

# **“Fight against epilepsy” initiative in Ghana**

**WHO Programme on reducing the epilepsy treatment gap 2012–2016**

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**World Health  
Organization**

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For all enquiries write to the publishers:

The Mental Health Authority, Ministry of Health

P. O. Box LG DTD 20035,

Tripoli Street, East Legon, Accra

Tel: +233 0303964878 / 0303964879

E-mail: [info@mhaghana.com](mailto:info@mhaghana.com)

Website: <http://www.mhaghana.com>

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**Graphic design and layout**

Erica Lefstad

**Technical editing**

Elisabeth Heseltine

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# Foreword

*Epilepsy is one of the world's oldest recognized conditions. It affects people of all ages in every country of the world. Today, more than 65 million people worldwide have epilepsy. The good news is that, with antiepileptic medication costing as little as US\$ 5 per year per patient, 70% of people with epilepsy could be free of seizures after two to five years. Unfortunately, despite the availability of treatment, millions of people worldwide and approximately 75% of affected people in low- and middle-income countries do not receive it. This is what is called the treatment gap. In some African countries, particularly in rural regions, the treatment gap is up to 85%.*

*World Health Organization (WHO) has been committed to improving epilepsy care worldwide for several decades. As part of this commitment, and following earlier epilepsy initiatives, WHO launched the WHO Programme on Reducing the Epilepsy Treatment Gap in 2012. The aim of this Programme is to reduce the treatment gaps in low- and middle-income countries by improving access to epilepsy care and services. Demonstration project teams are bringing early detection and treatment services closer to where people with epilepsy live and developing models of care that can be replicated in similarly resource-limited settings. Initial demonstration projects are being implemented in Ghana, Mozambique, Myanmar and Viet Nam.*

*In Ghana, a country of 27 million people, about 270 000 live with epilepsy; however, only 15% of them are receiving treatment and care, resulting in an epilepsy treatment gap of 85%. As epilepsy is the most prevalent neuropsychiatric condition seen in rural health clinics and among the top five medical problems in the country, national health authorities identified it as a high priority in 2011.*

*With the support of the WHO, the Ghana Ministry of Health launched the Fight against epilepsy initiative in 2012 in 10 districts in the country. Despite many challenges associated with the limited number and capacity of the workforce, the absence of national policies, high levels of stigma and discrimination, the project provided treatment and care to over 2700 people with epilepsy that had not been diagnosed before the project. With 21 315 consultations, over three-quarters of the patients managed in the project reported significant improvements in their quality of life.*

*The unwavering commitment and focus of the Ghana epilepsy project team shows that demonstration projects such as the Fight against epilepsy initiative can significantly increase access to high-quality care and hence reduce gaps in epilepsy treatment. The successes also demonstrate the feasibility of extending the management of epilepsy from pilot sites to an entire country, from countries to regions and from regions globally.*

*Hon. Kwaku Agyeman-Manu, Minister of Health, Ghana*

## Abbreviations

<b>CHW</b>	community health worker
<b>CHPS</b>	community health planning and services
<b>CPN</b>	community psychiatric nurse
<b>KAP</b>	knowledge, attitudes and practice
<b>mhGAP</b>	Mental health Gap Action Programme
<b>WHO</b>	World Health Organization

## Definitions

*For the purposes of this publication, the following definitions are used:*

**Active epilepsy:** two or more unprovoked epileptic seizures in the 12 months immediately preceding identification by project team

**Unprovoked seizure:** epileptic seizures not associated with a clear precipitating or triggering factor (such as fever, acute head injury, acute cerebrovascular accident, acute metabolic imbalance)

**Convulsive epilepsy:** primary or secondary generalized tonic-clonic convulsions, with or without other types of seizure

**Untreated epilepsy:** any case of active epilepsy that has not been treated regularly with antiepileptic medicines in the week preceding identification by project team

**Treatment gap:** the proportion of the population who require but have not received treatment for epilepsy



# Executive summary

*Epilepsy is a chronic noncommunicable disease of the brain that affects 65 million people worldwide. It accounts for 0.6% of the global burden of disease. Nearly 80% of people with epilepsy live in low- and middle-income countries, about 75% of whom do not receive the treatment they need.*

*Building on the Global Campaign Against Epilepsy, WHO in 2012 launched the WHO Programme on reducing the epilepsy treatment gap, with the aim of improving access to epilepsy care and services and the overall goal of reducing epilepsy treatment gap in low- and middle-income countries.*

*In Ghana, it is estimated that 1% of the population live with epilepsy, representing 270 000 people, with a treatment gap of 85%. It is in that context that the Ghana Ministry of Health, in collaboration with WHO, launched the Fight against epilepsy initiative in 2012. The goals of the five-year project were to improve the identification and management of people with convulsive forms of epilepsy within the existing primary health care system and to develop a model of epilepsy care at the community level that could be scaled up nationwide. The project was implemented gradually across five regions comprised of 10 districts<sup>1</sup> and 55 hospitals and clinics, in the following steps: (i) developing a strategy for delivering epilepsy care, (ii) training health care workers and volunteers, (iii) raising awareness and educating communities, (iv) engaging traditional and faith healers and (v) strengthening monitoring and evaluation of epilepsy.*

<sup>1</sup> Tolon-Kumbungu was separated into two districts, Tolon and Kumbungu, in 2014. Thus, as of 2016, a total of 10 districts were involved in the Initiative.

Comprehensive situation analyses were conducted at national, regional and district levels. Below is a snapshot of the districts before the project was implemented:

- The population was more than 1.1 million, living mainly in rural areas.
- Contact coverage was around 14.5%.
- The health system comprised a total of 1436 health care providers across 172 health facilities. Three of whom were mental health workers, 15 were community psychiatric nurses (CPNs), 33 were primary health care doctors, 34 were medical assistants, 920 were nurses, and 431 were community health workers (CHWs).
- Antiepileptic medicines such as carbamazepine, phenobarbital and phenytoin were available, but mainly only in hospitals, and their availability was inconsistent.

A survey of knowledge, attitude and practices (KAP) carried out among 929 community members and health professionals showed that:

- Most respondents knew about the disease called epilepsy.
- There were misconceptions about both the causes and treatment of epilepsy.
- People living with epilepsy experienced high levels of stigma and discrimination.

In order to integrate epilepsy care into primary health and ensure community participation, a cascade model of training was put in place with evidence-based tools from the mental health Gap Action Programme (mhGAP).

Over five years,

- 29 specialists, including neurologists and psychiatrists, were trained to become trainers and supervisors in epilepsy care management.
- 690 non-specialist primary health care providers, including CPNs, general practitioners and nurses, were trained to diagnose and treat epilepsy.
- 770 CHWs and volunteers, including traditional and faith healers, midwives, teachers, nongovernmental organization staff and other health staff, were trained to detect possible cases of epilepsy, to assist in acute seizure episodes and to refer cases for further medical care.

**Overall, 1386 community awareness-raising activities were conducted, with an estimated total audience of 96 094 people.**

Community awareness was raised through multiple channels, including mass community meetings, FM radio broadcasts, newspaper articles and health education sessions. Overall, 1386 community awareness-raising activities were conducted, with an estimated total audience of 96 094 people.

To ensure integration of epilepsy care into the Ghanaian cultural context, we considered it important to improve collaboration with community leaders, including traditional and faith healers.

## Contact coverage increased from 14.5% to 38.3% in four years...

284 meetings were held in all five implementation regions to increase awareness about the project and reduce stigmatization. Two-way referral systems have since been set up, and cross-sectorial care has been established. Up to 3% of new cases of epilepsy referred to community mental health units were being received from traditional and faith healers.

A comprehensive monitoring and evaluation system was established in all districts from the beginning of the project to give the team a clear understanding of the use of epilepsy services, patient outcomes and supplies of antiepileptic medication.

This five-year project confirmed that epilepsy care can feasibly and effectively be integrated into the primary health system in a low-income country. Service coverage increased from 14.5% to 38.3% by the end of the project, and people with epilepsy reported a significant improvement in their quality of life.

The project team therefore formulated recommendations for successful implementation in other low- and middle-income countries:

- use of a task shifting approach;
- use of the evidence-based mhGAP tools;
- training non-specialists in epilepsy management;
- involving mental health specialists and neurologists as trainers and supervisors;
- ensuring a consistent supply of antiepileptic medicines;
- integrating interventions in the primary health care system in order to provide holistic support and care to people living with epilepsy;
- including and collaborating with traditional and faith healers;
- instilling a culture of data collection and analysis from the inception of the project;
- forming a committed, solution-oriented team; and
- sharing challenges and successes with other low- and middle-income countries.

*Ghana's Fight against epilepsy initiative demonstrates that there are simple, cost-effective ways to treat epilepsy in resource-poor settings at community level. The many lessons learnt will be used to further inform the WHO Programme on reducing the epilepsy treatment gap and other efforts to treat epilepsy worldwide.*

# Epilepsy: a global public health problem

The global problem

The treatment gap

The global response

- Global Campaign Against Epilepsy
- WHO Programme on reducing the epilepsy treatment gap

*Epilepsy is a chronic noncommunicable disease of the brain that affects people of all ages. It is characterized by recurrent unprovoked seizures that may involve a part of the body (partial) or the entire body (generalized). The seizures are transient signs or symptoms of excessive neuronal activity; they are sometimes accompanied by loss of consciousness and control of bowel or bladder function.*

*There are many known risk factors for epilepsy, which range from a family history of seizures, genetics, perinatal trauma or head injury at any age, stroke or brain infections. In some people, no cause can be identified.*

*Risk factors for seizure and epilepsy differ between low- and middle-income countries and high-income countries. For example, epilepsy resulting from infection is a major cause of morbidity and mortality in low-income countries and the most preventable cause of epilepsy worldwide. The age of onset also differs; in high-income countries, the incidence of epilepsy presents a U-shaped curve with highest rates in children and people over age 65. By comparison, the incidence of epilepsy peaks in older children and young adulthood in low and middle-income countries. (1)*

*Head injury is a common cause of epilepsy worldwide (2), often associated with road traffic accidents, falls and trauma during warfare. The most common infections associated with seizure and epilepsy are neurocysticercosis, falciparum malaria (3), meningitis and encephalitis (4). Perinatal brain injury increases*

*the risk for epilepsy in low- and middle-income countries (5), which can be reduced with better obstetric and neonatal care. Similarly, inadequate management of childhood seizures and the absence of appropriate emergency treatment (6) to stop prolonged febrile and acute symptomatic seizures lead to status epilepticus, which is associated with the development of epilepsy (7).*

*Chronic noncommunicable diseases, including stroke and other vascular diseases, contribute to the burden of seizures and epilepsy in high-income countries (8), and, with changes in lifestyle, these diseases are likely to become more frequent causes of epilepsy in low- and middle-income countries as well. Improvements in life expectancy mean that epilepsy associated with malignancies or neurodegenerative diseases (e.g. Alzheimer's disease) (9) will increase. Misuse of illicit drugs, particularly consumption of synthetic drugs, is a potential trigger for epilepsy and is more common in high-income than in low-income countries, although underassessment of illicit drug use might be partly responsible for the lower figures in resource-limited countries (10).*

# The global problem

Worldwide, more than 65 million people have epilepsy (10), making it one of the most common neurological diseases globally. The median incidence per 100 000 population per year is higher in low- and middle-income countries (81.7; interquartile range, 28.0–239.5) than in high-income countries (45.0; interquartile range, 30.3–66.7) (11); it has been estimated that nearly 80% of people with epilepsy live in low- and middle-income countries (12,13).

