

## **How to do research in a patients association: the beginner's guide**

### 1. Why do research?

The main reason for doing a research is to find problems. Even without an answer, the question is sometimes such a good one that it is worth telling others about. Through research, you may summarize your experiences, contribute to knowledge, and share and exchange your findings with other people.

### 2. Organizing your research team

Usually your research team includes:

- A person who is responsible for study design and coordinating the study
- Persons who are responsible for data collection, eg. interviewers
- A librarian who helps for the literature search
- A statistician who is responsible for data management and statistic analysis

The interviewers can be your own staff, or can be hired. The librarian and statistician can be found from the academic institution or university close to you. Also you can invite an academic expert as a consultant of your study, and he will give you a lot of help for the design and other procedures of the study.

### 3. Identification of your resources

Resources for your research may be:

- Knowledge, such as the internet, books, journals, courses at nearby universities or institutes
- Professional researchers, who can be your consultants or collaborators
- Patient members in your association, patients at hospital and institutions, general population, can potentially be your study subjects
- Existing database of the patient registration information.

### 4. Management of funding

A patient association rarely has opportunity to be funded for doing research. Thus, you should know how to begin without funding or limited funding.

The most part of the budget is usually the personnel for the data collection and analysis. The personnel can be flexible based on how much funding you get. Also to

use the in-hand data, (eg. patients' registration information in your association), may help to save the budget. Another way is trying to attach your study to other funded studies, eg. doing an epilepsy knowledge survey with a national health survey.

It's always a big challenge to try various ways to find funding. Every year, IBE supports small projects for the Promising Strategy Program. Each project can receive between US\$1,000 and US\$5,000 in support (see IBE website). Besides, there are other resources of funding you may apply. Checking the internet may help you to find useful information.

## 5. Ethics

Any research involving humans should be approved, monitored and reviewed by an institutional review board (IRB), also known as an independent ethics committee or ethical review board. It can be found in the academic institution or university close to you.

Each study subject should sign the informed consent, for the agreement to participate the study. The format of the informed consent can be obtained from the IRB.

## 6. Types of research method

Primary research, consists of a collection of original primary data. It can be accomplished through various methods, including questionnaires and telephone interviews, or experiments and direct observations. Both qualitative and quantitative issues can be focused on by researchers.

Secondary research, involves the summary, collation and/or synthesis of existing research rather than primary research, where data is collected from, for example, research subjects or experiments. The principal methodology is the systematic review, commonly using meta-analytic statistical technique. Such secondary research uses the primary research of others typically in the form of research publications and reports.

## 7. Study interests and topics

Based on the patient association, you may do research about:

- Description of the characteristics of patients [example article: Widjaja E, et al. Patient and hospital characteristics are associated with cost of hospitalizations in children with epilepsy. *Epilepsy & Behavior* 2013;28:335-342]

- Quality of life [example article: Wu DY, et al. *Quality of life and related factors in Chinese adolescents with active epilepsy. Epilepsy Research* 2010; ]
- Prognosis [example article: Sillanpää M, et al. *SUDEP and other causes of mortality in childhood-onset epilepsy. Epilepsy & Behavior* 2013;28:249-255]
- Psychological: depression, anxiety, stigma [example article: Ghanean H, et al. *Self-perception of stigma in persons with epilepsy in Tehran, Iran. Epilepsy & Behavior* 2013;28:163-167]
- Knowledge and attitude to the disease [example article: Otte WM, et al. *Understanding of and attitudes towards people with epilepsy among community-based rehabilitation volunteers in Guinea-Bissau. Epilepsy & Behavior* 2013;28:196-200]
- Caring [example article: Thompson R, et al. *A qualitative study of carers' and professionals' views on the management of people with intellectual disability and epilepsy: A neglected population. Epilepsy & Behavior* 2013;28:379-385]
- Culture of the disease: name, tradition, etc. [example article: Lim KS, et al. *Name of epilepsy, does it matter? Neurology Asia* 2012; 17:87-91]
- Determine needs and policy making suggestion [example article: Schulz J, et al. *Counseling and social work for persons with epilepsy: Observational study on demand and issues in Hessen, Germany. Epilepsy & Behavior* 2013;28:358-362]

## 8. Literature search

The most used literature search engines are <http://www.google.com>, and <http://www.ncbi.nlm.nih.gov/pubmed/>. You may use your nearby university library to find the full length paper if you cannot see that from those two websites. If you have any questions about the paper, you may contact the corresponding author via the email and telephone which was mentioned at the first page of the paper.

Searching literatures related to your study interest will help you to know:

- What's already known worldwide, your region, your country, or your province
- Design, methods and questionnaires used in previous studies
- Any improvement or new findings will be in your study

## 9. Study designs

- **Cross-sectional study** (also known as prevalence study) forms a method that

involves observation of all of a population, or a representative subset, at one specific point in time. It is a descriptive study, and it can be used to describe some feature of the population, such as prevalence of a certain disease, and characteristics of people with that illness. [example article: *Tonini MC, et al. Primary headache and epilepsy: a multicenter cross-sectional study. Epilepsy Behav. 2012;23:342-347.*]

- **Case-control study** is an observational study of persons with the disease (or another outcome variable) of interest and a suitable control group of persons without the disease (comparison group, reference group). The potential relationship of a suspected risk factor or an attribute to the disease is examined by comparing the diseased and nondiseased subjects with regard to how frequently the factor or attribute is present (or, if quantitative, the levels of the attribute) in each of the groups (diseased and nondiseased). [example article: *Tran DS, et al. Risk factors for epilepsy in rural Lao PDR: a case-control study. Southeast Asian J Trop Med Public Health. 2007;38:537-542.*]

- **Prospective study** (also known as cohort study, follow-up study), is a study that follows over time a group of similar individuals (cohorts) who differ with respect to certain factors under study, to determine how these factors affect rates of a certain outcome. The prospective study is important for research on the etiology of diseases and disorders. This study method is typically ranked higher in the hierarchy of evidence than case-control study and cross-sectional study. [example article: *Berg AT, et al. Early development of intractable epilepsy in children, A prospective study. Neurology 2001;56:1445-1452.*]