NEUROLOGICAL DISEASES & NEUROSCIENCE

Epilepsy Management at Primary Health Level

Protocol for a demonstration project in the People’s Republic of China

Department of Mental Health and Substance Dependence
Noncommunicable Diseases and Mental Health Cluster
World Health Organization
Geneva
GLOBAL CAMPAIGN AGAINST EPILEPSY

EPILEPSY MANAGEMENT AT PRIMARY HEALTH LEVEL

PROTOCOL FOR A DEMONSTRATION PROJECT IN THE PEOPLE’S REPUBLIC OF CHINA

This protocol is for a demonstration project testing the feasibility of diagnosis and treatment of convulsive forms of epilepsy at the primary care level using phenobarbital as the first option. The long-term prospect is to integrate epilepsy management into the existing primary health delivery system of the People’s Republic of China. This project is one of the main activities being carried out by WHO, ILAE and IBE within the framework of the Global Campaign Against Epilepsy.
# TABLE OF CONTENTS

1. INTRODUCTION AND SITUATIONAL ANALYSIS ........................................... 4
2. EXECUTIVE COMMITTEE AND ADVISORY PANEL ..................................... 6
3. ORGANIZATIONAL CONTEXT ................................................................. 6
4. DEFINITIONS .......................................................................................... 8
5. AIMS ....................................................................................................... 8
6. METHODOLOGY ...................................................................................... 9
   6.1 Epidemiological Estimation ................................................................. 9
   6.2 Service Delivery (Intervention Study) .................................................. 10
      6.2.1 Identification of Patients .............................................................. 10
      6.2.2 Treatment of Patients ................................................................. 11
      6.2.3 Outcomes .................................................................................. 13
      6.2.4 Monitoring ................................................................................ 13
      6.2.5 Estimation of number of patients ................................................ 13
   6.3 Educational, Social and Community Intervention ......................... 14
      6.3.1 Education .................................................................................. 14
      6.3.2 Social and Community Intervention ........................................... 15
7. OUTCOME MEASURES .......................................................................... 15
8. REFERENCES .......................................................................................... 17
9. APPENDICES ......................................................................................... 18
1. INTRODUCTION AND SITUATIONAL ANALYSIS

The People’s Republic of China (PRC) is situated in the east of the Asian Continent. It is 9,600,000 km² and is divided into 23 provinces, 7 autonomous regions and 4 municipalities. These divisions contain 335 districts, 2,858 counties, 48,000 towns and 822,000 villages.

According to national records in 1998, China has a population of 1.25 billion of 56 different ethnic groups. The urban population is 379 million (30.4%) and the rural population is 869 million (69.6%). Chinese gross national product (GNP) was 7,955 billion RMB (US$980.2 billion in 1999 with GNP/capita being US$780¹). Urban resident was 5,425 RMB whilst rural resident net income was 2,160 RMB in 1998.

Since the adoption of policies leading to economic reform and opening to the outside world, the primary health care system (the 3-tier rural medicare system: county – town – village) has been further developed in its disease control activities and health campaigns. This system provides comprehensive and sustainable health care to rural and semi-rural populations and covers the great majority of the population.

In mainland China there are 15,000 hospitals at the county level and above, and about 50,000 town hospitals (which play an important part in the 3-tier rural Medicare system). Professional health workers (including Western and Chinese physicians) amount to 2 million people, averaging 1.6 per 1000 population. The Medicare service system is currently undergoing reforms with the result that health service coverage is expanding. This is part of the Chinese Government’s great efforts in attaining the strategic goal of “health for all”.

Epilepsy is one of the common neurological disorders and affects millions of people around the world with no age, racial, social class, national or geographic boundaries. It causes increased physical and psychosocial morbidity and it imposes a large economic burden on health care systems. Epilepsy constitutes a major public health problem in both developed and developing countries, but this is particularly the case in the latter countries where the majority of people with epilepsy live²,⁵.

A number of epidemiological surveys of the prevalence and incidence of epilepsy have been carried out in PRC. These surveys have suggested that the prevalence of epilepsy is between 3.0-5.0/1,000 people and a figure of 4.4.1000 is often quoted⁶. The incidence of epilepsy has been estimated to be approximately 30-40/100,000⁶. These studies suggest that the great majority of patients with epilepsy in the country suffer from convulsive forms of epilepsy. Based on these figures it is estimated that in PRC alone at least 5 million people suffer from epilepsy and its effects. Every year a further 400,000 people will become sufferers of epilepsy for the first time. However, it is also estimated that 40-50% of people with epilepsy in the PRC, particularly in rural areas, do not receive appropriate treatment. One of the reasons for this is the lack of trained health workers in the management of epilepsy in the 3-tier rural medicare system.
One of the greatest problems people with epilepsy face is the stigma placed upon them by the community at large. Studies in PRC suggest that people with epilepsy are generally withdrawn from society, feel isolated and are either overprotected or neglected. The attitudes toward sufferers of epilepsy are often negative and most people would object to their children marrying or even playing with a person with epilepsy. About half of the population believes that people with epilepsy should not be employed. Some of these negative attitudes may arise from the fact that epilepsy is not seen as a "normal" medical disease but a mental disorder, some even equating it to insanity.7

Most cases of epilepsy can be treated successfully. With appropriate treatment 70-80% of people with epilepsy can lead normal and productive lives. Unlike acute medical conditions, treatment is a long term prospect and requires zealous adherence to prescribed regimens by the patients. Abrupt withdrawal of medication or the irregular use of antiepileptic drugs (AEDs) is often associated with serious consequences. Appropriate counselling and education of patients is, therefore, an important part of the management of the condition.

The World Health Organization (WHO) has suggested that it would be appropriate to manage medical conditions requiring a low technological approach at a primary health care level. This includes the management of convulsive forms of epilepsy. Convulsions are usually relatively easy to diagnose and the majority of people will respond to simple treatment schedules with drugs in the WHO’s List of Essential Drugs.

Phenobarbital, a drug in the WHO’s List of Essential Drugs, is the mainstay of treatment for epilepsy, particularly in the developing countries. This is a result of its wide-spectrum of action, cost, availability and reliability. In PRC, phenobarbital is widely available and its use is considered to be safe and practical. The Ministry of Health of PRC and the Chinese neurological community consider this drug to be the realistic first option of treatment for epilepsy in rural areas of the country.

This protocol is for a demonstration project testing the feasibility of diagnosing and treating convulsive forms of epilepsy at the primary care level using phenobarbital as the first option. The long-term prospect is to integrate epilepsy management into the existing primary health delivery system in rural and semi-rural areas of PRC in a sustainable manner. If this project is shown to be effective it will be recommended for implementation nation-wide.

This demonstration project will be carried out under the auspices of the WHO’s collaborative programme Global Campaign Against Epilepsy (“Out of the shadows”)9,10. The work will be executed by a team of the Beijing Neurosurgical Institute headed by Professor Wu Jianzhong and Professor Wang Wenzhi and will be supported by a local team in each of the counties involved. A local coordinator will be appointed in each of the counties. This project will be supported by the Ministry of Health of the PRC through the Department for International Co-operation and the Division of Non-Communicable Diseases of the Department of Diseases Control. Local support will be provided by local universities and by the local Public’s Health Bureau's.
2. EXECUTIVE COMMITTEE AND ADVISORY PANEL

An Executive Committee will be established at the Beijing Neurosurgical Institute and will be integrated by Professors Wu Jianzhong and Wang Wenzhi. The members include each local co-ordinator and leader of Public’s Health Bureau's. The members of the Executive Committee and local personnel are listed in Appendix 1.

An advisory panel has also been constituted and it consists of a representative of WHO, a representative of the Global Campaign Against Epilepsy, a representative of the local WHO office, members of the Executive Committee, the local co-ordinators, a member appointed by the local Public Health Bureau from each of the counties involved, a representative of the Neurological Society of China, a representative of the Beijing Anti-Epilepsy Association and representatives from the Ministry of Health. (Please see Appendix 2).

3. ORGANIZATIONAL CONTEXT

This demonstration project is an important part of the Global Campaign Against Epilepsy, which was launched in 1997 with awareness-raising activities. Dr. L. Prilipko and Dr. J.W.A.S. Sander are the Regional Facilitators of this project on behalf of the Global Campaign’s Secretariat will also act as supervisors/monitors of the project. The Department of Diseases Control and the Department of International Co-operation of Ministry of Health, PRC are responsible for the demonstration project and have delegated to the Beijing Neurosurgical Institute the tasks of ensuring concerted action.