Epilepsy accounts for 0.6% of the global burden of disease, a time-based measure that combines years of life lost due to premature mortality and years lived in less than full health. In 2015, epilepsy caused more than 10 million "disability-adjusted life years" (DALYs) and ranked second only to stroke among selected neurological diseases in terms of years of potential life lost (14). It has significant economic implications in terms of health-care needs, premature death and lost work productivity. In a study in India in 1998, the cost of epilepsy treatment per patient was calculated to represent 88.2% of the country's per capita gross national product; epilepsy-related costs,

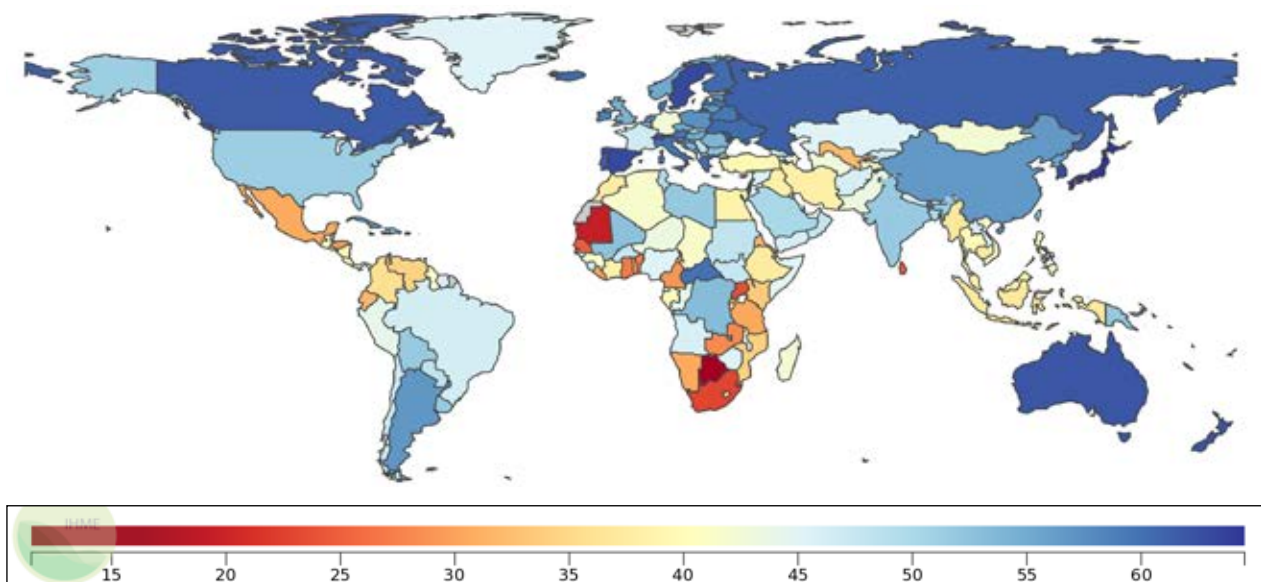
which included medical costs, travel and lost work time, exceeded US\$ 2.6 billion per year (2013 US\$) (15).

**Fig. 1** shows the ranking of countries by years lived with disability due to epilepsy in 2016.

People with epilepsy are at higher risk for physical problems like fractures and burns and have higher rates of other conditions like anxiety and depression (17). Epilepsy is also associated with a rate of premature mortality that is two to three times higher than that of the general population (18). Common causes of premature mortality include acute symptomatic disorders, such as brain tumour or stroke, sudden unexpected death, suicide and accidents (19). Epilepsy-related mortality is particularly high in low- and middle-income countries, where the risk for premature death is highest, whereas a large proportion of these deaths are potentially preventable (20).

Epilepsy also has severe social implications. The discrimination and social stigma that surround epilepsy worldwide are often more difficult to overcome than the seizures themselves. People living with epilepsy can be targets of prejudice, which often dissuades them from seeking treatment.

**Fig. 1. Global burden of disease 2016: Years lived with disability due to epilepsy per 100 000**



Source: reference (16)

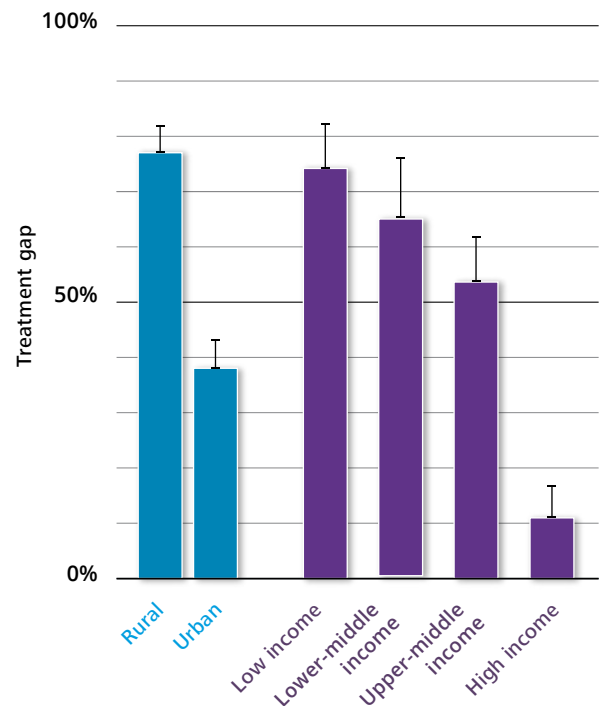
# Treatment gap

The gap in treatment for epilepsy in low- and middle-income countries is huge. A commonly used definition of the epilepsy treatment gap is the proportion of the population who require but have not received treatment for epilepsy (21). Systematic reviews show that the median gap in treatment for active epilepsy is > 75% in low-income countries, > 50% in most middle-income countries and < 10% in many high-income countries (21); similarly, treatment gaps are higher in rural than in urban areas (22) (Fig. 2). The reasons include (23):

- the low priority of epilepsy in many countries;
- limited capacity of health care systems to address epilepsy and inequitable distribution of resources;
- lack or severe shortage of appropriately trained staff;
- inadequate and inconsistent access to affordable medicines;
- societal ignorance and misconceptions; and
- poverty.

Epilepsy treatment is inexpensive and is effective in controlling seizures in around 70% of cases (24). Although effective antiepileptic medicines are on WHO's Model List of Essential Medicines (25) and are available in all countries (26), the supply, quality and availability of medicines are inconsistent. The antiepileptic medicines broadly available around the world (and on the WHO list) include phenobarbital, phenytoin, carbamazepine and sodium valproate. Phenobarbital is the cheapest antiepileptic medicine (costing less than US\$ 5 per year for an adult in 2005) (27), but its distribution has been restricted because it is classified as a controlled drug in some countries (28,29).

**Fig. 2. Disparities in the epilepsy treatment gap**



Source: reference (21)

In a study of the availability, price and affordability of antiepileptic medicines in a range of low- and middle-income countries (30), the availability of all antiepileptic medicines in the public sector was < 50%, and public sector procurement prices for generic carbamazepine and phenytoin were on average 1.56 and 2.53 times higher than the international reference prices. In countries where patients pay for medicines in the public sector, even the lowest-priced generic medication cost over four times more than international reference price, and generic phenytoin cost about 18 times more. In terms of affordability, epilepsy treatment with the lowest-price generic carbamazepine cost the lowest-paid worker the equivalent of 2.7 and 5.2 days' wages in the public and private sectors, respectively, whereas the original brand cost the equivalent of 10.3 and 16.2 days' wages, respectively. Because epilepsy management requires sustained treatment with antiepileptic medicines to avoid seizures and other health and social sequelae, the low, inconsistent availability and affordability observed in both the public and private sectors is a public health problem.



**“Analyses have concluded that the most cost-effective way of delivering epilepsy care in developing countries, in conjunction with increasing awareness and education, is delivery of standard antiepileptic medicines (especially phenobarbital) by non-specialized health care workers at primary care units in the community” (33).**



Other contributors to the epilepsy treatment gap include inadequate skilled manpower, cultural beliefs about the causes of epilepsy, use of traditional medicine and distance from a health care facility (31). For example, the median number of neurologists per 100 000 population is much lower in low-income countries (0.03) than high-income countries (2.96) (32). Analyses have therefore concluded that the most cost-effective way of delivering epilepsy care in developing countries, in conjunction with increasing awareness and education, is delivery of standard antiepileptic medicines (especially phenobarbital) by non-specialized health care workers at primary care units in the community (33).

Although the treatment gap is considered a useful measure for comparing access to care for people with epilepsy in different populations and is an important indicator for public health decision makers, its estimation requires substantial technical, human and financial resources, which are not necessarily available within a national epilepsy programme. Information on treatment gaps is usually derived from population-representative surveys to determine the number of epilepsy cases in need of services and those that receive the necessary/appropriate care. There are few such studies, their geographical coverage is limited, and their primary objective is not to collect information on the extent or effectiveness of a national programme (21).

Service coverage is a more comprehensive concept expressing the extent of interaction between the service and the target population (35). Service coverage ranges from the process of resource allocation to achievement of the desired objective.

Contact and effective coverage are two important dimensions of service coverage (35). Contact coverage is a measure of service use, which is the proportion of the target population in contact with services. Effective coverage is a measure of the impact of a programme on patient outcomes, i.e. the proportion of the target population who receive appropriate, effective care. De Silva and colleagues (36), who evaluated service coverage of health programmes, commented that estimates of contact and effective coverage are essential for scaling up of effective, equitable services for people with mental health conditions such as epilepsy and can guide improvement of the quality of existing services.

Within health information systems, data may be provided on new cases but routine data collection is often missing information on the follow-up cases, listed instead as total consultations. This makes it difficult to provide an accurate understanding of service coverage. Routine data collected by a programme can sometimes be used to calculate contact coverage, while determining effective coverage requires further information on patient health and functioning outcomes (36). However, in low-resource settings it may also be difficult to obtain routine data collected from health information systems on the number of new epilepsy cases in contact with services.





# The global response

## Global Campaign Against Epilepsy

WHO, in cooperation with the International League Against Epilepsy and the International Bureau for Epilepsy, recognizing that epilepsy is one of the most common serious chronic neurological diseases, affecting 65 million people of all ages globally, that people with epilepsy are often subjected to stigmatization and discrimination because of ignorance, misconceptions and negative attitudes about the disease and that they face serious difficulties in, for example, education, employment, marriage and reproduction, launched the Global Campaign Against Epilepsy in 1997, to bring epilepsy "out of the shadows" and to improve the treatment of people with epilepsy in resource-poor countries (37). As part of this campaign and in conjunction with other WHO projects on epilepsy, worldwide demonstration projects were set up to reduce epilepsy treatment gaps and related morbidity.

These projects, conducted in Argentina, Brazil, China, Georgia, Pakistan, Senegal, Timor Leste and Zimbabwe, have shown unequivocally that there are simple, cost-effective ways to treat epilepsy in resource-poor settings at community level, thereby significantly reducing epilepsy treatment gaps and costs.

For example, a demonstration project in China showed that trained primary health care physicians can diagnose and treat people with epilepsy. This care model resulted in a 13% reduction in the treatment gap over one year, with significant improvements in access to care for people living with epilepsy and significant reductions in costs to health systems (38). The mean total annual costs for health care and time for managing epilepsy in a sample of individuals in Ningxia Province decreased from 213 ¥ per person at baseline to 46 ¥ after the intervention. In the Shanghai region, the mean cost per patient decreased

over the same period from 1493 to 92 ¥ (39). In 2015 the project had been scaled up to 18 provinces by the national government and covering a population of 75 million (40).

**These projects...have shown unequivocally that there are simple, cost-effective ways to treat epilepsy in resource-poor settings at community level, thereby significantly reducing epilepsy treatment gaps and costs.**

To date, over 100 countries are conducting activities within the campaign, along two parallel tracks:

- raising general awareness and understanding of epilepsy; and
- supporting their departments of health in identifying needs and promoting education, training, treatment, services, research and prevention.

## WHO Programme on reducing the epilepsy treatment gap

Building on the activities of the global campaign, WHO launched the Programme on reducing the epilepsy treatment gap in 2012, to provide epilepsy care and services using a community based model.

This model combines several innovative strategies, and its implementation has demonstrated that they can be systematically and effectively applied at country level. The model includes extending the skills of non-specialist primary health care providers to diagnose, treat and follow up people with epilepsy; mobilizing nongovernmental organizations, community groups and volunteers

to raise awareness about epilepsy and support people with epilepsy and their families; and strengthening health systems to ensure sustainable access to antiepileptic medicines, reinforce referral systems and ensure better monitoring of epilepsy in health information systems. Pilot projects for the Programme were initiated in four countries: Ghana, Mozambique, Myanmar and Viet Nam.

For more information on the WHO Programme on reducing the epilepsy treatment gap, see **Annex 2**.

The Programme works in synergy with other WHO resources, including the mhGAP (41), which was launched in 2008 and includes epilepsy as one of eight priority

conditions. In this initiative, a multi-pronged approach is used to improve and scale up services for mental, neurological and substance use disorders, especially in lower-income countries. The mhGAP Intervention Guide (mhGAP-IG) (42) includes a model for epilepsy care in low-resource settings, evidence-based guidelines and treatment recommendations, which can be easily accessed and readily adapted to specific language and/or cultural contexts.

At the political level, in 2015 the World Health Assembly (WHA) adopted a resolution on the global burden of epilepsy and the need for coordinated action at the country level to address its health, social, and public knowledge implications (see below).

