

International Bureau for Epilepsy

member organizations - research activities: a survey by the IBE research task force

The International Bureau for Epilepsy (IBE) was established in 1961 as an organization of laypersons and professionals interested in the medical and non-medical aspects of epilepsy. The IBE offers international support by creating means for worldwide exchange of information and, where possible, by setting standards which provide an international policy focus and identity for all persons with epilepsy.

The IBE Research Task Force was formed in 2011 to advise the IBE, in a consultative role, on epilepsy research pertinent to people with epilepsy. Of specific interest to the IBE was the identification and promotion of research useful to lay epilepsy associations in their efforts to improve the situation for people with epilepsy worldwide, with particular attention to research that would make a difference in the following, as well as additional areas identified by the taskforce: (a) Stigma, and research that could be used to reduce stigma; (b) epidemiology; (c) pregnancy; (d) SUDEP; (e) epilepsy-related or relevant legislation, and further understanding how legislation differs between countries; and (e) issues and problems faced by people with epilepsy with respect to education and schooling.

In accordance with this mission, in 2012 the research taskforce completed an international survey of member organizations. The survey was designed to develop an overview of members' research activities and participation, to map out research that is ongoing within IBE member associations, to identify examples of good practice, and to identify obstacles and barriers to conducting and participating in local and regional research.

Methods

Survey Instrument

A draft survey questionnaire was developed by a committee of the IBE Research Taskforce, and then reviewed and approved by the complete taskforce membership after a period of comment and input. The survey was translated and made available in English.

In addition to general information about the member organization and respondent (including the association name and the name and role of person completing questionnaire), the questionnaire included questions concerning the following topics:

1. The extent to which the organization currently participates in research, including through partnerships or liaison with other organizations, such as medical and educational units or other epilepsy organizations, such as the International League Against Epilepsy (ILAE).
2. Whether the member organization would like to have increased involvement in epilepsy research, and if so, the nature and form of this involvement.
3. New developments or improvements the member organization would you like to see in epilepsy research at a local level.
4. New developments of improvements the member organization would like to see in epilepsy research at an international level.

Procedure

The survey was distributed to 119 IBE member associations, and 36 completed surveys were returned, providing a response rate of 30.25%. Regional response rates varied, as noted in the table below, but responses were received from at least one member in each of the IBE's 7 global regions.

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Table: IBE Member Research Questionnaire: Response Rate and Region

Region	Responses: Number (% of total)
Africa	5 / 19 (26%)
Eastern Mediterranean	1 / 7 (14%)
Europe	20 / 52 (38%)
Latin America	5 / 10 (50%)
North America	1 / 5 (20%)
South East Asia	1 / 9 (11%)
Western Pacific	3 / 17 (18%)

Results

Member Research Involvement

The participating member organizations varied greatly with respect to their size, scope, and focus, and there was considerable diversity in terms of the members' research participation. The organizations included: entirely service-focused entities, with no research involvement or interest; organizations with a service focus that are also participating in, and in some cases funding research; service organizations with a strong research focus with members actively engaged in collaborative research relationships with local or regional medical or educational entities (e.g., medical centers, universities) or international epilepsy associations; and research centers whose primary mission is research.

The majority of the member organizations were either currently actively involved in research or else interested in becoming more involved in research. Twenty-seven of the 36 participating organizations (75%) reported that they are currently participating in research (8 were not, and 1 did not respond). Seventy-five percent of the organizations also indicated that they would like to have more involvement in epilepsy research; with only 4 indicating that they would not (5 did not respond to this question).

Current Member Organization Research

The member organizations were currently engaged in a wide spectrum of research, including clinical, genetic, biomedical, educational, and psychosocial research. A few of the large member organizations described well-developed strategic research plans, ongoing research partnerships, and the ability to provide funding support to research applicants. Some organizations have managed to self-fund projects on specific topics, while others have formed partnerships with universities or other research institutions.

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More frequently, however, the member organizations expressed that increased funding was necessary in order to conduct or fund needed research.

Identified research topics included, among others, research related to treatment, including anti-epilepsy drugs (AEDs); genetics; regional incidence and epidemiological studies; patient management; professional practice and education for epilepsy health professionals; education programs; and many epilepsy-related health and psychosocial research topics, including: employment and legal issues for people with epilepsy, depression and epilepsy, SUDEP, stigma, educational issues, cognition, compliance, self-management, QOL, and public awareness and public education campaigns.