This project will be carried out in Mulin and Dongning counties of Heilongjiang Province, Wuzhong and Qingtongxia counties of Ningxia Province, Wuzhi county of Henan Province, Zezhou county of Shanxi Province, and Hanjiang county of Jiangsu Province. The setting of the demonstration project will be the primary health care level as managed by local Public Health Bureau's. The responsibility for the activities at the local level will rest with the local neurologists of a medical university or general hospital and local Public Health Bureau's (see Fig.1).

The initial epidemiological exercise aimed at estimating the prevalence of active epilepsy and the treatment gap amongst the patients identified will be carried out in 5 counties rural areas each with a population of about 10,000 people (total population: 50,000).

The main project (Service Delivery and Educational, Social and Community Intervention) will be carried out in 7 counties of 5 provinces each with a population of 500,000 to 600,000 people living in rural or semi-rural areas over a four-year period. Therefore, the project will cover a population of 2.5-3 million. These counties are located in 5 distinct provinces and are thought to be representative of the country as a whole. Most of the people in these areas are subsistence farmers and the great majority have a low level of education. The selection of these localities was based on personal contacts and because of local willingness to participate in the project.
Each country already has primary health care facilities in place. Each of the counties has about 20 primary health care hospitals (town hospital) and it is estimated that the 7 counties have a total of 116 town hospitals. Each town has about 20-25 villages. Most villages have a clinic with 1-2 village doctors. The village doctor has an average list size of about 1,000 people. On average, a team of two town hospital doctors (senior primary health care physicians – rural doctor) supervises the work of every 20-25 village doctors. All the people in the study areas are covered by the primary health care system and this is the only modality of formal health delivery in the study areas. The town hospitals will be responsible for the management of patients with epilepsy and social intervention and education.
4. DEFINITIONS

For the purpose of this project the following definitions will be used:

**Active Epilepsy:** Someone who has suffered 2 or more unprovoked convulsive seizures in the 12 months immediately preceding identification by study officials.

**Unprovoked Seizure:** Epileptic seizures not associated with a clear precipitant or triggering factor (such as: drugs, fever, acute head injury, acute cerebro-vascular accident, acute metabolic imbalance).

**Convulsive Epilepsy:** Primary or secondarily generalised tonic clonic convulsions, with or without other seizure types.

**Untreated Epilepsy:** Any patient with active epilepsy who has not received regular antiepileptic drug treatment in the week preceding identification by study officials.

**Appropriate Treatment:** Appropriate treatment of active epilepsy would include diagnosis and treatment of underlying causes, as well as treatment of recurrent seizures according to international standards, using anti-epilepsy drugs and surgery where feasible.

**Treatment Gap:** The difference between the number of people with active epilepsy and the number whose seizures are being appropriately treated in a given population at a given point in time, expressed as a percentage.

5. AIMS

**Overall Aims:**
1. To generate procedures that will improve the identification and management of people with convulsive forms of epilepsy in rural and semi-rural areas of the country within the existing primary health care system and with community participation.

2. To develop a model of epilepsy treatment at primary health level that can be applied nation-wide.

**Specific Aims:**
1. To assess current management practices (identification, treatment, and follow-up) of patients with convulsive forms of epilepsy cases in rural and semi-rural areas of the country.

2. To estimate: a) the prevalence of active forms of convulsive epilepsy, b) the scale of the treatment gap via an active case finding methodology, and c) changes the project may bring to these figures in the study area.

3. To ascertain the knowledge, attitudes and practice of epilepsy amongst health practitioners at the primary health level prior to the study and after they have undergone training for epilepsy.

4. To develop technical norms for the identification, education, treatment and follow-up of patients with epilepsy at a primary health care level.

5. To carry out a feasibility study of the treatment of convulsive forms of epilepsy using phenobarbital by primary health care doctors.
6. To develop a programme for continuous professional education on epilepsy for primary health

7. To promote public awareness about epilepsy via an educational programme aimed at the community.

8. To develop local advocacy and support groups for people with epilepsy.

9. To reduce the economic and social burden of epilepsy in the study areas.

6. METHODOLOGY

This demonstration project is composed of three parts:

1. **Epidemiological Estimation** – this will provide a realistic estimation of the prevalence of untreated active epilepsy in the study areas.

2. **Service Delivery (Intervention Study)** – this will cover the issues of diagnosis, phenobarbital treatment, follow-up referral networks.

3. **Educational, Social and Community Intervention** – this will cover the educational and social aspects of the project.

**Duration of the Project**

This project will last 5 years. During the first year, the following activities will be carried out:

- Preparation of training modules
- Design of instruments, including the screening questionnaire
- Compose training material and work menu
- Validation of screening questionnaire
- Door to door survey
- Training of trainers
- Training of all rural physicians and a number of village doctors
- End of first year assessment

During the next four years patients will be recruited into the intervention study. As the study will finish after 5 years and the final assessment of the patient is carried out 12 months after maintenance dose has been reached, the last patient will be recruited into the study by the end of the third quarter of the fourth year. In view of the effect of the pool of prevalent cases most patients will be recruited over the first year of the study.

6.1 Epidemiological Estimation

The epidemiological exercise aims to estimate the prevalence of active epilepsy and the treatment gap. The door-to-door survey will be carried out in 5 representative counties each with a population of about 10,000 people (total population: 50,000).
A door-to-door screening questionnaire will be carried out in each of the selected areas (see Appendix 3). The screening questionnaire will be designed to identify cases of epilepsy and pay special attention to convulsive seizures. The screening questionnaire will then be validated at the Beijing Neurological Institute for specificity and sensitivity. The validation process will involve the application of the questionnaire to a sample of patients known to have epilepsy and to a group of healthy controls. The questionnaire will be based on the WHO screening questionnaire previously used in China and on the ICBERG screening instrument\textsuperscript{11}. Adjustments to the questionnaire will be made according to the results of the validation. In order to estimate the prevalence of active epilepsy and the treatment gap, definite and possible patients with epilepsy will be asked how many seizures they have had in the last one, two and five years and whether they received any treatment.

All participants will be trained to use the validated screening questionnaire and will have mastered the standard before survey. Participants using the validated screening questionnaire will carry out door-to-door survey. The survey will be repeated using a similar methodology and instruments at the end of a five-year period to ascertain if there has been a measurable change in the treatment gap in the areas surveyed.

6.2 Service Delivery (Intervention Study)

6.2.1 Identification of Patients

The target population will be patients with untreated convulsive epilepsy who fulfil the entry criteria and live in one of the five study areas. A variety of case-finding methods may be used. Identification of patients will be primarily carried out by senior primary health care physicians or rural doctors and by consulting diagnostic indexes that may exist at the local health system. Each village doctor usually knows each resident’s health condition and family situation and this will help identification of patients. Patients will be encouraged to self-report and key-informants may be used.

The village doctor will apply a diagnostic questionnaire (see Appendix 4) to those patients preliminary identified as possible cases of convulsive epilepsy. Senior primary health care physicians will then confirm the diagnostic. All senior primary health care physicians and a number of the village doctors in the study area will receive compulsory training in epilepsy and a continuous educational programme in epilepsy will be initiated. The local neurologists (acting as supervising doctor) will be responsible for checking the patients selected.

The average list size of each village doctor is about 1,000 people and estimating that the prevalence for convulsive epilepsy is about 2-4/1,000, then each doctor may have up to 2-4 patients with convulsive forms of epilepsy under their care. A team of two senior primary health care physicians based at town hospital supervises the work of about 20-25 village doctors and therefore, each team will have up to about 50-100 patients with epilepsy under their care. Each local neurologist of a medical university or general hospital and local Public Health Bureau will be responsible for this aspect of the project.
The diagnostic criteria for convulsive seizures are as follows:

1. Lost consciousness
2. Rigidity
3. Generalised tonic clonic movements
4. Incontinence of urine and/or faeces
5. Tongue bitten or injury sustained in falling
6. Post-ictal fatigue, drowsiness, headache or muscles aches.

The patients must experience two of the first 3 criteria above and one of the last 3 criteria for the diagnosis to be of a definite convulsion. The village doctor will be encouraged to discuss those cases where there is diagnostic uncertainty with the senior physician. Senior primary health care physicians and local neurologists should make the conclusive diagnosis and provide the treatment for patients.

Patients for whom the diagnosis of convulsive epilepsy is confirmed and who are not receiving regular antiepileptic drug treatment will be considered for inclusion into the study.

The following inclusion and exclusion apply:

1. Inclusion criteria:
   ← Patients with at least 2 convulsive in the previous 12 months. The patient may have other seizure types in addition to the convulsive seizures.
   ↑ Patient or guardian able and willing to give informed consent to participate in the study.