## WHA68.20

### *Global burden of epilepsy and the need for coordinated action at the country level to address its health, social and public knowledge implications*

WHO and its partners have long recognized that epilepsy is a major public health concern. Over several decades, international and nongovernmental organizations, academic societies and other bodies have worked in collaboration with national governments and WHO to improve access to epilepsy care and reduce stigma. In support of these efforts, the World Health Assembly in 2015 adopted a resolution, WHA68.20: Global burden of epilepsy and the need for coordinated action at the country level to address its health, social and public knowledge implications (43).

This resolution urges governments to formulate, strengthen and implement national policies and legislation to promote access to care and protect the rights of people living with epilepsy. It emphasizes the importance of training non-specialist health care providers in order to reduce epilepsy treatment gaps.

The resolution specifically calls on all Member States, with coordination by WHO, to:

- strengthen effective leadership and governance and improve provision of epilepsy care;
- integrate epilepsy management into primary health care and increase access to medicines;
- support strategies for the prevention of epilepsy;
- increase public awareness of and education about epilepsy;
- strengthen health information and surveillance systems; and
- increase investment in research and research capacity.

*This resolution is a powerful tool for WHO to help strengthen countries' capacity to address epilepsy and facilitate resource mobilization. The Fight against epilepsy initiative conducted in Ghana is one example of how the recommendations in WHA68.20 can be put into action at national level.*

For more information please visit: [http://www.who.int/mental\\_health/neurology/epilepsy/resolution\\_68\\_20/en/](http://www.who.int/mental_health/neurology/epilepsy/resolution_68_20/en/)

# The initiative to fight epilepsy in Ghana

Rationale

Project goals

Methods

- Develop a strategy for delivering epilepsy care
- Train health care workers and volunteers
- Raise awareness and educate communities
- Engage traditional and faith healers
- Strengthen the monitoring and evaluation system



**In Ghana, the treatment gap, or the percentage of people who have epilepsy and are not receiving treatment and care, is estimated to be 85% (47). Thus, of the 270 000 people estimated to have epilepsy, only 40 500 are receiving treatment.**

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# Rationale behind the initiative

## Background

Ghana lies along the Gulf of Guinea in West Africa, a few degrees north of the equator. It is a multicultural nation with a population of approximately 27 million, more than half of whom (56%) live in rural settings.<sup>2</sup>

Ghana's health system combines curative, preventive and promotional health approaches. Public health is central, with an emphasis on primary health care. Recent successes with the concept of community health planning and services have lent credence to use of community-based primary health care for increasing the access of Ghanaians to health services in both urban and rural settings.

Ghana has 10 regional hospitals and over 200 district hospitals of varying sizes and development; several other health facilities (clinics and maternal and child health services) are also available. Some private health facilities provide vital health services, but the majority of Ghanaians use public health services. Secondary and tertiary (specialist) health services are limited to three teaching hospitals in the national capital (southern belt), the middle belt and the northern belt and a few of the regional hospitals, mainly in Accra, Kumasi and Tamale. Each national, regional and district facility is autonomous but works within the regulations of the Ghanaian Ministry of Health. The structure of the Ghanaian health system is shown in [Fig. 3](#).

Like many countries in the African region, Ghana faces enormous mental health challenges, including a limited mental health workforce and infrastructure, poor or inconsistent access to medication, and social

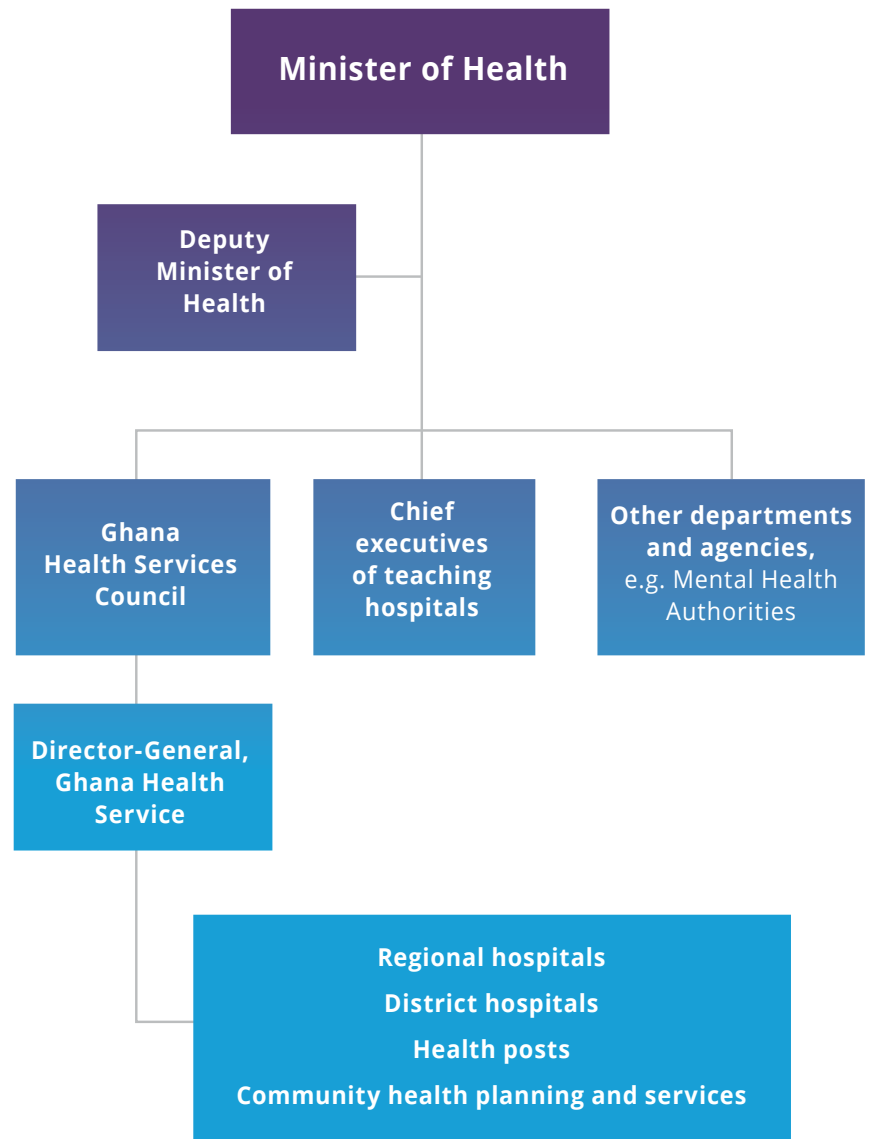
stigma. Epilepsy treatment is largely provided by specialists. Ghana has only six neurologists and 18 psychiatrists (0.07 per 100 000 population) mostly based in the country's three psychiatric hospitals or in teaching hospitals in urban areas.

A mental health workforce at community and primary care levels does exist, but their coverage is limited. At the community level, community health nurses identify and refer cases of epilepsy to the community psychiatric nurse (CPN) who are responsible for assessment and management, as well as prescribing antiepileptic medicine. At the district level, medical doctors or medical assistants assess people with epilepsy for further management. If the condition does not improve for the person with epilepsy, referral is made. There is a need to strengthen the referral networks across levels of care, offer peer support and supervision to cadres of the workforce, and raise awareness of epilepsy and its treatment options in the health services.

Faith and psychic healers are ubiquitous in Ghana, and most Ghanaians use a herbalist or spiritualist when they are ill, especially for epilepsy. There are currently about 45 000 traditional healers in the country, and 70% of people, especially in rural areas, consult traditional healers for mental health problems (44).

## Epilepsy is identified as one of the five most burdensome medical problems in Ghana.

<sup>2</sup> Ghana Fight against epilepsy initiative. Situation analysis. Accra: Ministry of Health Ghana; 2012. Unpublished.

**Fig. 3. Ghanaian Health System**

## Rationale

Epilepsy is identified as one of the five most burdensome medical problems in Ghana. It is a leading reason for referral to specialized neurological services throughout the country. In 2011, the mental health system in Ghana, including neurological disorders such as epilepsy, was assessed with an instrument devised by WHO,

**...the percentage of people who have epilepsy and are not receiving treatment and care, is estimated to be 85%.**

the WHO assessment instrument for mental health systems (50). The main reasons for attending outpatient departments in mental health facilities include epilepsy, organic mental disorders or intellectual disability (39%) (46). No other published data were available on Ghana's epilepsy treatment gap before the project.

The Korle Bu Teaching Hospital, located in the capital, Accra, estimates that it is in contact with over 1600 people with epilepsy during any one year (45). Additionally, figures published by the Ministry of Health in 2013 signalled epilepsy as the most prevalent neuropsychiatric condition seen at district and rural mental health clinics (46). This places a large burden on a country with very little capacity to care for people with mental health and neurological disorders and conditions.

The exact prevalence of epilepsy in Ghana is unknown, but Ae-Ngibise et al. in 2015 (47)

calculated it to be 10.1 per 1000, or 1% of the population, representing approximately 270 000 people. This is similar to the estimated prevalence of active convulsive epilepsy in sub-Saharan Africa as a whole, which is about 10.2/1000 people (48).

The study was conducted in Kintampo district, Brong Ahafo region (47), and found that active convulsive epilepsy was associated with a family history of epilepsy, perinatal difficulties and parasitic infection. It was concluded that strengthening health systems to include information about the risk factors for active convulsive epilepsy in

outreach programmes could reduce the prevalence of epilepsy in Ghana. These findings are similar to those of a meta-analysis carried out in 2014 (49), which indicated that the most common risk factors for epilepsy in sub-Saharan Africa were a family history of seizures, previous febrile seizures, perinatal trauma, head injury and central nervous system infections.

This study estimated the treatment gap, or the percentage of people who have epilepsy and are not receiving treatment and care, to be 85% in Ghana (47).

<sup>3</sup> Ghana Fight against epilepsy initiative. Situation analysis. Accra: Ministry of Health Ghana; 2012. Unpublished.

# Project goals

The two goals of the Fight against epilepsy initiative to be achieved in the five years 2012–2016 were to:

- 1** 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 and
- 2** develop a model of epilepsy care at primary health care level that could be scaled up and applied nationwide.







## The specific aims and steps of the project were to:

- conduct situational analyses and estimate the service coverage in the selected districts;
- assess current management (identification, treatment and follow-up) of patients with convulsive forms of epilepsy in rural and semi-rural areas of the country;
- ascertain the knowledge, attitudes and practice (KAP) with respect to epilepsy among community members in selected pilot districts;
- assess the KAP of health practitioners at the primary health level before and after undergoing training in epilepsy;
- develop a programme for continuous professional education on epilepsy for primary health care providers working in community mental health systems;
- develop outreach services for more remote district areas;
- promote public awareness about epilepsy through an educational programme for both community members and allied health care workers, including midwives;
- develop a system for monitoring and evaluating activities for epilepsy that could be integrated into established primary care and mental health information systems;
- quantify stocks of antiepileptic medication by monitoring and evaluation in order to improve procurement and distribution;
- assess the extent to which the Initiative might increase epilepsy service coverage in the districts involved in the project; and
- develop technical norms for the identification, education, treatment and follow-up of patients with epilepsy at primary health care level.



# Methods

The subsequent activities were implemented to integrate epilepsy care into Ghana's primary health care system:

- 1** Develop a strategy for delivering epilepsy care.
- 2** Train health care workers and volunteers.
- 3** Raise awareness and educate communities.
- 4** Engage traditional and faith healers.
- 5** Strengthen the monitoring and evaluation system.

# 1. Develop a strategy for delivering epilepsy care

Developing an efficient strategy for delivering epilepsy care comprised several steps: establishing a project coordination committee, establishing collaboration with stakeholders, selecting the appropriate approach and implementation sites, analysing the situation, surveying KAP and using the information to identify important potential barriers to implementation.

