foundation	Meghan Buzby	USA
	Deborah Henscheid Lorenz	USA
	Rachel Koh	USA
Association Française Contre l'Algie Vasculaire de la Face	Kalina Tyminski	France
European Headache Alliance	Elena Ruiz de la Torre	Spain
	Alison Turner	Belgium
	Olivia Serratosa	Spain
Headache and Migraine Policy Forum	Lindsay Videnieks	USA
Help for Headaches	Brent Lucas	Canada
Migraine Action	Simon Evans	UK
Migraine Association of Ireland	Audrey Craven	Ireland
Migraine Quebec	Louise Houle	Canada
Migraine World Summit	Carl Cincinnato	Australia
	Paula Dumas	USA
National Patient Advocate Foundation	Alan Balch	USA
OUCH UK	Scott Bruce	UK
'Out of my Head' film producers	Jacki Ochs	USA
	Susanna Styron	USA
	Nancy LaPook Diamond	USA

(continued)

Continued.

The Daily Migraine	Lisa Jacobson	USA
ZS Associates	Lisa Bance	Switzerland
Independent	Vicki Passman	USA
	Teri Robert	USA
	Carolin Synshyn	Canada
	Michelle Tracy	USA
Partner societies		
American Headache Society	Andrew Charles	USA
	Linda McGillicuddy	USA
American Academy of Neurology	Angela Babb	USA
	Catherine Rydell	USA
European Academy of Neurology	Stefan Evers	Germany
European Headache Federation	Matthias Linde	Norway
	Antoinette Maassen van den Brink	Netherlands
International Association for the Study of Pain	Allen Finley	Canada
Lifting the Burden	Rigmor Jensen	Denmark
National Headache Foundation	Mary Franklin	USA
World Federation of Neurology	Wolfgang Grisold	Austria
IHS Board members		
President (until September 2017)	David Dodick	USA
President (from September 2017)	Lars Edvinsson	Sweden
Honorary Secretary	Stefan Evers	Germany
Honorary Treasurer	Wendy Thomas	UK
President-elect (from September 2017)	Messoud Ashina	Denmark
	Fayyaz Ahmed	UK
	Anna Ambrosini	Italy
	Werner Becker	Canada
	Rami Burstein	USA
	Rigmor Jensen	Denmark
	Arne May	Germany
	Patricia Pozo-Rosich	Spain
	Allan Purdy	Canada
	Alan Rapoport	USA
	Todd Schwedt	USA
	Mamoru Shibata	Japan
	Gisela Terwindt	Netherlands
IHS Affiliate Member Society representatives		
Argentina	Pablo Schubaroff	Argentina
Brazil	Mario Peres	Brazil
Canada	Elizabeth Leroux	Canada
Czech Republic	David Dolezil	Czech Republic
Estonia	Mark Braschinsky	Estonia
Greece	Dimos Mitsikostas	Greece
India	K Ravishankar	India
Japan	Norihiro Suzuki	Japan
Lithuania	Diana Obelieniene	Lithuania
Portugal	Isabel Luzeiro	Portugal
Serbia	Srdjan Sretenovic	Serbia

(continued)

Continued.

S Korea	Chin-sang Chung	S Korea
Switzerland	Christoph Schankin	Switzerland
Taiwan	Shuu-Jiun Wang	Taiwan
IHS key international contacts		
	Anna Andreou	UK
	Hans-Christoph Diener	Germany
	Alan Finkel	USA
	Peter Goadsby	UK
	Koichi Hirata	Japan
	Anders Hougaard	Denmark
	Aynur Özge	Turkey
	Fumihiko Sakai	Japan
	Toshihiko Shimizu	Japan
	Stephen Silberstein	USA
	Takao Takeshima	Japan
	Cristina Tassorelli	Italy
	Ron van Oosterhout	Netherlands
Regulatory		
European Medicines Agency	Maria Luttgén	Sweden
Health Canada	Fuhu Wang	Canada
US Food and Drug Administration	Heather Fitter	USA
World Health Organisation	Tomohiko Makino	Japan
Industry partners		
Amgen	Andras Fehervary	Switzerland
Eli Lilly	Kay Anderson	USA
Novartis	Stephanie Ribbe	Switzerland