2. Exclusion criteria:
   ← Seizures occurring only during pregnancy.
   ↑ Seizures associated only to alcohol and/or drug withdrawal.
   → Children younger than two years of age at the time of the study.
   ↓ History of hyperkinetic syndrome.
   ° Presence of a progressive neurological condition.
   ± Patients with heart liver or kidney diseases, or severe hypertension (diastolic pressure >110 mmHg; systolic pressure >180 mmHg)
   ″ History of status epilepticus only.
   ≥ Patient already on adequate medical treatment.
   × Patient with active psychiatric condition.

Patient who fulfil the above criteria and are willing to participate will be entered into the study. Patients with other medical conditions or who have active epilepsy but do not fulfil the above criteria should be referred for appropriate treatment.

6.2.2 Treatment of Patients

Patients who qualify for entry into the study will then receive treatment with phenobarbital according to the technical norms set out in Appendix 5. The town hospital physicians will complete a study entry form at this point (see Appendix 6).
Demographic details, and a pragmatic retrospective estimation of the numbers of seizures, particularly convulsions, that the patient has experienced in the previous, week, month and year will be recorded. A record of the current occupation status of the patient (work and school) will be made. If the patient is employed or attends school, an estimation from work or school due to epilepsy will be made and recorded.

The senior primary health care physicians and village doctor will explain to the patient the importance of regular compliance with the medication and how it should be used. The patient will be told about common side-effects of the drug and advised to report to the doctor any untoward effect that they may experience once treatment is started. The patient will be given contact information for the primary health care team and also instructed on the importance of follow up visits.

Patients included in the study will be invited to attend the town hospital or village clinic every two weeks for the first two months and monthly thereafter, for dose adjustments, side-effects assessment, compliance checking and to receive further supply of the medication. The doctor will fill a follow-up form (see appendix 7) for each visit. Seizure numbers, side effects and effects of treatment will be recorded. If the patient reports the presence of side effects, the senior primary health care physicians will deal according to instructions in the technical norms of Appendix 8. In case of doubts, or if the side-effects are severe or persistent, the patient should be referred to the local neurologist.

It is also important to assess compliance at every follow-up appointment. Compliance will be assessed according to instructions in Appendix 9. The patients or his/her parents will record their seizures, the medicine taken, any effects of treatment and other problems. Those patients working or at school will be questioned about their attendance record from the previous visit and any changes of occupational status will be recorded (see Appendix 10).

The village doctor may also at any time request a review by the senior physician if severe side-effects develop, or in the case of clinical uncertainty or if the patient’s seizure control difficult. The patient will be reviewed at least once every three months by the local neurologist in charge of the case.

Patients may be withdrawn from the study if one or more of the following situation arises:
1. The treatment is found not to be effective by the supervising doctor.
2. The patient experiences an important deterioration in seizure control (i.e. an increase of 50% or more of seizures or status epilepticus).
3. Patient or guardian decides against continuing treatment.
4. The patient is found to be non-complaint with the treatment in 3 consecutive opportunities.
5. The patient fails to attend 3 follow-up appointments.
6. The patient is found to have a progressive neurological disorder.
7. The patient develops a heart, liver or kidney condition.
8. The patient develops severe side-effects to phenobarbital, confirmed by the supervising doctor.

If a patient withdraws from the study, a termination form will be filled recording the reasons for the drop out. The patient will receive alternative or further treatment or will be referred to another level of care, according to clinical needs.
6.2.3 Outcomes

The study will last for 12 months after the maintenance dose for a given patient has been reached. At the end of this 12 months, an objective assessment and two subjective assessments will be carried out to determine the effectiveness of treatment.

1. Objective assessment: According to the number of the seizures reduced in the previous 12 months when compared to seizure in the 12 months prior to the study. It will be divided into three levels:
   (A) Excellent: The patient became seizure-free during the last six months of follow-up or had > 75% reduction in the number of seizures.
   (B) Effective: Seizures reduced by 50-75%.
   (C) No effect: Seizures reduced by < 50%.
2. Doctors assessment: The physician and village doctor will rate, in their opinion, whether overall the patient is better, the same or worse when compared to the 12 months previous to the study.
3. Patients or Guardians assessment: The patients or guardians will also be asked if in their opinion they are better, the same or worse during the study period when compared to the period before the study.

A completion form will be filled-in by the senior physician and these assessment recorded (see Appendix 11).

Patients who complete the study successfully will continue to receive treatment and will be followed up in the usual clinical set up.

6.2.4 Monitoring

In order to ensure the quality of the project, a framework for monitoring the project has been devised. The members of Executive Committee will monitor the project’s progress and they will check each study area every 6 months. The local members of the Executive Committee will monitor the local study every 3 months. This monitoring will be to check compliance of the sites with the study protocol and to elucidate any doubts that may arise. The Executive Committee will meet to discuss its findings and report these to WHO and the Ministry of Health of PRC at the end of the year.

6.2.5 Estimation of the number of patients

These estimations are provisional and are based on current available epidemiological data. These estimations will be reviewed in the light of the results of the epidemiological estimation phase.

The project will be carried out in 5 local areas. Each of these areas will have a population of around 500,000 people. Each area is served by 15-30 town hospitals and it is estimated that the total number of clinics is around 116 town hospitals. The estimated number of people with epilepsy in each of these areas is about 2,200 using a lifetime-prevalence figure of 4.4/1,000. The total estimated number of cases in the 5 sites will, therefore, be 11,000 people. Of these 8,800 (about 80%) will have convulsive forms of epilepsy, of whom about 50% will probably not be receiving treatment (4,400 patients). In addition, as the project will be recruiting patients over a 4-year period, new cases will arise and this is estimated to be a further 875 patients a year (875 x 4 year = 3,500 patients) if the incidence rate of 35/100,000 is applied. Of these, about 80% will have convulsions (700 x 4 years = 2,800 patients)
Each of the 116 clinics will have to treat about 35 patients from the prevalent pool at the onset of the study. In addition, 5 to 6 new patients (2,800 patients/4 years/116 clinics) will come forward for treatment every year. In each county, therefore at the end of the study up to 600 patients will have been treated. The total number of patients expected to be treated at the end of the project will, therefore, be 7200 patients.

6.3 Educational, Social and Community Intervention

6.3.1 Education

(i) Physicians and Village Doctors

All physicians and a number of the village doctors in each of the study areas will receive basic epilepsy training. This will be provided by the team of the Beijing Neurosurgical Institute and by the local neurologists who will collaborate with the study. The training module will cover the following aspects:

- Epidemiology of epilepsy
- Public health aspects of epilepsy
- The causes of epilepsy
- The differential diagnosis of epilepsy
- The diagnosis of epilepsy and particularly of generalised tonic clonic convulsions
- The drug treatment of epilepsy
- The management of epilepsy
- The nature of the study and how to fill-in the study forms

Each of the doctors attending this project in training will receive a work plan.

All doctors prior to the first training will complete a questionnaire to ascertain their knowledge, attitudes and practice (KAP) in relation to epilepsy. To assess the effectiveness of the training module, all participants will be asked to complete the same questionnaire between 3 and 6 months later. A Chinese version of the KAP questionnaire that was developed by the Pan American Health Organisation (PAHO) will be used (see Appendix 12).

(ii) Patients and Families

An educational programme will be directed at patients and their families. It is aimed at informing them about:

- The nature of epilepsy, its characteristics, cause and prognosis.
- The nature of treatment, its objectives, the use of drugs, the importance of compliance, the potential side effects of drugs, and the duration of treatment.
- General health measures and the emergency treatment of seizures.

The content of this programme will be prepared by the team at the Beijing Neurological Institute and by the Beijing Epilepsy Association. Information sheets will be handed to the patients and their families. It is envisaged that a number of the local physicians and neurologists will lecture patients and families on a regular basis.
6.3.2 Social and Community Intervention

(i) Community Education

An educational programme aimed at decreasing the amount of social stigma, in areas of social relations, employment, leisure activities, schooling, etc. will be developed. This will be aimed at local primary and secondary school teachers because they exercise an important role in their communities. The aim of this programme would be to address attitudes regarding aetiology, shame and the lack of infectiousness of epilepsy. A revised version of the instrument used in a survey of public awareness, understanding and attitudes toward epilepsy in Henan province will be applied to the teachers before and after the educational programme to assess changes (see Appendix 13).

The following activities will also be carried out in communities:

- Informing people about epilepsy through public-address systems.
- Distribution of materials on epilepsy.
- Putting up posters.

(ii) Developing Local Advocacy/Support Groups

The advocacy/support groups will be composed of local Public Health Bureau officers, doctors of town and village and patients.

7. OUTCOME MEASURES

A number of evaluations will be carried out to measure the effectiveness of this project. The outcomes to measure the project’s effectiveness have been taken from a Global Campaign Report on the Burden of Epilepsy (see Appendix 14).