## Establishing a project coordination committee

In collaboration with WHO, the Ghanaian Ministry of Health assembled a national coordination committee in 2012, which was led by Accra Psychiatric Hospital in partnership with the Ghana Health Service, the Ghana Medical School and nongovernmental organizations, including BasicNeeds Ghana. The organigram in **Fig. 4** shows implementation of the Fight against

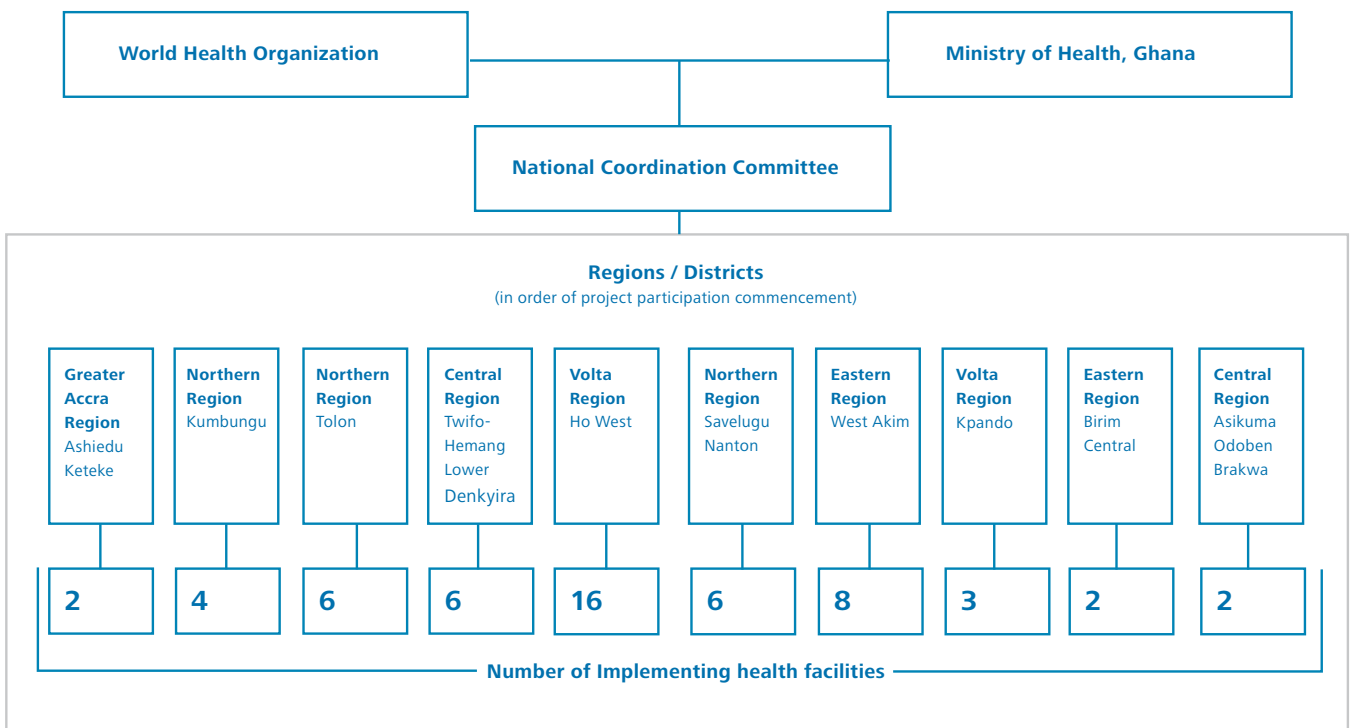
epilepsy initiative in five regions, 10 districts and 55 health facilities.

## Engaging with stakeholders

Successful implementation of projects depended on the commitment of and partnerships between government, health professionals, civil society, communities and families, with support from the international community. Over the five years of the Fight against epilepsy initiative, stakeholders provided advice and inputs on strategy and best practices and to strengthen collaboration. The discussions involved local organizations, thus ensuring their ownership and maintaining momentum to sustain the Initiative beyond the funding period. The many local organizations included the Ghana Health Services, Ghana Medical School, Christian Health Association Ghana and BasicNeeds Ghana. Refer to **Table 1** and **Fig 5**.



**Fig. 4. Organigram of the Fight against epilepsy initiative**





The responsibility of the national coordination committee was to oversee project implementation in all the regions and districts involved. The project was conducted at primary health care level, where local mental health district coordinators both took ownership of and managed the project.

In Ghana, stigma and discrimination are major obstacles to early identification, treatment and social integration of people with epilepsy. The majority of the population believes that epilepsy is caused by evil spirits and must therefore be treated by traditional and faith healers. Thus, from the start, traditional and faith healers were included in the model of epilepsy care, in addition to the most obvious stakeholders at all levels (Fig. 5 and Table 1).

**Selecting the appropriate approach and implementation sites**

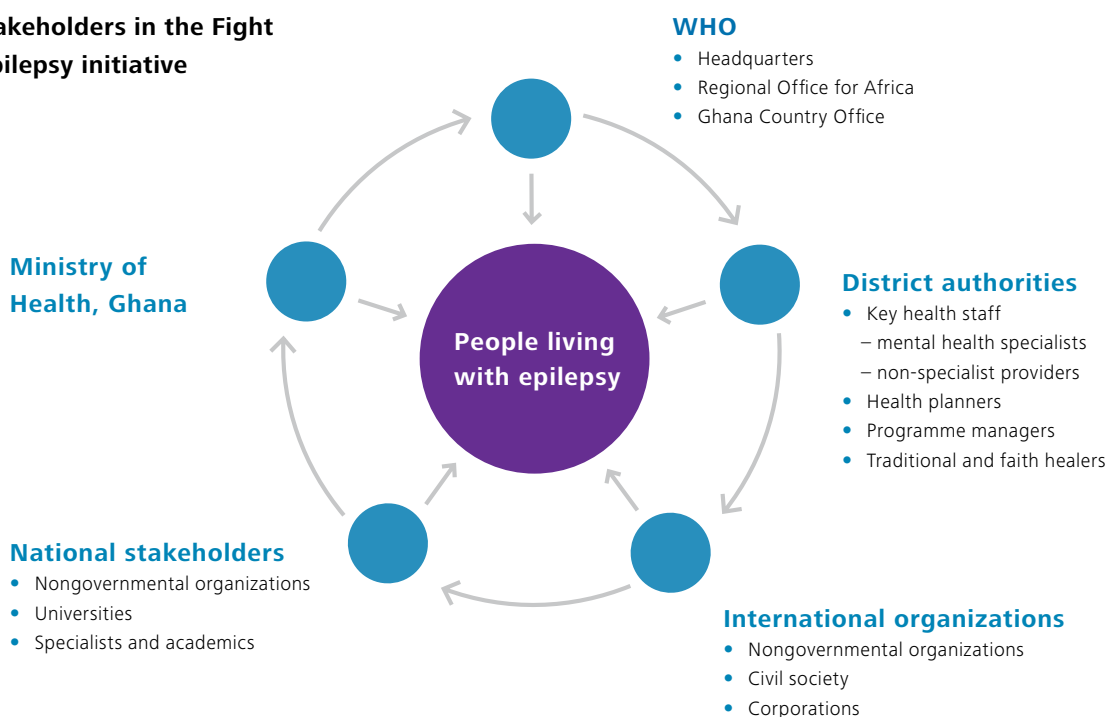
The project was implemented as a pilot strategy followed by a phased scale-up approach. In their commitment to ensure treatment of epilepsy in Ghana, the project team

developed a unique strategy for accelerated achievement of its goals and to ensure the sustainability of epilepsy treatment and care in the country. The national coordination committee first visited the district to meet with the regional health director. Together they chose a district within the region for implementation based on availability of a health workforce, high prevalence of epilepsy, and the existence of health facilities which were easily accessible.

During its first year, the project was pilot-tested at two sites in two regions: one in the Northern Region and one in the southern part of the country where the national coordination committee could learn from the successes and challenges before gradual scale up to other districts. The following year, five implementation sites in four regions were enrolled in the project. In the third year, the project was implemented in nine<sup>4</sup> districts in five regions. Overall, the project was implemented progressively in five regions. In 2014, Tolon-Kumbungu was separated into two districts, Tolon and Kumbungu. As of 2016, a total of 10 districts and 55 hospitals and clinics were involved in the Initiative (Fig. 6).

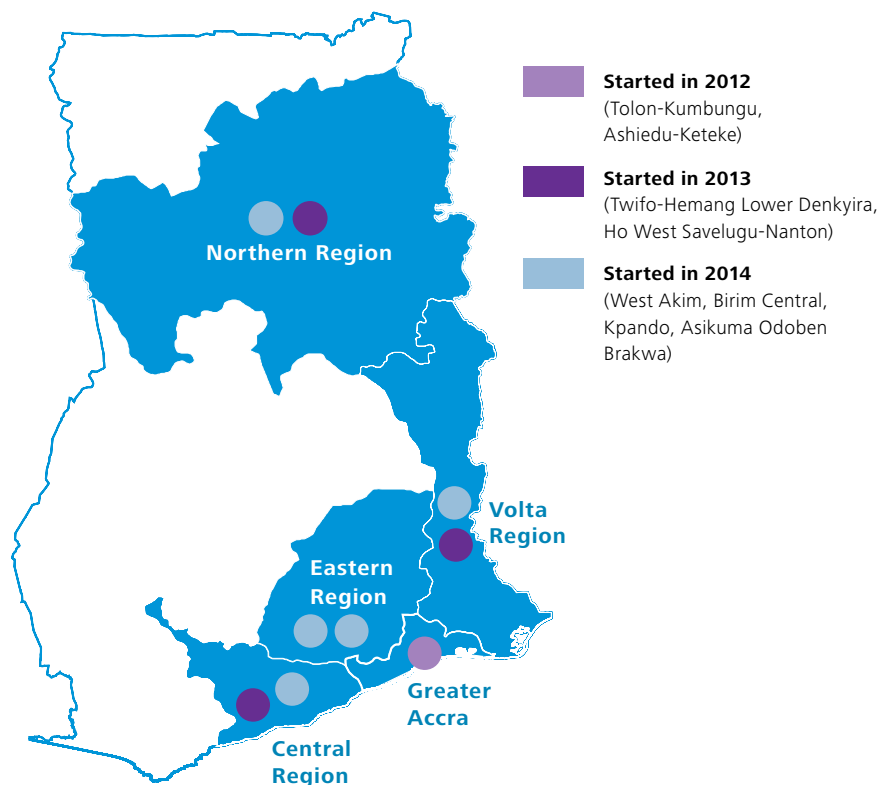


**Fig. 5. Stakeholders in the Fight against epilepsy initiative**



**Table 1. Stakeholder collaboration in Ghana's Fight against epilepsy initiative**

Stakeholder	Role
Ministry of Health officials	<ul style="list-style-type: none"> <li>Centrally involved in all decision-making and responsible for project implementation in the country.</li> </ul>
Specialists and academics	<ul style="list-style-type: none"> <li>Specialists on the national coordination committee were consulted on the design and implementation of project activities.</li> </ul>
District mental health coordinators	<ul style="list-style-type: none"> <li>District coordinators were involved in all activities implemented in their districts. They also provided feedback on achievements and challenges and supervised monitoring and evaluation of other primary health care providers.</li> </ul>
Health care providers	<ul style="list-style-type: none"> <li>General practitioners and nurses at community clinics were involved in managing epilepsy cases and provided feedback on the achievements and challenges of the project.</li> </ul>
Nongovernmental organizations	<ul style="list-style-type: none"> <li>BasicNeeds Ghana and Christian Health Association Ghana were consulted during the planning of certain activities. Both were involved in implementing many of the project's activities.</li> </ul>
International organizations	<ul style="list-style-type: none"> <li>WHO headquarters, the Regional Office for Africa and the Ghana Country Office were involved in decision-making and provided technical guidance.</li> </ul>

**Fig. 6. Regions and districts of Ghana in which the project was implemented**



## Analysing the situation

During the first year of project implementation, the Ghana project team conducted situation analyses at national, regional and district levels.<sup>5</sup> **Table 2** summarizes the information collected at each level of the health system to assess its capacity and needs for integrating epilepsy care.

All the components of the health system (51) were assessed to obtain the most comprehensive overview of the system and the factors that could affect general health and epilepsy care at each level. **Annex 1** outlines the results for each of the districts.

The situation analyses showed that the project covered 1.1 million people living mainly in rural areas with limited access to roads and communication networks. The health system comprised 1436 health care providers allocated to 172 health facilities. Of the 172 health facilities, 141 were public and 31 were private. As shown in **Fig. 7**, the public sector comprised mainly health posts (62%) and health centres (27%).

In terms of human resources, of the 1436 health care workers in the project areas, 15 were CPNs, 33 were primary care doctors, 37 were medical assistants, 920 were nurses, and 431 were CHWs. As shown in **Fig. 8**, nurses and CHWs were the main human resources available in the health system in the project areas.