Developments or Improvements in Epilepsy Research at the Local Level

At the local level, the member organizations identified developments, needed improvements, and research topics that they would like to see receiving increased attention. Among the most frequently occurring were: (1) the need for increased funding from national, and less frequently, university sources for epilepsy research, which was identified by approximately 31% of respondents; and (2) the need to have better epidemiological data at the regional or national level, identified by approximately 20%, or 1 in 5 members.

Other commonly identified issues included, where treatment resources are limited, the need for improved access to anti-epilepsy drugs (AED) and access to treatments with less side effects, as well as the need for research on the impact of treatment on quality of life (QOL).

Member organizations also frequently identified the need for increased research on access to organization services and service provision, including research on service design and development, and research exploring the service needs of people with epilepsy and the need for epilepsy-related education programs.

Several organizations identified research related to health professionals, including such topics as the effectiveness of/need for epilepsy nurses, the confidence of general practitioners in treating patients with epilepsy, and continuing epilepsy education for health professionals.

A range of epilepsy-related health and psychosocial issues were identified as requiring additional research attention, including most frequently, employment and legal issues for people with epilepsy, with other topics including depression and epilepsy, SUDEP, stigma, social insertion, cognition, compliance, self-management, QOL, Public awareness, and caregiver burden.

Developments or Improvements in Epilepsy Research at the International Level

In terms of developments or improvements the member organization would like to see in epilepsy research at an international level, there were again several commonly occurring topics.

The most frequently identified, however, was the desire for increased international research collaboration. Some of the specific suggestions under this general topic included the development of multi-center collaborations, international exchanges of research experts, and greater inclusion of developing countries in international research opportunities, and specifically in multi-center research. Along the same lines, several respondents identified the desire to see international research databases or registries established. Specifically identified were the need for an open-access international registry for epilepsy research, an international database of psychosocial research, and international patient registries (e.g., for people with rare forms of epilepsy or specific epilepsy syndromes).

International research funding was also identified by several organizations as an area of needed attention and some organizations expressed the hope that international epilepsy organizations such as IBE and ILAE will increase research funding opportunities, particularly in developing countries.

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Other commonly identified topics in this area included the need for international research related to diagnosis, treatment, and patient management, and increasing access to affordable medication.

Specific epilepsy-related health and psychosocial issues were also identified, including employment and driving laws, and transnational comparative legal evaluations; SUDEP; stigma; QOL; and gender-specific epilepsy research topics, such as epilepsy and pregnancy, and epilepsy in men.

Summary

Several important observations and conclusions relevant to the identification and promotion of research useful to lay epilepsy associations worldwide emerge from this survey.

Internationally, there is significant variability in the degree to which lay epilepsy associations engage in conducting, supporting, and participating in research, however there is almost universal agreement on the importance of research, and many organizations would like to increase their level of participation in research activities. The most frequently identified barrier to increased research participation was funding, and many organizations identified the need for increased funding at the national level.

The survey results suggest that many research topics are of common interest, or are recognized as important internationally. Increased attention to expanded access to research participation and funding opportunities, as well as to research results was consistently identified as a priority. Specifically, the development of multi-center collaborations, international exchanges of research experts, and greater inclusion of developing countries in international research opportunities in multi-center research were identified. Also, the development of international research databases and registries was emphasized.

International epilepsy conferences should actively explore opportunities to increase formal and informal interactions on research. This may include both the inclusion of sessions on conducting research, obtaining research funding, and disseminating research, and the establishment of informal research discussions for interested participants.

There is a need for enhanced access to information on research findings, position statements, and guidelines in formats that are easily understood and universally accessible. Similarly, there is a need for local training to support and encourage organizations and groups that are interested in learning about research.

Finally, the fact that so many organizations identified common themes underscore the importance of universal informational and access mechanisms. For example, much research on social issues is being undertaken at the regional and local level that lacks recognition and calls for expanded opportunities for both coordination and dissemination. In particular, psychosocial research undertaken by local organizations and groups often appears to be unrecognized and lacking a mechanism for dissemination. Lay people often have important research ideas, but don't know how to move the research forward. Mechanisms for international research sharing beyond professional publications is needed, and the benefits of, and need for the development of international research expertise-sharing mechanisms was clearly emphasized.

The IBE and ILAE should explore the opportunity of providing resources to: (1) provide examples of research practices that could be adapted for use locally, (2) provide opportunities for research participation, (3) increase awareness of funding sources and opportunities for collaborative research funding, and (4) identify researchers willing to share research expertise, and (5) disseminate research conducted by regional and local organizations.