1. The overall effectiveness of the project in reducing the treatment gap in these region will be determined by the two epidemiological estimations of the gap that will be carried at the onset of the study and 5 years later by measuring changes in the number of untreated patients between the two estimation points.

2. The effectiveness of the management of people with epilepsy at primary health care level will be determined by:

- The clinical efficacy of the intervention (number of patients seizure free and with significant improvement in seizures).
- Safety and tolerability of treatment (number of people who drop-out due to side effects).
- Social changes observed in patients and community.

3. The effectiveness of the training module to induce changes in knowledge, attitudes and practice amongst health professional will be measured by:

- Changes in the information recorded in KAP questionnaires prior to training and 3-6 months later.
- Changes in the number of patients identified and treated by the trainees.
4. The effectiveness of the programme to reduce the social and economic burden will be measured by:

- The numbers of patients that return to gainful work or start work for the first time.
- Changes in the attendance record of those at work and school.
8. REFERENCES


9. **APPENDICES**

Appendix 1- Executive committee and local members

Appendix 2- Advisory Panel

Appendix 3- Screening questionnaire for epidemiology of epilepsy

Appendix 4- Screening and diagnostic for convulsive epilepsy

Appendix 5- Phenobarbital treatment schedules

Appendix 6- Patient entry form

Appendix 7- Follow-up form

Appendix 8- Side effects and management of phenobarbital treatment

Appendix 9- Compliance of the patient

Appendix 10- Seizure diary and compliance form

Appendix 11- Completion form

Appendix 12- Survey of knowledge, attitudes and practices of epilepsy for primary health care personnel

Appendix 13- Survey of public awareness, understanding and attitudes towards epilepsy

Appendix 14- Outcome Measures
Executive Committee and Local Members

Executive Committee
Wang Wenzhi: Head of Department of Neuroepidemiology, Beijing Institute
Wu Jianzhong: Prof. of Beijing Neurosurgical Institute and Secretary of Beijing Anti-epilepsy Association
Wang Desheng: Prof. of Department of Neurology, Heilongjiang Haerbin Medical University
Dai Xiuying: Prof. of Department of Neurology, Ningxia Medical College
Li Jianzhang: Prof. of Department of Neurology, Henan Medical University
Li Kuntun: Prof. of Department of Neurology, Shanxi Changzhi Medical College
Li Zuohan: Prof. of Department of Neurology, Jiangsu Nanjing Medical University

Local members

Heilongjiang Province
Wang Desheng: Prof. Department of Neurology, Haerbin Medical University (in charge of Heilongjiang Province)
Huang Rihe: Director of Mulin Public Health Bureau
Wen Guangzhu: Director of Mulin Hospital
Ma Guangyu: Director of Moudanjiang Hospital
Lv Weichang: Director of Dongning Public Health Bureau
Yu Xianlong: Dongning First Hospital

Ningxia Province
Dai Xiuying: Prof. Department of Neurology, Affiliated Hospital of Ningxia Medical College (in charge of Ningxia Province)
Kong Fanyuan: Affiliated Hospital of Ningxia Medical College
Chen Guisheng: Affiliated Hospital of Ningxia Medical College
Li Chengai: Director of Wuzhong Public Health Bureau
Zhao Xinning: Wuzhong Litong Hospital
Liu Jingguo: Director of Qingtongxia Public Health Bureau
Hua Hongju: Qingtongxia Xiaoba Hospital
Zhi Xiuxuan: Affiliated Hospital of Ningxia Medical College
Xu Zhaoli: Ningxia Medical School

Henan Province
Li Jianzhang: Prof. Department of Neurology, Second Affiliated Hospital of Henan Medical University (in charge of Henan Province)
Yao Shufen: Second Affiliated Hospital of Henan Medical University
Yang Bin: Department of Neurology, Jiaozuo Hospital
Qin Dongxiang: Department of Neurology, Jiaozuo Hospital
Wang Ligui: vice Director of Wuzhi Public Health Bureau
Yang Genglin: Wuzhi Public Health Bureau
Appendix 1 (cont.)

Shanxi Province
Wang Taiping: Department of Neurology, Zezhou Hospital (in charge of Shanxi Province)
Xu Zhigang: Director of Zezhou Hospital
Song Peilin: Director of Zezhou Public Health Bureau
Sun Yunping: Zezhou Hospital
Li Fenxia: Zezhou Hospital
Wei Junxiu: Zezhou Hospital
Wang Liqin: Zezhou Hospital
Li Kuntun: Prof. Department of Neurology, Changzhi Medical College

Jiangsu Province
Li Zuohan: Prof. Department of Neurology, Brain Hospital of Nanjing Medical University (in charge of Jiangsu Province)
Zhao Xuexu: Brain Hospital of Nanjing Medical University
Yuan Chenglin: Department of Neurology, Subei People Hospital
Zheng Hengzhong: Department of Neurology, Subei People Hospital
Lu Zhengtong: Director of Hanjiang Public Health Bureau
Xu Zaiquan: Hanjiang Public Health Bureau
Qi Fenggen: Hanjiang People Hospital
Gao Bin: Hanjiang Qiaotou Hospital
Appendix 2

Advisory Panel

WHO: L Prilipko, J Sander, Li Shichuo and a representative of the local WHO office

Ministry of Health, PRC:
Kong Lingzhi: Director of NCDs Control, Department of Diseases Control
Zheng Li: Deputy Director of Division of NCDs Control, Department of Diseases Control
Qi Qingdong: Director of Division of International Organization, Department of International Co-operation

Neurosurgical Society of China:
Whang Chong Cheng: Director of Neurosurgical Society of China
Director of Beijing Neurosurgical Institute

Neurological Society of China:
Wu Xun: Secretary of Neurological Society of China and vice Director of group of epilepsy and EEG and vice Director of Beijing Anti-epilepsy Association

Beijing Neurosurgical Institute:
Wu Zhongxue: Deputy Director of Beijing Neurosurgical Institute
Wang Wenzhi: Director of Department of Neuroepidemiology
Wu Jianzhong: Professor and Secretary of Beijing Anti-epilepsy Association

Heilongjiang Province
Wang Desheng: Prof. Department of Neurology, Haerbin Medical University
Huang Rihe: Director of Mulin Public Health Bureau
Lv Weichang: Director of Dongning Public Health Bureau

Ningxia Province
Kong Fanyuan: Affiliated Hospital of Ningxia Medical College
Li Chengai: Director of Wuzhong Public Health Bureau
Liu Jingguo: Director of Qingtongxia Public Health Bureau

Henan Province
Li Jianzhang: Prof. Department of Neurology, Henan Medical University
Wang Ligui: vice Director of Wuzhi Public Health Bureau

Shanxi Province
Li Kuntun: Prof. Department of Neurology, Changzhi Medical College
Song Peilin: Director of Zezhou Public Health Bureau

Jiangsu Province
Li Zuohan: Prof. Department of Neurology, Nanjing Medical University
Lu Zhengtong: Director of Hanjiang Public Health Bureau
Screening Questionnaire for Epidemiology of Epilepsy

Unique ID: / / / / / / Province:_________ County:_________

Name:_________ Sex:____ Age:____ (Birthday:_______)

Occupation:________________ Nationality:______________

Address:___________________________________________

Householder:______________

Questionnaire:
1. Have you ever had attacks of shaking of the arms or legs which you could not control?
2. Have you ever had attacks in which you fall and become pale?
3. Have you ever lost consciousness?
4. Have you ever had attacks in which you fall with lost consciousness?
5. Have you ever had attacks in which you fall and bite your tongue?
6. Have you ever had attacks in which you fall and lose control of your bladder?
7. Have you ever had brief attacks of shaking or trembling in one arm or leg or in face?
8. Have you ever had attacks in which you lose contact with the surroundings and experience abnormal smells?
9. Have you ever been told that you have or had epilepsy or epileptic fits?
10. Have you ever had attacks in which you lose contact with your surroundings and experience a sensation in which objects change shape or size?
11. Did you ever have attacks of convulsions in fever before the age of 5?
12. Have you ever suddenly in a daze or amazement, lost something from your hand during an activity, writing or eating?
13. Have you ever had suddenly in a daze, smack, purposeless activity of hands which you subsequently have no memory?

For those with definite or possible epilepsy:

1. Onset age:_____
2. Number of attacks:
   Recent 1 year: ←=have attacks (____times); ↑=no attack □ □ □
   Recent 2 years: ←=have attacks (____times); ↑=no attack □ □ □
   Recent 5 years: ←=have attacks (____times); ↑=no attack □ □ □
3. Are there any causes of attack?