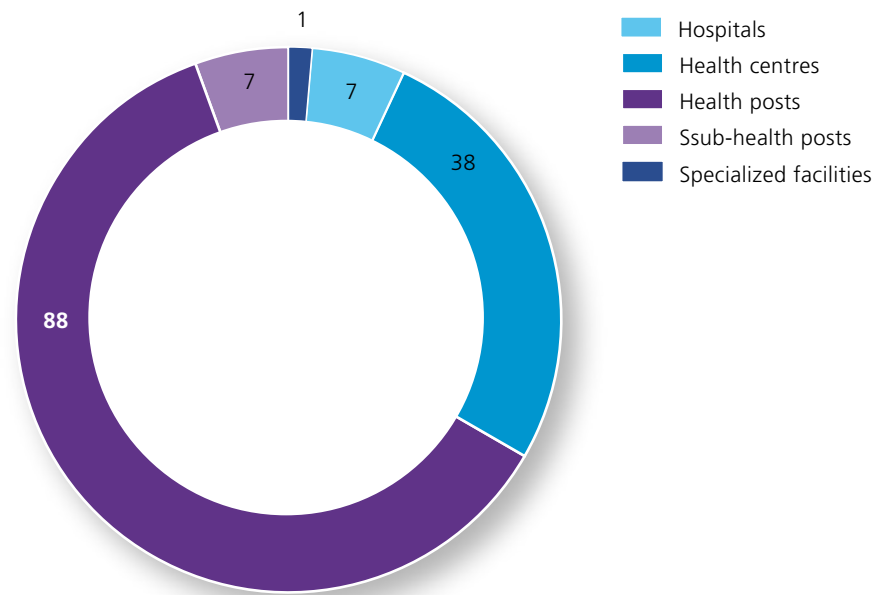


**Table 2. Components of situation analyses at each level of the health system**

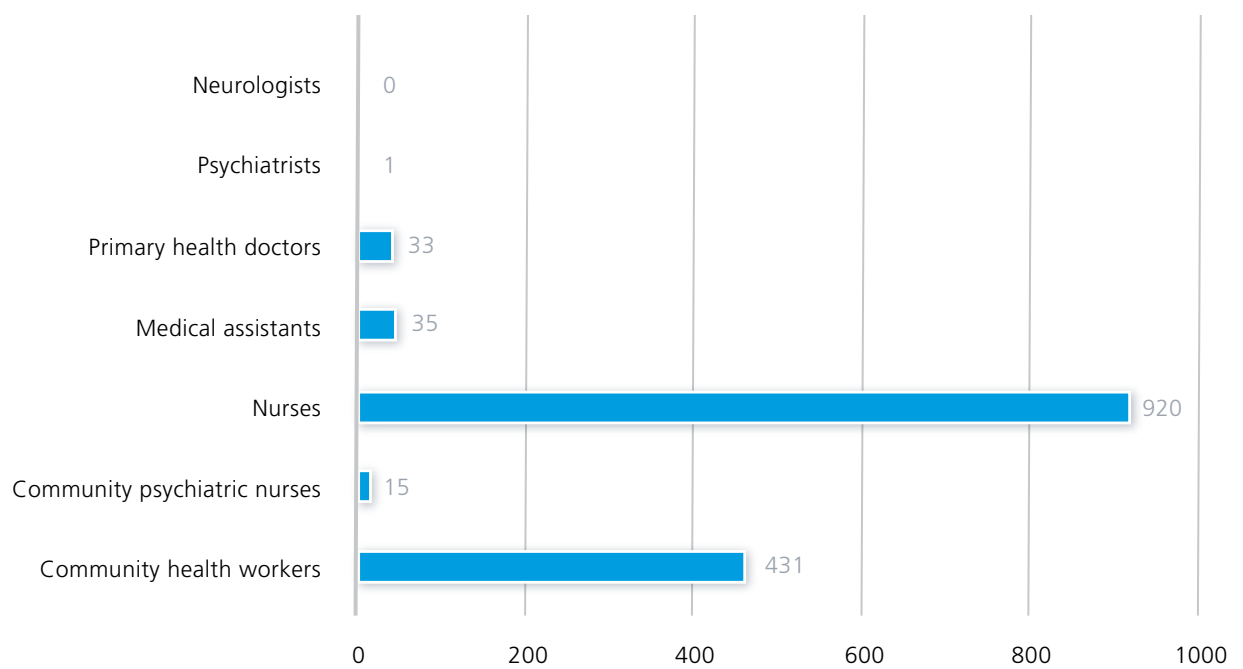
Health system building block	Component	Level of health system		
		National	Regional	District
<b>Leadership and governance</b>	Political structure, sociodemographic and economic factors	●	●	●
	Health service structure	●	●	●
	General health and epilepsy indicators	●	●	
	Psychosocial aspects of epilepsy		●	●
	Policy and legislation for epilepsy			
	Key stakeholders in epilepsy	●	●	●
	Nongovernmental organizations for people with epilepsy and their families	●	●	●
<b>Service delivery</b>	Epilepsy care guideline	●		
	Overview of health facilities			●
	Diagnostic equipment		●	●
	Pathway of care			●
	Epilepsy service use	●		●
<b>Access to medicines</b>	Epilepsy medications and treatment	●	●	●
<b>Health workforce</b>	Human resources	●	●	●
	Epilepsy care training			●
<b>Financing</b>	Budget and financing	●		●
<b>Health information system</b>	Epilepsy information systems	●		●
<b>Community awareness and promotion</b>	Public education and promotion programmes	●	●	●
	Informal care for people with epilepsy and their families		●	

<sup>5</sup> Ghana Fight Against Epilepsy Initiative. Situation analysis. Accra: Ministry of Health Ghana; 2012. Unpublished..

**Fig. 7. Number and type of health facilities in the public sector in project areas**



**Fig. 8. Human resources available in the project areas**



Situation analyses at district level included estimates of the number of people registered as having received epilepsy care at the facilities before the project. From this information and published estimates of the prevalence of epilepsy in Ghana, the approximate contact coverage was estimated in the districts involved in the project. These ranged from 0% in Birim Central to 49.9% in Tolon; the overall contact coverage was estimated to be approximately 14.5% (Table 3).

Contact coverage is calculated as the ratio between the number of people with epilepsy contacting services of those estimated to need those services in the population (36). To understand the impact of the project on contact coverage, routine clinical information on the number of new cases of epilepsy would be needed before the project began. In Ghana this information was not available, thus the estimated number of cases (based on prevalence estimates) was used to estimate contact coverage before the project.

Regarding the availability of antiepileptic medicines, the analysis revealed that carbamazepine, phenobarbital and phenytoin were available in most districts but usually only in hospital. There were frequent shortages.

The situation analyses showed that people living with epilepsy frequently faced stigmatization and discrimination, especially with regard to marriage, education and employment. In order to obtain better understanding of the underlying social concepts of epilepsy, a KAP survey was conducted.

### Understanding knowledge, attitudes and practice

Successful integration of epilepsy care into the primary health system requires good understanding of the community's representations, including KAP, of the disease and its treatment. A KAP survey is a method for obtaining both quantitative and qualitative information about a topic. KAP surveys reveal misconceptions or misunderstandings that may represent obstacles to certain activities in a project and potential barriers to behaviour change.

A KAP survey was therefore conducted during the first year of the project among both community members and health professionals. Predefined questions were formatted in a standardized, culturally sensitive questionnaire. The survey was conducted in four districts (Asikuma Odoben

**Table 3. Estimated contact coverage in each district before project implementation (2012)**

District	Population	Estimated no. of cases <sup>a</sup>	Cases registered before project	Contact coverage before project (%)
Ashiedu Kete	117 525	1175	110	9.4
Asikuma Odoben Brakwa	115 881	1159	156	13.5
Birim Central	140 978	1410	0	0
Ho West	100 364	1004	No data	0
Kpando	112 037	1120	No data	0
Kumbungu	39 341	393	196	49.8
Savelugu Nanton	139 283	1393	98	7.0
Tolon	72 990	730	364	49.9
Twifo–Hemang Lower Denkyira	138 696	1389	97	7.0
West Akim	165 931	1659	642	38.7
<b>Total</b>	<b>1 143 026</b>	<b>11 432</b>	<b>1663</b>	<b>14.5<sup>b</sup></b>

<sup>a</sup> Based on an estimated prevalence of epilepsy in Ghana of 1% (47)

<sup>b</sup> Based on the proportion of cases registered before the project and the estimated number of cases.



Brakwa, Birim Central, Kpando and West Akim), with 929 respondents. The target group was people who had direct contact with patients with epilepsy, comprising mainly community nurses, psychiatry nurses and physicians' assistants in charge of psychiatry units in various health centres; it also included students, unemployed people, privately employed people, farmers and homemakers. Some of the questions and results are listed in **Table 4**, showing quantitative data, while **Table 5** gives qualitative information obtained from the survey.

The data collected in the KAP survey suggest that, while most of the respondents knew about epilepsy, more than one third would object to their children associating with or marrying a person with epilepsy. More than half of the respondents said that epilepsy was associated with insanity or madness. Qualitative analysis revealed misconceptions about both the etiology and treatment of epilepsy.

These results, in addition to other information collected from the KAP survey, revealed specific misconceptions about epilepsy and its treatment. This information was used to prepare targeted education programmes to tackle epilepsy stigma.

### **Using the information to identify important potential barriers to implementation**

The information collected during the situation analyses and the KAP survey show that access to care in Ghana for people with epilepsy is limited by both cultural factors and health system issues.

Cultural beliefs and misconceptions about the disease are common and lead to stigmatization of people living with epilepsy. Stigmatization is commonly based on myths and beliefs about contagion and spiritual afflictions and often results in discrimination. People living with epilepsy in Ghana may be refused schooling, employment and marriage and may even be disassociated from

their families. As a consequence, people living with epilepsy may conceal their disorder and avoid seeking or attending medical treatment.

Because the majority of the population believes that epilepsy is caused by evil spirits, they believe it requires treatment by traditional and faith healers. Traditional practices are widely accepted, and unrealistic perceptions of causes and treatments are common. With witchcraft, these ideas tend to fuel the perception of epilepsy as a stigma (52). At present, there are no protective policies or legislation in Ghana for people with epilepsy. Similarly, no government-supported public education or awareness programmes have been developed.

## **The lack of capacity of health care workers to diagnose and manage epilepsy is a significant barrier to epilepsy care in Ghana. Many districts have no neurologists, and specialists are found only in the main cities.**

Access to care for people with epilepsy in Ghana is also limited by structural health system barriers related to service delivery, the health workforce, access to medicine, the health information system, financing and leadership and governance.

Epilepsy care in Ghana is not harmonized throughout the country. There are no national guidelines for epilepsy care, no referral mechanisms and no technical supervision of non-specialist health workers offering care and services to people with epilepsy. The distance and cost of transport to attend health facilities is also a major barrier to accessing medical treatment.



**Table 4. Results of the Ghana KAP study (N = 929)**

Question	Response option (n, %)			
	Yes	No	Not familiar with epilepsy	No opinion
Have you ever heard of or read about a disease called "epilepsy" or "convulsive seizures" (fits)?	868 (93.4%)	61 (6.6%)	–	–
Have you ever known anyone who had epilepsy?	678 (73.0%)	249 (26.8%)	2 (0.2%)	–
Have you ever seen anyone having a seizure or fit?	723 (77.8%)	203 (21.9%)	3 (0.3%)	–
Would you object to any of your children associating with others who sometimes had seizures (fits) in school or at play?	355 (38.2%)	368 (39.6%)	206 (22.2%)	–
Would you object to your son or daughter marrying a person who sometimes had seizures (fits)?	304 (32.7%)	419 (45.1%)	206 (22.2%)	–
Do you think people with epilepsy should be employed like other people?	866 (93.2%)	0 (0.0%)	63 (6.8%)	–
Do you think epilepsy is a form of insanity or madness?	465 (50.1%)	321 (34.6%)	87 (9.4%)	56 (6.0%)

**Table 5. Example responses about the treatment of epilepsy**

Treatment	Examples given by respondents
<b>Spiritual</b>	<i>"Women with epilepsy are married to spirits called 'jinni'. These spirits are exorcised by spiritualists."</i>
<b>Diet restriction</b>	<i>"Patients with epilepsy who are receiving local traditional treatment are often forbidden to eat some protein foods, such as fresh goat and poultry meat, eggs, blackfish and cow meat." "Patients with epilepsy should not bathe or drink water that has been fetched from the river the previous day." "Patients with epilepsy should not eat food that was purchased the previous day."</i>
<b>Extreme treatment</b>	<i>"A patient with epilepsy can never be healed if he or she falls into a fire." "A virgin female patient with epilepsy will be healed if she has sex with an elderly man." "A patient with epilepsy can be treated by bathing in equal quantities of hot and cold water successively twice daily for 10 days."</i>
<b>Incurable</b>	<i>"Epileptic seizures that occur in a public place such as a market or at church cannot be cured." "Epilepsy that occurs as a result of witchcraft cannot be treated." "If a patient with epilepsy falls onto a fire, treatment cannot be effective again."</i>
<b>Herbs</b>	<i>"Only herbs can cure epilepsy." "If a herbalist provides medicines and a patient has seizures after the third day, the medicine will not be effective."</i>

<sup>5</sup> Ghana Fight Against Epilepsy Initiative. Situation analysis. Accra: Ministry of Health Ghana; 2012. Unpublished.