____________________________________________________

____________________________________________________
Appendix 3 (cont.)

4. Did the patient take any treatment?
   (1) Never accepted any treatment: 1 = Yes; 2 = No
   (2) To be Treated: 1 = Yes; 2 = No
   If answer yes: 1 = Western medicine; 2 = Traditional medicine
   Drug name and dosage:

   | Effect: 1 = Excellent; 2 = Good; 3 = No effect |
   | Treatment assessment: 1 = Regular; 2 = Irregular |
   | (3) Last week: 1 = treatment; 2 = Not treatment |
   | Effect: 1 = Excellent; 2 = Good; 3 = No effect |

Investigator: ___________________________        Date: ______________

Check result:

**Conclusion:**
1 = Diagnose epilepsy    2 = Excluded epilepsy

**Seizure type:**
1. Simple Partial Seizures
2. Complex Partial Seizures
3. Secondarily Generalized Seizures
4. Generalized Tonic-clonic seizures
5. Absences
6. Others (Myoclonic, Atonic etc)

Checked by Dr. ______________        Date: ______________
Screening and Diagnosis for Convulsive Epilepsy

Unique ID: / / / / /  Province:_____________County:_____________
Name:________________________Sex:_____
Age:_____ Birthday:( _________ ) Nationality:________________
Address:______________________________________
Householder:___________
Height:_____ cm            Weight:_____  kg             Occupation:______________

1. History of Epilepsy (symptoms, duration of the attack and frequency in last 12 months)
Q1: Does patient lose consciousness during the attack?
   1= yes   2= no   3= not every time
Q2: How long unconscious?  1= >5 minutes      2= <5 minutes
Q3: Do their arms and legs jerk repetitively?
   1= yes   2= no   3=not every time
Q4: Is there incontinence of faeces or and urine?
   1= yes   2= no   3= not every time
Q5: Are there injuries to the tongue or body?
   1= yes   2= no   3= not every time
Q6: Does patient feel fatigue, sleepy, headache or muscle pain after seizure?
   1= yes   2= no   3= not every time
Q7: Have someone seen your seizure?    1= yes      2= no
Age of first seizure:___
Total times of seizures:
Frequency of the attacks in last six months:____/week; ____/month; ____/year

2. Previous treatment
Q1a: Did you go to hospital and see doctors: (Hospital name_____________ )
Q1b: Was Epilepsy diagnosed?    1= yes    2= no
Q2: What methods have you used:
   ← West medicine (name, dosage duration, etc.)
   ↑ Other methods (Traditional Chinese Medicine, acupuncture, witch, etc)

3. Seizures in the last 12 months
   ← The patient took anticonvulsant regularly
   Seizures times: __/week; __/month;  no attack __ months
   ↑ Taking drugs irregularly or without any treatment
   Seizures: __/week; __/month;  no attack __ months

If the Patient agrees to attend this study:  Signature:______________

Name of investigator:__________________________  Date:__________________
Phenobarbital Treatment Schedules

1. Basic principles
   (1) We use the 30 mg tablet of phenobarbital.
   (2) Tablets are administered once a day, preferably at bedtime.
   (3) To obtain steady levels of phenobarbital in the blood, 14 to 21 days of continuous administration are needed. Therefore, if during this period the seizures do continue, they are not to be considered as treatment failures.
   (4) We should start with the minimum dose and slowly increase it until reaching the best dose for each patient.
   (5) If after this initial period seizures do continue, the dose should be increased whenever possible, and if side effects do not occur.
   (6) When the patient wants to stop the treatment, we should slowly decrease the dose, preferably by 30 mg every month. In this case, it is better to have a consultation with the supervising physician.

2. Phenobarbital dosage in adults
   In this category are included patients over 15 years old and weigh more than 30 kg.
   (1) Initiate with a dose of about 1 mg/kg/day. In the majority of adults this means 2 tablets (60 mg) at bedtime.
   (2) Keep this dose for two weeks.
   (3) Raise the dose to approximately 2 mg/kg/day. In the majority of cases, this means 4 tablets (120 mg) at bedtime.
   (4) Keep it for 6 to 8 weeks.
   (5) If there have been no seizures in the last 4 weeks, keep the same dose.
   (6) If seizures have been present in the last 2-4 weeks the dose to 3 mg/kg/day. This means 4 tablets to 6 tablets at bedtime.
   (7) Keep this dose for 6-8 weeks.
   (8) If there have been on seizures in the past 4 weeks, keep the same dose.
   (9) If seizures persist, go through this checklist:
       a) Check the patient’s weight and recalculate the dose at 3 mg/kg/day.
       b) Control medicine compliance.
       c) If a) and b) are correct, refer to the supervising physician.
       d) If the dose is insufficient, raise up to 3 mg/kg/day and wait another 6-8 weeks.
       e) If compliance is lacking, read the instructions to increase compliance.

ADMINISTRATION FOR PHENOBARBITAL

<table>
<thead>
<tr>
<th>Age Weight</th>
<th>2-5 y.o. &lt;15 kg</th>
<th>6-10 y.o. 15-20 kg</th>
<th>11-15 y.o. 21-30 kg</th>
<th>&gt;15 y.o. 31 kg +</th>
</tr>
</thead>
<tbody>
<tr>
<td>1st dose</td>
<td>15 mg</td>
<td>30 mg</td>
<td>60 mg</td>
<td>60 mg</td>
</tr>
<tr>
<td>(to start)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2nd dose</td>
<td>30 mg</td>
<td>60 mg</td>
<td>75 mg</td>
<td>120 mg</td>
</tr>
<tr>
<td>(maintenance)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3rd dose</td>
<td>60 mg</td>
<td>75 mg</td>
<td>90 mg</td>
<td>180mg</td>
</tr>
<tr>
<td>(maximum)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix 5 (cont.)

3. Phenobarbital dosage in children

In this category are included children 14 years of age or less, or people weighing <29 kg.

(1) Initiate with a dose of about 2 mg/kg/day. In the majority of children this means 1-2 tablets (30-60 mg) at bedtime.
(2) Keep this for two weeks.
(3) Raise the dose to approximately 3 mg/kg/day. In the majority of children this means 2-3 tablets (60-90 mg) at bedtime.
(4) Keep it for 6 to 8 weeks.
(5) If there have been no seizures in the last 4 weeks, keep the same dose.
(6) If seizures been present in the last 2-4 weeks, increase the dose to 4 mg/kg/day. This means from 3 tablets to 4 tablets at bedtime.
(7) Keep this dose for 6-8 weeks.
(8) If there have been no seizures in the past 4 weeks, keep the same dose.
(9) If seizures persist, go through this checking list:
   1. Check the patient’s weight and recalculate the dose at 4 mg/kg/day.
   2. Control medicine compliance.
   3. If a) and b) are correct, refer to the supervising physician.
   4. If the dose is insufficient, raise up to 4 mg/kg/day and wait another 6-8 weeks.
   5. If compliance is lacking, read the instructions to increase compliance.

4. How many tablets are given to the patient?

To calculate the number of tablets to be delivered to the patient until his/her next visit, we will follow this procedure:

(1) Calculate the daily dose in tablets for example patient needs 90 mg/day, this means 3 tablets/day.
(2) The daily number of tablets multiplied by the number of follow-up interval days. Patient should take all tablets in the follow-up interval period. In order to evaluate the compliance of patient, an additional week dosage of phenobarbital is given. If the follow-up interval is two weeks, daily dose is 90 mg (3 tablets), the number of tablets to be given should be 3 x (14+7) = 63 (tablets). If the follow-up interval is four weeks, daily dose is 90 mg (3 tablets), the number of tablets to be given should be 3 x (28+7) = 105 (tablets).

5. Evaluation of patient’s compliance

Calculate the number of drugs taken by patients to evaluate compliance of patients. It means good compliance if the surplus drugs equal 7 day’s dosage. It means noncompliance if the drugs were more or less 7 day’s dosage. If non-compliant, you should:

1) repeat counseling about the importance of compliance,
2) tell patient that further noncompliance will mean being excluded from this project, and
3) ask the reason of noncompliance
Appendix 6

Patient Entry Form

Unique ID: / / / / / /  Province: ___________ County: ___________

Name: ____________________________  Sex: ______

Age: ______  Birthday: ( _______ )  Nationality: ______________

Address: ______________________________________

Householder: ____________

Height: _____ cm  Weight: ___ kg  Occupation: ___________

1. Epilepsy History

   (1) Onset age: ______
   (2) Seizures type: ____________________________
   (3) Possible aetiology: ____________________________
   (4) Number of seizure__/week__/month__/year
   (5) Previous treatment:
       ● West medicine (name and dosage):
       ● Traditional medicine (name and methods):

   (6) Family history: ____________________________
   (7) Occupation or study status: 1=No impact; 2=Impact; 3=Severity impact □

2. Phenytoin treatment:

   (1) Starting dosage: ____mg/day
   (2) Maintenance dosage: ____mg/day
   (3) Side effects: 1=No; 2=Mild; 3=Moderate; 4=Severe □
   (4) Patient’s compliance: 1=Compliance; 2=Noncompliance;
       3=Severe compliance □
   (5) Occupation or study status: 1=no impact; 2=impact; 3=severity impact □

3. Results:

   (1) Objective assessment: 1=Excellent; 2=Good; 3=No change; 4=Worse □
   (2) Doctor’s assessments: 1=Excellent; 2=Good; 3=No change; 4=Worse □
   (3) Patient’s assessments: 1=Excellent; 2=Good; 3=No change; 4=Worse □
   (4) Patient drop out: 1=Yes; 2=No □

Observer: ________________  Date: _____________
Follow-up Form

Unique ID: / / / / / Province:___________ County:___________

Name:______________ Sex:___ Age:____ (Birthday:__________ ) Nationality:_____

Address:__________________________________ Householder:_________________

Height:_____cm      Weight:_____kg     Occupation:______________

1. Dosage of phenobarbital:___mg/day  ( ___tablets/day )

2. How many times of seizures occurred from last follow-up: / / / /

3. Side effects:

<table>
<thead>
<tr>
<th>Side effects</th>
<th>No=1</th>
<th>Mild=2</th>
<th>Moderate=3</th>
<th>Severe=4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sleepiness</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trouble walking</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Control hand movements</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hyperactivity</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nausea</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vomiting</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diarrhea</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Loss of appetite</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Skin rash</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Headache</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dizziness</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nervousness</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Patient’s reactions to phenobarbital: 1=No; 2=Mild; 3=Moderate; 4=Severe  □

4. Compliance: 1=Compliance; 2=Noncompliance  □

(1) Estimate the surplus tablets:

(2) Reality the surplus tablets:

5. Did not take drug in the evening, the reason: 1=Forget; 2=Leaving home; 3=Others  □

6. Did not the patient follow-up on time, the reason: 1=Forget; 2=Leaving home; 3=Others  □

7. Did any changes of the patient’s vigor, ability of work and study compare with last month? 1=Better; 2=Same; 3=Worse  □

Investigator:______________________        Date:______________
Appendix 8

Side Effects and Management of Phenobarbital Treatment

Some patients may develop problems when taking phenobarbital to control their seizures. Usually this situation is present only at the beginning of the treatment. With time this situation usually disappears and the patient can go on taking the medication without any untoward effects. This is why we should not stop the medication if initially an individual does complain of some uncomfortable reaction. We should encourage the patient to keep taking the medication for a few more days until his body adapts to it.

Phenobarbital is a safe medication when administered appropriately. However, the PHCW should be aware of all these untoward reactions in order to be able to handle this situation with his patients. Let us review these sides of phenobarbital:

1. Sleepiness
Phenobarbital can produce increased sleepiness. That is why it is useful to know before starting treatment how many hours the patient used to sleep and whether he used to take a nap in mid afternoon or if he/she usually felt sleepy on awakening in the morning. These data should be included in the visit sheet. In this way we could better assess if phenobarbital has changed the patient’s sleep habits.

Not all individuals react in the same way, so we should learn to grade these reactions:

- **Mild.** The patient wakes up sleepy, but as the journey continues he does not feel at work. During the evening again he becomes very sleepy after taking the medication. However this situation does not bother him during his activities.
- **Moderate.** The patient takes a nap in the afternoon. At times he/she has problems in keeping awake during working hours.
- **Severe.** The patient has difficulty in keeping awake. He/she would go to sleep while working. This situation interferes with his/her working schedule.

2. Trouble walking
Phenobarbital can induce trouble in walking. To know how did this person walk before treatment is useful in order to evaluate the intensity of his/her present situation. In order to do so, we, first, ask the patient to walk in front of us and to turn around as fast as possible. We then ask the patient to walk following a line touching heel-to-toe:

- **Mild.** We classify as a mild impairment when the patient is able to walk heel-to-toe but has some difficulty in turning around.
- **Moderate.** The patient is very unstable can fall when doing the heel-to-toe test. The patient walks slowly and with a wide based gait.
- **Severe.** The patient is unable to walk following a line; he/she even needs help to walk straight. If he/she walks alone he/she could fall.

3. Problems to control hand movements
To assess this problem we ask the patient to extend his/her arms and to touch his/her nose with the index finger. We can also watch the patient carefully while he/she is drinking a glass of water:
Appendix 8 (cont.)

Mild. The patient can touch his/her nose. He/she cannot get a good grip of the glass and there is a bit of trembling.

Moderate. The patient has difficulty in touching his/her nose. A clear-cut tremor is seen. He/she needs to take the glass with both hands.

Intense. The patient falls most of the intents to touch the nose. A severe tremor is evident. The glass contents are spilled.

4. Hyperactivity
Phenobarbital can produce restlessness, specially in children. They are seen in constant activity. We should ask the parents how are the child’s behaviours in different situation, at home, in the school, while playing or taking food.

Mild. The child is definitively more active than children his/her age. He/she stays quiet only for a few moments. He/she does obey when asked to stay quiet.

Moderate. The child is seen running climbing up furniture and taking everything within his/her reach. The child has problems in finishing school tasks and obeys with difficulty.

Severe. The child is unable to concentrate in a given activity. He/she acts without thinking in the consequences of his/her actions. The child does not obey any commands at all.

5. Other side effects
Rarely, phenobarbital can induce other problems. Some of these are:

(1) Digestive problems. Nausea, vomiting, diarrhea, loss of appetite.
(2) Skin rash. Skin allergies can be seen with phenobarbital use. The patients feel itchy and scratch his/her skin. Sometimes, red macules are seen and rarely blisters.
(3) Behavior and neurological problems. Headache, albeit mild, dizziness, anxiety, nervousness and difficulty in concentrating.

According to patients’feeling and interfering with his/her working, it can be divided into mild, moderate and severe.

4. How to grade all these problems
According to all listed phenobarbital sides effects, we can have an objective evaluation of the patient’s reactions to phenobarbital:

NO PROBLEMS: There are no any side effects to all listed problems.
SEVERE: if there is at least one severe or three or more moderate.
MODERATE: when there are up to two moderate.
MILD: when there are up to two mild.

This classification will guide us to treatment of phenobarbital side effects.
6. Treatment of phenobarbital side effects

(1) SEVERE PROBLEMS:
   1. Find out if there is another reason for the patient’s condition. Does he/she have any other current illness?
   2. Do not advise to discontinue the phenobarbital and discuss with supervising physician to make decision.

(2) MODERATE PROBLEMS:
   ← Reexamine the patient to be sure he/she does not have an intense problem.
   ↑ Investigate if there is no other illness that is precipitating these problems.
   → Call the patient up for a shorter follow-up visit in two weeks.
   ↓ Continue the phenobarbital at the same dose.
   ° If in the follow-up visit the problems continue, refer to your supervising physician.
   ± If the patient develops severe problems in this interval. Inviting supervising physician makes decision.

(3) MILD PROBLEMS:
   ← Continue with the medication.
   ↑ Continue with the regular follow-up.
   → If needed, as in case of continuing seizures, the phenobarbital dose can be increased.
1. **Evaluation of patient’s compliance**

Compliance means that the patient is taking their medication in the correct way. This is assessed in the following ways:

1. Asking the patient if he/she is taking all the tablets daily.
2. Reviewing the Pathography Form (see Appendix 10) where the presence or absence of seizures is noted.
3. According to the number of tablets in the bottle, assess compliance of patient. (An additional week’s dosage of phenobarbital will have been given at the last visit. The surplus drug tablets should equal 7 times the amount of their normal daily dose of tablets).

The standard of patient’s compliance should be recorded as:

1. Good compliance (if the surplus drugs equal 7 day’s dosage).
2. Non compliance (if the follow-up interval is 2 weeks and the surplus drug tablets are more or less than one day’s number of tablets in the bottle).
3. Non compliance (if the follow-up interval is 4 weeks and the surplus drugs are more or less than two day’s number of tablets in the bottle).