The lack of capacity of health care workers to diagnose and manage epilepsy is a significant barrier to epilepsy care in Ghana. Many districts have no neurologists, and specialists are found only in the main cities. In 2012, Ghana had a total of five neurologists (including one in the private sector), 19 psychiatrists (five in the private sector), three neuropsychologists, one neurosurgeon, one occupational therapist, 260 CPNs and no neurology nurses<sup>6</sup> (Fig. 9). Other than neurologists and psychiatrists, health care workers do not receive formal training or supervision in epilepsy management.

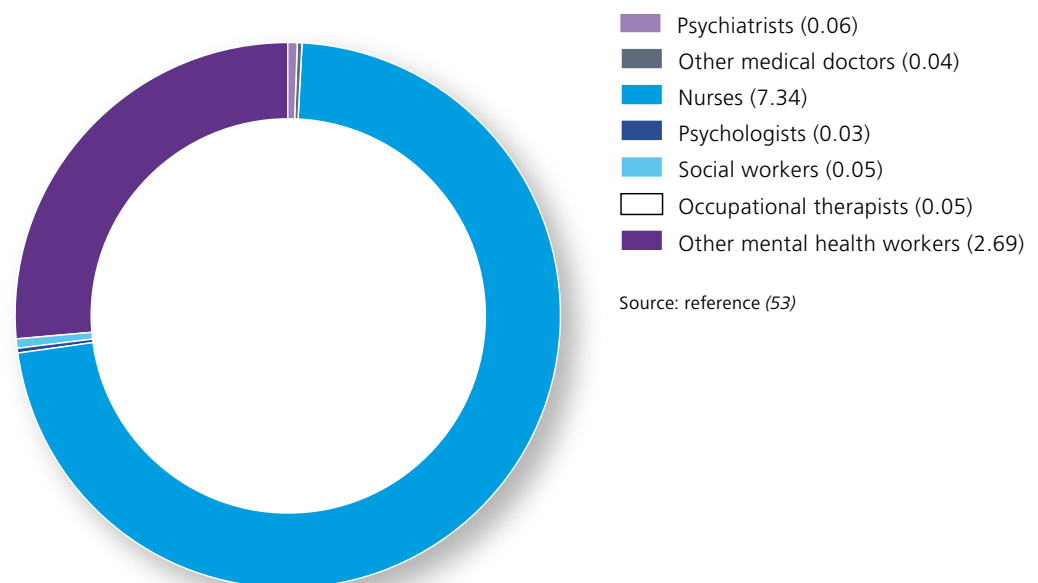
The quality of health information systems for the collection, storage and analysis of data on epilepsy varies by district, so that monitoring, data synthesis and evaluation at regional or national level are difficult. No national indicators on epilepsy are collected.

The availability of medication is an essential part of service provision for epilepsy. Ghana has problems with medication

stock-outs, and medication financing also limits access. A major difficulty is accessing epilepsy medications through the national health insurance scheme. Financing for epilepsy care is very limited, as there is no national budget or assistance programme specific for epilepsy. Nationally, although epilepsy has been identified as a major health problem, it is neither part of the noncommunicable diseases policy nor the mental health policy. These governance barriers obviate national coverage of epilepsy care in Ghana.

Similar challenges are found in all developing countries. Recommendations to improve access to care include integration of epilepsy management into primary health care by regular training and supervision of primary health care workers, support for prevention strategies, increasing public awareness and education and strengthening health information systems and research on epilepsy (23,43,55).

**Fig. 9. Ghana's mental health workforce, per 100 000 population**





## 2. Train health care workers and volunteers

Training of primary health care providers and CHWs is a key element in the integration of epilepsy care into the primary health care system. Regular supervision by specialists is also essential to ensure the delivery of high-quality epilepsy care by trained primary health care providers (54). Following these principles, a cascade model of training was put in place in Ghana.

- Specialists, such as neurologists and psychiatrists, were trained to become trainers and supervisors in epilepsy care management.
- Non-specialist primary health care providers, including CPNs, general practitioners and nurses, were trained to diagnose and treat epilepsy.
- CHWs and volunteers, including traditional and faith healers, midwives, teachers, nongovernmental organization staff and other health staff, were trained to detect potential cases of epilepsy, to assist in acute seizure episodes and to refer patients for further medical care.

The WHO epilepsy-related mhGAP materials (41) and its intervention guide (42) were adapted to the cultural context of Ghana. The materials included PowerPoint slides, brochures, pamphlets, posters and videos showing the management of convulsive seizure episodes. Overall, 1514 people were trained in the project, comprising 29 trainers and supervisors, 690 non-specialist health-care workers, 770 community volunteers and 25 psychiatric nurses and district pharmacists in all the participating districts in quantification of antiepileptic medicines and inventory control (Table 6).

**Table 6. Training conducted in Ghana's Fight Against Epilepsy Initiative, 2012–2016**

Training sessions	Year	No. of participants
<b>Trainers and supervisors</b>	2013	14
	2016	15
<b>Non-specialists</b>	2012	81
	2013	95
	2014	228
	2015	286
	2016	286
<b>Community volunteers</b>	2013	150
	2014	180
	2015	440
	2016	440
<b>Psychiatric nurses and district pharmacists (quantification of antiepileptic medicines)</b>	2014	25
<b>Total</b>		<b>1514</b>

**“Proper medication, proper medical attention,  
and a supportive environment can make a person  
with epilepsy live a better and more fulfilling life  
.... It is my wish and prayer that together we will  
educate everybody on epilepsy.”**

---

Mrs Francesca Aba Larbie,  
health care provider, Ghana

### 3. Raise awareness and educate communities

Raising awareness of epilepsy in communities is an important aspect of integration of epilepsy care into the primary health system and ensuring contact between people with epilepsy and health facilities. From the outset, the project team therefore invested time and energy into community awareness-raising about epilepsy.

The team first identified and engaged various community groups to collect information on attitudes towards epilepsy, stigma and associated factors and then prepared educational materials and carried out educational and awareness-raising campaigns. A communication strategy was adopted in which a number of channels of communication were used to disseminate the messages and to encourage people with epilepsy to seek treatment. These included mass community *durbars*<sup>7</sup>, FM radio broadcasts, newspaper articles and health education sessions. In addition, pamphlets and posters were prepared, which were distributed and posted in community clinics, larger hospitals and outreach services.

Overall, 1386 community awareness-raising activities were conducted with a total estimated audience of 96 094. The audiences included service users and carers, church members, students, schoolteacher, health care workers at local hospitals and outpatient clinics, the general public at *durbars*, market women, pregnant women and nursing mothers. The topics of the talks on epilepsy included:

- epilepsy and its management
- causes of epilepsy
- debunking myths about epilepsy
- living with epilepsy
- compliance with medication
- the availability and use of antiepileptic medicines
- what to do during a seizure
- home management of epilepsy
- prevention of accidents
- reducing stigmatization of epilepsy and
- the role of the community in supporting people with epilepsy.

These formal and informal communication strategies not only assisted in reducing stigma but also promoted awareness about the Initiative and increased the referral of undiagnosed cases of epilepsy.

*After attending information sessions on epilepsy organized by the Fight Against Epilepsy Initiative, Thomas Papa Nil Larbie was bold enough to bring his wife, Francesca, to a project-led clinic, where antiepileptic medicines were prescribed for her for the first time – medicines that have completely changed her life for the better. People previously told Francesca that she couldn't give birth because of her epilepsy. But she has! And she and her husband now have two lovely children. Thomas and Francesca have become role models and are living examples of how cost-effective medications and treatment for epilepsy can change lives.*

<sup>7</sup> A *durbar* in Ghana is a gathering of a community of people during which issues concerning the welfare of the group are discussed or information is shared. Members are given the opportunity to share their opinions and views.

**“At first, I would try curing them myself, rather than taking them to a hospital. But now I combine the two, and healing is faster.”**

Hannah Kyere, prayer group leader, West Akim





## 4. Engage traditional and faith healers

Traditional or faith healers are a popular first port of call for treating epilepsy. As people believe that epilepsy is a spiritual ailment, they also believe that it must be treated by traditional and faith healers. In some regions of Ghana, spiritual healing or prayer camps are often preferred to medical treatment. This results in delayed medical treatment and possibly irreversible brain damage, particularly in children (55).

From the inception of the project, a major goal of the Fight Against Epilepsy Initiative was to improve collaboration with community leaders, including traditional and faith healers. About 284 meetings were held in the five implementation regions to increase awareness of the project and to reduce stigmatization. Two-way referral systems have since been developed, and cross-sectoral care has been achieved. Up to 3% of new cases of epilepsy are now referred to community mental health units by traditional and faith healers.

## 5. Strengthen the monitoring and evaluation system

Monitoring and evaluation help to improve current and future management of outputs, outcomes and impact by ensuring collection of information, evaluation of project performance and comparisons with the goals and plans of Ghana's Fight against epilepsy initiative.

A monitoring and evaluation plan was developed and implemented. It included new patient forms, follow-up patient forms, facility forms and a follow-up register to collect information on patients coming for follow-up reviews and treatment. Patient data included gender, age, referral method, national health insurance status, adherence to medications and improvements in seizures and quality of life. Facility data included the total numbers of new patients and follow-up patients seen each month, supervision visits, stocks of antiepileptic medication, the numbers of outreach clinics and home visits conducted, the number of epilepsy education sessions and meetings with traditional and faith healers. This information helped the team to understand the patterns of epilepsy service use, patient outcomes and supplies of antiepileptic medication.

*Like Hannah Kyere, Stephen Kontoh now also refers some people with epilepsy to health facilities for treatment. Stephen, Kotokye's most popular faith healer, oversees all other faith healers in the three districts of Ghana's central region. He runs a prayer camp in Kotokye, where people with various illnesses stay for up to 6 months and those with epilepsy stay for two years.*

*Stephen believes that there are two kinds of epilepsy: "spiritual epilepsy" and "physical epilepsy". When he meets a person with epilepsy, the spirits tell him which kind of epilepsy the person has. If it is of spiritual origin, he treats the person himself, in the prayer camp, with prayers and sometimes herbs. If the epilepsy is of physiological origin, he refers the person to the nearest health facility for medical treatment.*

*Stephen's prayer camp is only 20 metres from the community health clinic where the WHO Programme for reducing the epilepsy treatment gap was implemented. As part of the project, several community volunteers who work at the health clinic were trained about epilepsy and to support people with epilepsy in the community. Stephen welcomes the initiative and supports it by sending many people for treatment.*

# Review & next steps

Results

Lessons learnt

Moving forward: sustaining epilepsy care in Ghana

- National epilepsy policy
- National plan to scale up epilepsy care

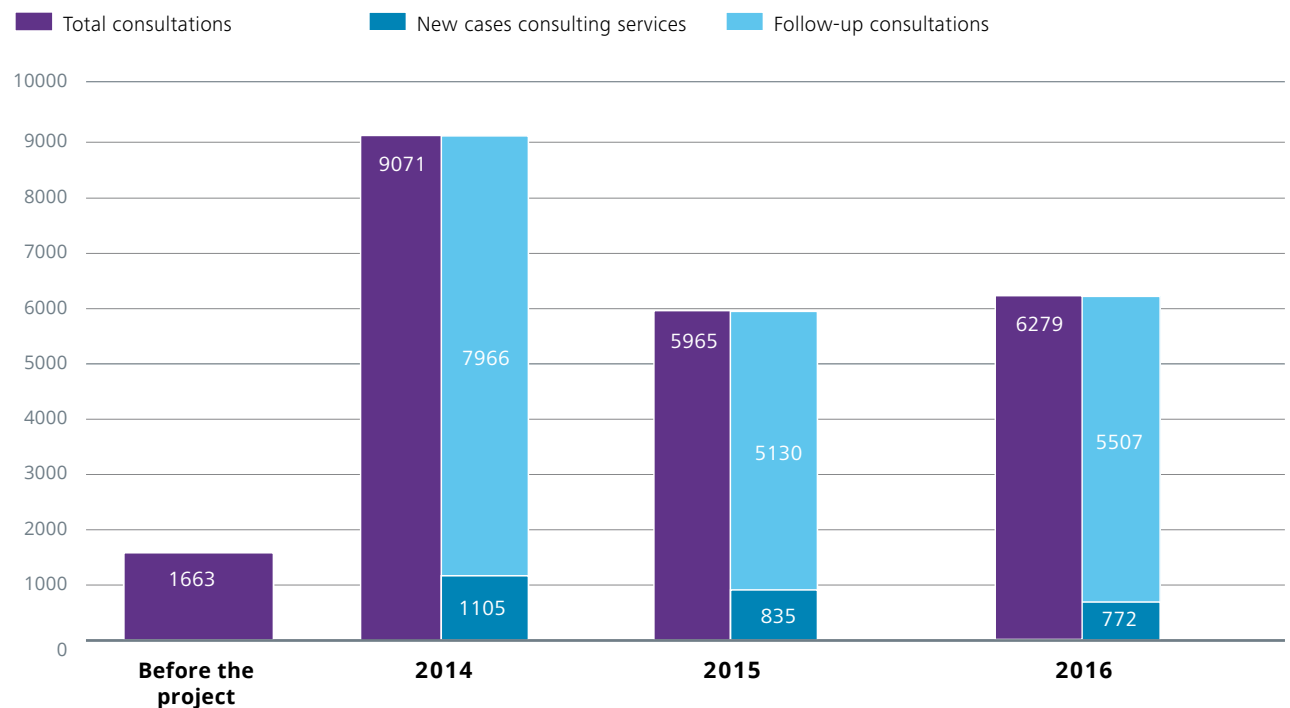
# Results

The implementation of the project in ten districts led to 21 315 epilepsy consultations, with 2712 new cases identified in the community. As shown in **Fig. 10**, the number of annual epilepsy consultations increased four times in the course of the project.

When calculating service coverage, data should include both new and follow-up cases. The ideal method to determine service coverage is the actual number of people using epilepsy services as the numerator and the target population in need of services based on population-representative surveys as the denominator. In the absence of such data, data on the prevalence of epilepsy in Ghana (47) was used as a proxy measure to estimate the number of people living with epilepsy in the project districts and contact coverage estimates were based on the number of new cases only.

**Table 7** and **Fig. 11** show the improvements in contact coverage (i.e the proportion of the target population in contact with services) over the course of the project in all the districts involved. Overall, epilepsy contact coverage improved from 14.5% to 38.3% in five years. This is an underestimate of actual contact coverage as it's only based on the number of new cases. As shown in **Fig. 10**, the number of follow-up consultations also increased during the project thus reflecting a further increase in service utilisation. As data were only available on follow-up visits and not on cases, this information could not be used for estimating changes in contact coverage. Differences were found between districts, Twifo-Hemang Lower Denkyira showing the maximum increase, from 7% to 48.5%. Differences in the improvement of contact coverage among sites can be explained by the different starting dates of the project and the frequent turnover of health care providers in Ghana. For example, districts that started implementing the project in 2014 showed a smaller increase in contact coverage than those that started in 2012 and 2013.

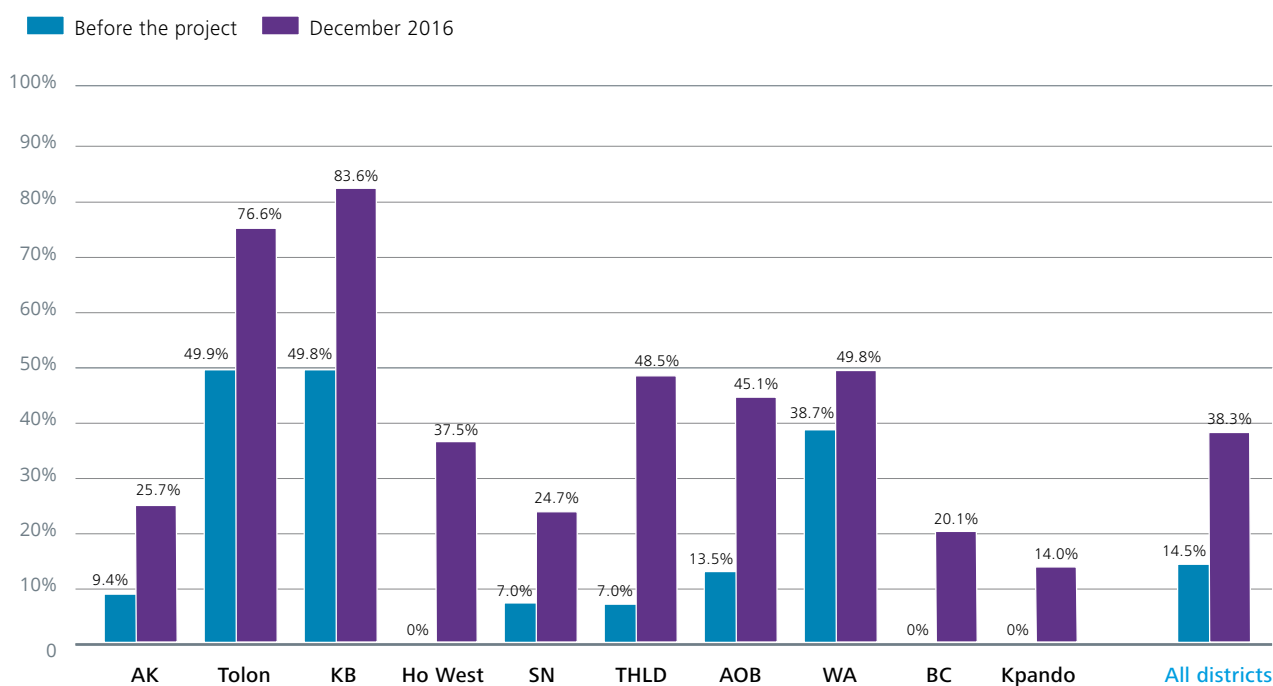
**Fig. 10. Number of epilepsy consultations provided in the ten implementing districts in Ghana, 2012–2016**



**Table 7. Contact coverage improvement for epilepsy in ten districts in Ghana, 2012–2016**

District	Start	Estimated no. of new cases <sup>a</sup>	No. of cases before 2012	Total no. of new cases as of December 2016	Contact coverage as a percentage	
					Before 2012	December 2016
Ashiedu Kete	2012	1175	110	302	9.4	25.7
Tolon	2012	730	364	559	49.9	76.6
Kumbungu	2012	394	196	329	49.8	83.6
Ho West	2013	1004	No data	377	0.0	37.6
Savelugu Nanton	2013	1393	98	344	7.0	24.7
Twifo–Hemang Lower Denkyira	2013	1389	97	674	7.0	48.5
Asikuma Odoben Brakwa	2014	1159	156	523	13.5	45.1
West Akim	2014	1659	642	826	38.7	49.8
Birim Central	2014	1410	No data	284	0.0	20.1
Kpando	2014	1120	No data	157	0.0	14.0
<b>Total</b>		<b>11 432</b>	<b>1663</b>	<b>4375</b>	<b>14.5</b>	<b>38.3</b>

<sup>a</sup> Based on 1% estimated prevalence of epilepsy in Ghana (47)

**Fig. 11. Changes in contact coverage by district, 2012–2016**

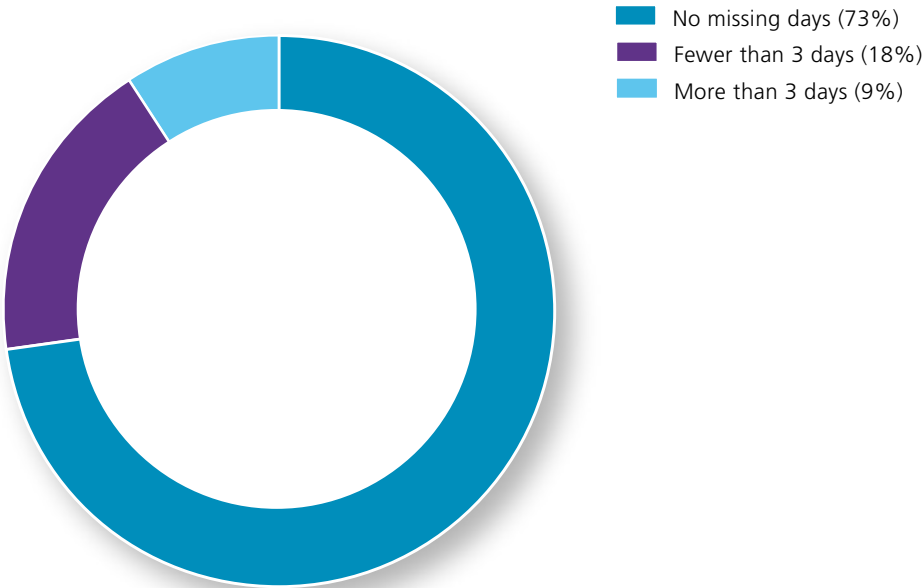
AK, Ashiedu Kete; KB, Kumbungu; SN, Savelugu Nanton; THLD, Twifo–Hemang Lower Denkyira; AOB, Asikuma Odoben Brakwa; WA, West Akim; BC, Birim Central

The adherence of people with epilepsy to their medication varied by district. The best adherence rates were recorded in West Akim and Birim Central, with 91% and 90% of patients not missing any days of medication, respectively. The average rates across districts were 73% of patients who missed no days, 18% who missed fewer than three days of medication per month and 9% who missed more than three days of medication per month (Fig. 12). Factors that may explain the differences among districts include inconsistent supplies of medication during the year. The district that reported the most frequent stock-outs of antiepileptic medications, Ashiedu Kete, was also that which recorded the poorest rate of adherence to medication.

On average in the project districts, 98% of patients reported reduced seizure frequency; of these, 52% reported being seizure free. Similarly, 93% of patients reported improved quality of life, which included health, work and interpersonal well-being. Only 3% of cases in all district health units required referral to specialist services for epilepsy management.

These data enabled the team to evaluate the performance of the project and its impact on people living with epilepsy, to estimate reductions in the epilepsy treatment gap continually and to identify areas that require improvement.

**Fig. 12. Average medication adherence rates in all districts**



# Lessons learnt

*Lessons learnt are an important part of demonstration projects. The many lessons learnt from Ghana's Fight against epilepsy initiative are useful to inform the WHO Programme on reducing the epilepsy treatment gap and other programmes in treating epilepsy worldwide.*

## **Approach**

The dearth of specialists in Ghana to provide mental health and neurological care indicated that task-shifting would be the most appropriate approach to meet the mental health and epilepsy needs of the population. "Task-shifting" is delegation of tasks, when appropriate, to less specialized health workers (56). Additionally, a decentralization policy promoted gradual involvement of regional health bureaux and specialists at both administrative and technical levels.

## **Using effective tools**

Since their introduction in 2010, mhGAP tools have supported countries in providing mental health services where they were not previously available. As in Ghana, integrating mhGAP resources into training and other health systems can accelerate health system strengthening and expansion.

## **Training non-specialists**

Training health care workers who are not mental health professionals in recognizing, referring and managing people with epilepsy is a pivotal aspect of the WHO Programme on Reducing the Epilepsy Treatment Gap. In most low- and middle-income countries, where the prevalence of epilepsy and the epilepsy treatment gap are

highest, the number of mental health specialists for the overall population is very low, especially in rural areas.