2. **Instructions to reinforce the importance of the treatment**

When the patient is not following the daily dosage or is not attending his/her regular follow-up visits, he/she needs to have reinforced his/her interest in continuing the treatment. Adherence to any therapeutic regimen will improve it:

1. The patient perceives his/her condition (in this case the presence of seizures) as a real problem in his/her life.
2. The patient is convinced that the proposed treatment has a reasonable probability of improving his/her condition, by reducing the number of seizures and their severity.
3. The patient views the side effects of the treatment as transitory and tolerable as opposed to the expected benefits.
4. The patient accepts the treatment as an easy-to-follow procedure.
5. The treatment goal is the reduction in the number of seizures to a minimum or the total absence of them.
6. The patient understands that in order to achieve these benefits, a time period should elapse, usually 2-6 weeks, before the treatment goals are obtained, when the medication reaches a level in blood.
7. The patient and his/her family understand that the prescribed dose cannot be altered without consent of the PHCW.
8. The patient understand that an abrupt discontinuation of the treatment can have serious consequences to his/her health.
9. The language used to explain all these aspects to the patient is as simple and straightforward as possible. The health worker should listen to the patient and try to understand his/her reasons as to why the treatment was not followed as indicated.
Appendix 9 (cont.)

3. The following methods have been helpful to ensure compliance:
   (1) Have the family members help the patient to remember to take his/her tablets at bedtime.
   (2) Combining the taking of the tablets with daily activities, such as going to bed or with dinner.
   (3) Increasing the number of visits to the patient’s home, explaining the necessity of a long-term intake of the medication and possible although transitory side effects.

   If the patient is not taking the medication or not attending the clinic visits, analyse the cause for lack of compliance or failure to show up at the clinic. Is the patient not sure about the efficacy of the medication? Is he/she insecure? Is he/she uninterested?

   Emphasize the problems that can be caused by seizures, such as falls, head/injuries, burns, drowning, etc. Reinforce the thought that only with regular taking of the medication can the patient be spared these serious problems.

   If the patient does not come to the clinic at regular intervals, hand him a calendar clearly marked with the dates of the next visits.

   If in subsequent visits the patient persists with a lack of compliance and attendance to the clinic, find out if the causes are the same or if new situations have come up, such as change in jobs, or family problems. Is the patient confident on the treatment offered? Does he/she wants to continue or not with the treatment? Encourage him/her to continue by nothing that the treatment is helping to reduce the seizure frequency and severity. Insist on the minimum amount of drug to be taken and that fewer visits that will be needed in the future. Note that if the medication is discontinued all possible gains will be lost.

   You can confront difficult patients with another one who is following the instructions more faithfully and who is benefiting from the prescribed treatment.

   If after every effort has been made and there is still poor compliance so that the patient should be excluded from the study, the health worker should explain this to the patient. The worker should then refer the patient to the physician for detailed instructions on how to go off the medication.

4. Stopping treatment
   The treatment of patient should be stopped as following:
   (1) The patient or guardians wish to stop treatment.
   (2) The patient continued to be noncompliant three times.
   (3) The patient continued to miss follow up appointment three times.
   (4) The patient could not take their drugs for some cause over one month.
   (5) The patient suffered from a progressive neurological disorder or severe heart, liver or kidney diseases.
   (6) The supervising doctor diagnosed patient with severe side effects phenobarbital.
Seizure Diary and Compliance Form

To be filled by patient or family:

Unique ID: / / / / / / Province:_____ County:_____

Name:______________ Sex:_____ Age:____ (Birthday:_______) Nationality:_____

Address:__________________________________________________

Householder:_____________

From:__(mth)__(day) to __(mth)__(day)

1) Please record the day you forgot to take the medicine. (circle as appropriate)

<p>| | | | | | | | | | | | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
<td>11</td>
<td>12</td>
<td>13</td>
<td>14</td>
<td>15</td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>17</td>
<td>18</td>
<td>19</td>
<td>20</td>
<td>21</td>
<td>22</td>
<td>23</td>
<td>24</td>
<td>25</td>
<td>26</td>
<td>27</td>
<td>28</td>
<td>29</td>
<td>30</td>
<td>31</td>
</tr>
</tbody>
</table>

For what reason?

2) Please record the day and times that you have a seizure. (circle as appropriate and mark number of times under each day circled)

<table>
<thead>
<tr>
<th>Seizure date</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
<th>12</th>
<th>13</th>
<th>14</th>
<th>15</th>
</tr>
</thead>
<tbody>
<tr>
<td>No. of times</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Seizure date</th>
<th>16</th>
<th>17</th>
<th>18</th>
<th>19</th>
<th>20</th>
<th>21</th>
<th>22</th>
<th>23</th>
<th>24</th>
<th>25</th>
<th>26</th>
<th>27</th>
<th>28</th>
<th>29</th>
<th>30</th>
<th>31</th>
</tr>
</thead>
<tbody>
<tr>
<td>No. of times</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

3) Effects of treatment:

- Perceived seizure severity: none/mild □ moderate □ severe □
- Side effects: none/mild □ moderate □ severe □

4) Was the patient’s study interfered with by seizures in last month?

- Attending school: no □ yes □
- Away from school: no □ yes □ __days

5) Was the patient’s work be interfered with by seizures in last month?

- Work status in the last month: not working □; work __days
- Salary earned in the last month: no □; earned__RMB

6) Daily life:

- Able to travel independently: no □; yes □
- Attending community activities: no □; yes □ __hours
- Household tasks (cleaning, shopping, etc.): everyday __hours

7) Were there any changes in the patient’s vigour, ability to work/study compared with last month?

Better □; Same □; Worse □;

Name of person filling in the form: __________ Date: __________
**Appendix 11: Completion Form**

Unique ID: / / / / / / Province:_____ County:_____ Doctor:________

<table>
<thead>
<tr>
<th>Patient No.</th>
<th>Name</th>
<th>Sex</th>
<th>Age</th>
<th>Seizure type</th>
<th>Side effects</th>
<th>Treatment time</th>
<th>Effectiveness of treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Objective assessment</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Doctor assessment</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Patient assessment</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>


Appendix 12

Survey Of Knowledge, Attitudes And Practice Of Epilepsy For Primary Health Care Personnel
(Self-administered survey)

Confidential

INSTRUCTIONS
Please circle the response that seems most correct. Thank you for your assistance.

Name: (optional) …………………… …………………… …………………… …………………… ……………………
Age: ……………………
Profession: Physician – Nurse : ………………… Date of graduation: …./……/19……
Health center: Name: …………………… …………………… ………………… City: ………………… Tel: …………………
Date: …./……/……

1. SECTION I

1.1 How much knowledge do you have on epilepsy?
   1 = a great deal  2 = some  3 = little  4 = none

1.2 What type of training have you had on epilepsy?
   1 = theoretical  2 = practical  3 = theoretical + practical  4 = none

1.3 What percentage of epilepsy do you believe is controllable?
   1 = 100%  2 = 80%  3 = 50%  4 = 30%  5 = 10%  6 = 0%

1.4 Is every convulsion synonymous with epilepsy?
   1 = always  2 = usually  3 = rarely  4 = never

1.5 Should people with epilepsy be treated?
   1 = always  2 = rarely  3 = never  4 = it depends

1.6 How effective is the treatment for epilepsy?
   1 = very good  2 = good  3 = ok  4 = bad

1.7 Which of the following drugs is utilized in the treatment of epilepsy?
   1 = warfarin  2 = carbamazepine  3 = chlorpromazine  4 = methyldopa
   5 = buspirona  6 = phenobarbital  7 = none of the options  8 = 2 and 6

1.8 Which of the following drugs is not utilized in the treatment of epilepsy?
   1 = phenobarbital  2 = furosemide  3 = difenilhidantoina  4 = valproate
   5 = diazepam

1.9 What do you believe is the major cause of epilepsy in your region? …………

1.10 Is it possible for some types of epilepsy to be transmitted from parent to child?
   1 = definitely yes  2 = very possible  3 = possible
   4 = not very possible  5 = definitely not
Appendix 12 (cont.)

1.11 Is epilepsy a contagious disease?
   1 = definitely yes          2 = very possible          3 = possible
   4 = not very possible      5 = definitely not

1.12 Can epilepsy be caused from blows to the head?
   1 = definitely yes          2 = very possible          3 = possible
   5 = not very possible      5 = definitely not

1.13 Is epilepsy always a brain disorder?
   1 = definitely yes          2 = very possible          3 = possible
   4 = not very possible      5 = definitely not

1.14 Can chronic drinking lead to epilepsy?
   1 = definitely yes          2 = very possible          3 = possible
   4 = not very possible      5 = definitely not

1.15 Can epilepsy begin at any age?
   1 = definitely yes          2 = very possible          3 = possible
   4 = not very possible      5 = definitely not

1.16 Do you believe that epilepsy only manifests with generalized convulsions?
   1 = always; 2 = almost always; 3 = sometimes; 4 = almost never; 5 = never

1.17 Do you think that epilepsy can be treated?
   1 = always; 2 = almost always; 3 = sometimes; 4 = almost never; 5 = never

1.18 Do you believe that epilepsy is a public health problem?
   1 = definitely yes          2 = very possible          3 = possible
   4 = not very possible      5 = definitely not

2. SECTION II

2.1 What is the general attitude of an individual with epilepsy toward his/her own illness?
   1 = acceptance          2 = resignation          3 = indifference          4 = fear          5 = rejection

2.2 Generally, what is the attitude of the family toward the patient with epilepsy?
   1 = acceptance          2 = resignation          3 = indifference          4 = fear          5 = rejection

2.3 What is the predominant attitude of the community toward patients with epilepsy?
   1 = acceptance          2 = resignation          3 = indifference          4 = fear          5 = rejection

2.4 What is the predominant attitude of health care personnel toward patients with epilepsy?
   1 = acceptance          2 = resignation          3 = indifference          4 = fear          5 = rejection

2.5 Who do you believe should initially treat patients with epilepsy?
   1 = neurologist          2 = another specialized physician          3 = general practitioner
   4 = nurse          5 = healer

2.6 What activities can a person with epilepsy engage/not engage in? (Put the appropriate number of options to the right of the listed words)
Appendix 12 (cont.)

<table>
<thead>
<tr>
<th>Activity</th>
<th>1 = definitely yes</th>
<th>2 = very possible</th>
<th>3 = possible</th>
<th>4 = not very possible</th>
<th>5 = definitely not</th>
</tr>
</thead>
<tbody>
<tr>
<td>Become pregnant</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Give birth</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breast-feed</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dance</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Participate in Sports</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Read</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Take liquor</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Work</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Study</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Get Married</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have children</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Play (children)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Swim</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Travel alone</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Go to the physician</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Go to the healer</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drive vehicles</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cook</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Write</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Manage machinery</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

3. **SECTION III**

3.1 How many people with epilepsy live in your community?

1 = Many    2 = Some    3 = Almost none    4 = None

3.2 How much experience do you have in the care of people with epilepsy?

1 = Much    2 = Some    3 = Almost none    4 = None

3.3 How many cases of epilepsy have you diagnosed in the last 12 months?

1 2 3 4 5 6 7 8 9 or more

3.4 How many cases of epilepsy have you treated in the last 12 months?

1 2 3 4 5 6 7 8 9 or more

3.5 What would you not do to a patient who is having a tonic-clonic seizure?

1 = Turn him/her on their side  2 = Provide oxygen  3 = Place a hard object in their mouth  4 = Not embracing them with strength
## Survey of Public Awareness, Understanding and Attitudes Towards Epilepsy

### A. What language do you prefer to use in your everyday conversation? □
1 = Mandarin; 2 = Dialect

### B. Demographic data:

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td>1 = Male  2 = Female</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Education</strong></th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 = never went to school</td>
<td>1 = elementary school (grade school)</td>
</tr>
<tr>
<td>2 = junior high school</td>
<td>3 = senior high school</td>
</tr>
<tr>
<td>4 = college or above</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Occupation</strong></th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 = medical profession (doctor, nurses, pharmacists, medical student)</td>
<td></td>
</tr>
<tr>
<td>2 = non-medical teaching profession</td>
<td>3 = non-medical student</td>
</tr>
<tr>
<td>4 = peasant/fisherman</td>
<td>5 = factory worker</td>
</tr>
<tr>
<td>6 = businessmen</td>
<td>7 = non-specialized government employee</td>
</tr>
<tr>
<td>8 = other</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Marital status</strong></th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 = unmarried</td>
<td>2 = married  3 = divorced</td>
</tr>
<tr>
<td>4 = separated</td>
<td>5 = widow/widower</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Number of children</strong></th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1 = 1</td>
</tr>
<tr>
<td></td>
<td>2 = 2</td>
</tr>
<tr>
<td></td>
<td>3 = 3</td>
</tr>
<tr>
<td></td>
<td>4 = 4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Residence</strong></th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 = city</td>
<td>2 = suburban</td>
</tr>
<tr>
<td>3 = rural</td>
<td>4 = others</td>
</tr>
</tbody>
</table>

### C. Questionnaire

#### Q1. Have you ever heard of or read about the disease called “epilepsy” or “convulsive seizures” (fits)?
1. yes
2. no

#### Q2. Did you ever know anyone who had epilepsy?
1. yes
2. no
3. not familiar with epilepsy

#### Q3. Have you ever seen anyone who was having a seizure?
1. yes
2. no
3. not familiar with epilepsy

#### Q4. Would you object to having any of your children in school or at play associate with persons who sometimes had seizures (fits)?
1. yes
2. no
3. not familiar with epilepsy
Appendix 13 (cont.)

Q5. Would you object to your son or daughter marrying a person who sometimes had seizures (fits)?
   1. yes
   2. no
   3. not familiar with epilepsy

Q6. Do you think people with epilepsy should or should not be employed in jobs like other people?
   1. should
   2. should not
   3. no opinion
   4. not familiar with epilepsy

Q7. Do you think epilepsy is a form of insanity or not?
   1. yes
   2. no
   3. not familiar with epilepsy

Q8. What do you think is the cause of epilepsy? (multiple answers are allowed)
   1. don’t know
   2. brain disease, disorder or injury
   3. hereditary, inherited disease
   4. birth defect
   5. mental or emotional stress, disorder
   6. blood disorder
   7. other (please specify)
   8. not familiar with epilepsy

Q9. What do you think an epileptic attack is (multiple answers are allowed)
   1. convulsions, shaking
   2. loss of consciousness
   3. transient changes of behavior
   4. period of amnesia
   5. don’t know

Q10. If your relatives or friends have epilepsy, what kind of treatment would you suggest?
     (multiple answers are allowed)
     1. ask for an “M.D.”
     2. to get medicine from drugstore by him/herself
     3. ask for an herbal medicine doctor
     4. acupuncture
     5. surgical treatment
     6. ask for God’s help
     7. think “epilepsy is untreatable”
     8. no need to treat
     9. don’t know what to recommend
Appendix 14

Outcome Measures

The Report of the Meeting on the Burden of Epilepsy provided the following guidance on outcome measures:

The main outcomes of the Demonstration Projects will be:
1. diminishing treatment gap
2. reduction of economic burden
3. reduction of individual burden of disease

Study Variables
10. The population and treatment characteristics
   • Age of onset
   • Sex
   • Years of education
   • Ethnicity

11. The treatment
   • Who provided the treatment?
     - village doctor
     - rural physician
   • Where?
     - name of village/province
     - name of city/province
   • Services and procedures performed during visit?
     - diagnostic procedures
     - physical and or mental examination
     - patient and family interview
     - referrals
     - other

12. Immediate effects of treatment
   • Seizure frequency per month
   • Perceived seizure severity
     - none/mild
     - moderate
     - severe
   • Side effects
     - mild
     - moderate
     - severe
13. Functional impact of treatment

- Work status in the last month
  - not working in last month
  - number of hours working less than 10 hours
  - number of hours working between 10 and 20 hours
  - number of hours working between 20 and 30 hours
  - number of hours working more than 30 hours

- Salary earned in last month
  - no
  - yes
  - amount earned in the last month

- Training status in the last month
  - no training in last month
  - number of hours of training less than 10 hours
  - number of hours of training between 10 and 20 hours
  - number of hours of training between 20 and 30 hours
  - number of hours of training more than 30 hours

- Type of training in the last month
  - formal academic training
  - special job training

- Intention to work
  - I am developing a work plan
  - yes
  - no

- Travel capability, in the last month I have been able to travel independently
  - yes
  - no

- Carer support
  - my carer is now not working because of my epilepsy
  - no
  - yes

- Work status of carer in the last month
  - not working in last month
  - number of hours working less than 10 hours
  - number of hours working between 10 and 20 hours
  - number of hours working between 20 and 30 hours
  - number of hours working more than 30 hours

- Social and community activities
  - in the last month the number of hours on social and/or community activities

- Household contributions
  - in the last month the number of hours I spent in household tasks (for example cleaning, shopping, etc.)
14. Perceived impact (the impact of epilepsy scale)

Does your epilepsy and its treatment affect:

A LOT    SOME    A LITTLE    NOT AT ALL    NOT APPLICABLE

1. Your relationship with your spouse/partner
2. Your relationship with other close members of your family
3. Your social life and social activities
4. Whether or not you are able to work in paid employment
5. The kind of paid work you can do
6. Your health overall
7. Your relationship with friends
8. The way you feel about yourself
9. Your future plans and ambitions
10. Your standard of living