## **Involving mental health specialists**

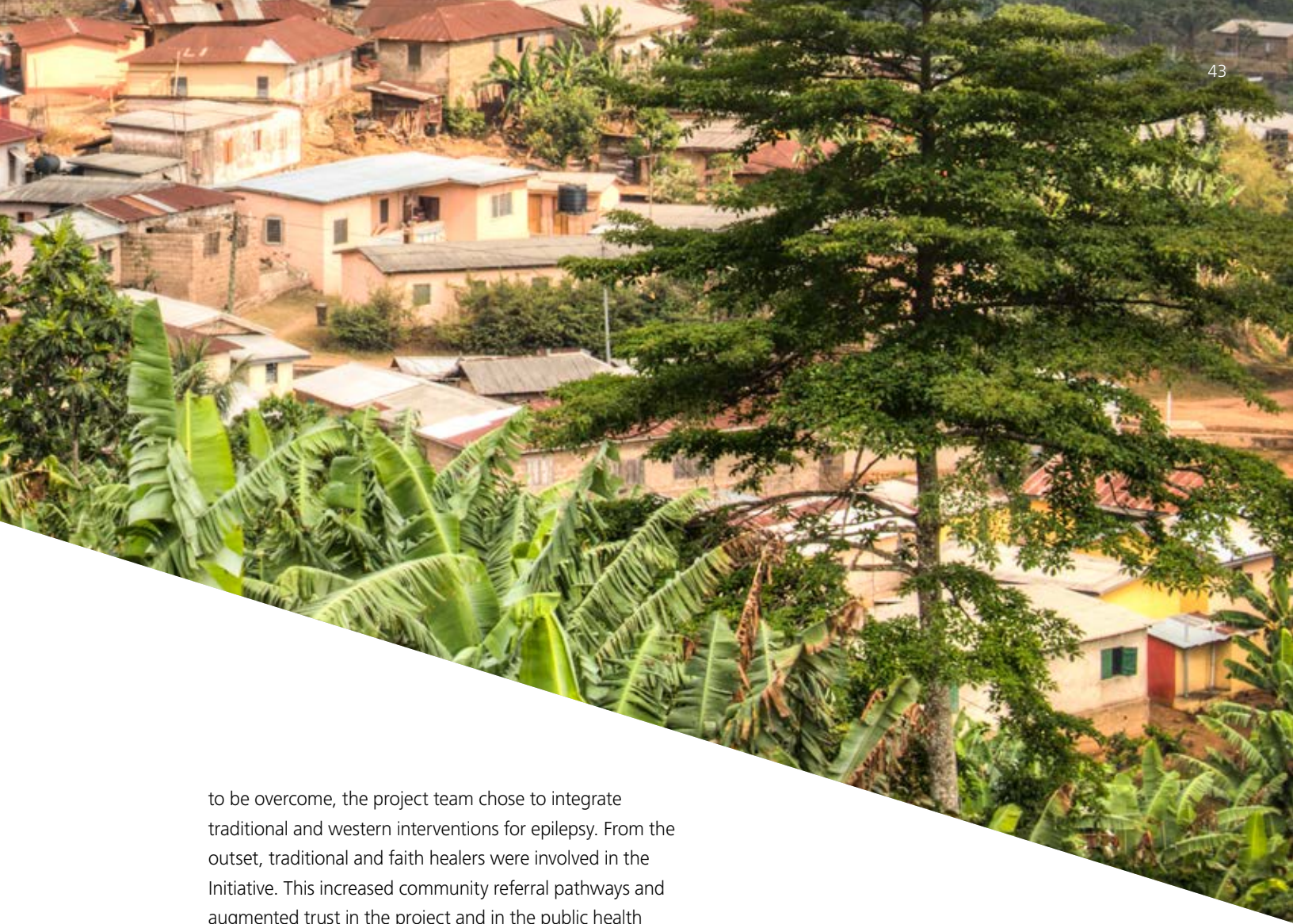
Training mental health professionals to train and supervise others has proved to be effective in delivering a basic package of services for people with epilepsy and other mental disorders. The supervisory skills acquired enable them to support non-specialist health workers, thus contributing to the sustainability of diagnosis, treatment and management of epilepsy and people with epilepsy over time and over larger geographical areas.

## **Ensuring a consistent supply of antiepileptic medications**

For as little as US\$ 5 per day, 70% of people with epilepsy can live a symptom-free life. Yet most people in the countries with the highest treatment gaps do not have consistent access to these inexpensive medications. Lack of a consistent supply and poor distribution to rural areas significantly affect the care of patients. While a key element of the WHO Programme on Reducing the Epilepsy Treatment Gap is the provision of a regular supply of antiepileptic medications, it is equally important to ensure that the distribution infrastructure and pharmaceutical legislation are supportive.

## **Collaboration with traditional and faith healers**

In Ghana, beliefs and cultural traditions are deeply entrenched in society. Rather than viewing them as barriers



to be overcome, the project team chose to integrate traditional and western interventions for epilepsy. From the outset, traditional and faith healers were involved in the Initiative. This increased community referral pathways and augmented trust in the project and in the public health approach to treating epilepsy. Respectful cooperation with and education of traditional and faith healers and other community members can improve the rate of medical treatment of epilepsy and reduce stigma.

### **Instilling a culture of data and analysis**

In order to better serve people with epilepsy worldwide, it is essential to have information on who they are, where they live and how many they are. This is possible only with a robust data collection and analysis system. In Ghana, data on epilepsy are now being collected on mhGAP supervision forms. The results will provide further insight into the epidemiology of epilepsy and other mental health disorders in Ghana and, eventually, throughout the African continent.

### **Establishing a committed, solution-oriented team**

Challenges are inevitable in projects, particularly those that involve integration and cultural changes. Ghana's Fight

against epilepsy initiative team stood firm in its commitment, showed resilience, and continued to nurture its ambitious but attainable vision. Communication and feedback at all levels were particularly important, promoting a functional, focused team.

### **Sharing challenges and successes with other low- and middle-income countries:**

Almost four years into the demonstration project, more than 150 stakeholders from 17 countries convened in Accra, Ghana, to discuss the project's achievements and the challenges that remain in improving epilepsy care in the African Region. The discussions resulted in a framework for advancing epilepsy care in the Region. Sharing experiences, challenges and successes creates momentum and serves as an impetus for others to embark on the journey to reduce the epilepsy treatment gap in their countries.

# Moving forward: sustaining epilepsy care in Ghana

Ghana's Fight Against Epilepsy Initiative has demonstrated that simple, cost-effective strategies for delivering epilepsy care at the primary health-care level are achievable and effective in increasing service coverage. The Ministry of Health, Ghana has taken steps to improve access to epilepsy care beyond the pilot project. This has included discussions about endorsing a national model of epilepsy care and expanding the Initiative within the regions already involved, followed by complete nationwide scale up.

**“Ghana is ready to own this project and scale it up to all 10 regions of the country to improve access to quality care and services for people with epilepsy, and raise epilepsy as a priority on the national health agenda.... We believe that the learning that has taken place will be replicated and scaled up in all the regions of Africa and elsewhere.”** >>

Honourable Mr Alex Segbefia,  
Former Minister of Health, Ghana







## National epilepsy policy

National policies govern the treatment of medical disorders in a country and the population affected by the disorder. A well-formulated policy is the first step towards improving access to care and services. Apart from implementation of the epilepsy initiative, Ghana has made significant progress on these fronts, including approval in 2012 of the new Mental Health Act, the first since 1972. The Act ensures the standards, conditions and promotion of human rights in mental health care facilities throughout Ghana, promotes treatment in primary health care services and emphasizes the importance of health education.

Given this major change in legislation, the Mental Health Authority was created in 2013, with supporting administrative structures such as a governing board (the Mental Health Authority Board) and regional and district coordinating committees. The Act includes a clause to establish a mental health fund in order to make mental health treatment truly free and equitable. It is planned to set up departments of quality control, financing, institutional care, community care, policy, planning and monitoring and evaluation; and an administrative division to support the other departments. Epilepsy is included in the Mental Health Act. Over the next 5–10 years, the Mental Health Authority Board envisages extension of services and large training and recruitment drives to increase the mental health workforce. There are future plans for epilepsy to be managed by general practitioners with support from neurologists and not only by mental health practitioners.

Community education programmes play a vital role, as do innovative means to support people with mental illness, such as outreach, crisis intervention and tele-psychiatry services. These aims and values are shared with the Initiative, thereby supporting it at a national political level.

In addition, momentum has increased over the past year towards creating a new national health insurance

**Over the next 5–10 years, the Mental Health Authority Board envisages extension of services and large training and recruitment drives to increase the mental health workforce.**

scheme. The aim of the scheme will be to abolish the “cash-and-carry” system of health delivery currently in place. A law enacted in 2012 consolidated the national health insurance scheme by removing administrative bottlenecks, improving transparency, reducing opportunities for abusing the system and improving effective governance (57). The scheme will assist in ensuring equity in health care coverage by improving access of the poor to health care services, including those living with epilepsy, and improving access to medications, including antiepileptic medicines.



## National plan to scale up epilepsy care

On the basis of the achievements and momentum already created, the project team is extending epilepsy services across the country. Four areas have been identified for further work:

- enhancing policies for epilepsy care, including a national epilepsy care plan;
- integrating epilepsy programmes into the concept of universal health coverage and the national health insurance scheme;
- reducing stigmatization by continuing collaboration with traditional and faith healers and others to improve education about epilepsy; and
- extending coverage of the project, so that services are available for all people with epilepsy in Ghana.

In order to scale up the project, the Fight against epilepsy initiative team have drafted a step-wise national plan.

- Extend coverage to include all districts in the five regions already involved.
- Then, extend coverage to additional regions of Ghana to complete coverage of all 10 regions of the country, incrementally, to ensure at least two districts providing epilepsy care in the remaining five regions by 2020.
- Use eLearning and eSupervision modalities for training and supervising health care workers to enhance the efficiency of these processes and coverage.

- Develop policies and programmes to improve the procurement and distribution of antiepileptic medications, and ensure that all regional and district hospitals stock them.
- Continue collaboration to remove the stigma of epilepsy, including with nongovernmental organizations and private industry, traditional and faith healers, religious groups, schools and colleges, people living with epilepsy and their caregivers and media organizations.
- Integrate monitoring and evaluation into existing mental health systems, and advocate for national indicators for epilepsy.

*Through the Fight against epilepsy initiative, part of the WHO Programme on reducing the epilepsy treatment gap, Ghanaian health authorities are responding to the global call to prevent and treat neurological disorders. In Ghana alone, this means ensuring that tens of thousands of people whose quality of life is severely reduced will lead a meaningful existence, so that, in the future, hundreds of thousands of people will not have to experience the pain and stigma of living with untreated epilepsy.*

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## Annex 1. Summary of district situation analyses

District	Demographics and resources relevant to health care	No. of epilepsy patients seen in previous year (and % population)	Financing for epilepsy care	No. and type of public and private health facilities
<b>Ashiedu Kete*</b>	<ul style="list-style-type: none"> <li>• 117 525 population</li> <li>• 100% urban</li> <li>• Good radio and TV network</li> <li>• Adequate mobile phone network</li> <li>• Mobile communications van</li> </ul>	110 (0.09% of population)	None	Public: <ul style="list-style-type: none"> <li>• 1 hospital</li> <li>• 1 specialist facility</li> </ul> Private: <ul style="list-style-type: none"> <li>• 1 children's hospital</li> <li>• 4 health centres</li> </ul>
<b>Tolon–Kumbungu*</b>	<ul style="list-style-type: none"> <li>• 112 331 population</li> <li>• 92% rural</li> <li>• Reasonable roads but large areas isolated by floods in rainy season</li> <li>• Inadequate internet services</li> <li>• Radio and TV network intact</li> <li>• Mobile phone network adequate</li> <li>• Mobile communications van</li> </ul>	560 (0.5% of population)	None	Public: <ul style="list-style-type: none"> <li>• 1 district hospital</li> <li>• 5 health centres</li> <li>• 1 health post community health planning and services (CHPS)</li> <li>• 7 sub-health posts</li> </ul> Private: <ul style="list-style-type: none"> <li>• 1 district hospital</li> </ul>
<b>Ho West</b>	<ul style="list-style-type: none"> <li>• 100 364 population</li> <li>• 90% rural</li> <li>• Inadequate Internet services</li> <li>• 75% of roads tarred</li> <li>• Good radio and TV network</li> </ul>	No data	None	Public: <ul style="list-style-type: none"> <li>• 13 health centres</li> <li>• 7 CHPS compounds</li> </ul> Private: <ul style="list-style-type: none"> <li>• 2 facilities</li> </ul>
<b>Savelugu– Nanton*</b>	<ul style="list-style-type: none"> <li>• 139 283 population</li> <li>• 60% rural</li> <li>• Reasonable roads but large areas isolated by floods in rainy season</li> <li>• Inadequate Internet services</li> <li>• Good radio and TV network</li> <li>• Mobile phone network adequate</li> <li>• Mobile communications van</li> </ul>	98 (0.07% of population)	None	Public: <ul style="list-style-type: none"> <li>• 1 district hospital</li> <li>• 7 health centres</li> <li>• 1 health post (CHPS)</li> </ul> Private: <ul style="list-style-type: none"> <li>• 1 hospital</li> <li>• 2 health centres</li> </ul>
<b>Twifo– Hemang Lower Denkyira</b>	<ul style="list-style-type: none"> <li>• 138 696 population</li> <li>• 75% rural</li> <li>• Roads poor and main barrier to care</li> <li>• Radio, TV, mobile phone and Internet networks intact, although some areas better than others</li> <li>• Mobile communications van</li> </ul>	97 (0.07% of population)	None (cited as major barrier)	Public: <ul style="list-style-type: none"> <li>• 1 district hospital</li> <li>• 4 health centres</li> <li>• 12 health post</li> </ul> Private: <ul style="list-style-type: none"> <li>• 4 facilities</li> </ul>
<b>Asikuma Odoben Brakwa</b>	<ul style="list-style-type: none"> <li>• 127 344 population</li> <li>• 65% rural</li> <li>• Most roads untarred</li> <li>• Inadequate Internet services</li> <li>• Radio and TV network intact</li> <li>• Mobile phone network inadequate</li> </ul>	156	None	Public: <ul style="list-style-type: none"> <li>• 1 district hospital</li> <li>• 2 health centres</li> <li>• 14 health posts (CHPS)</li> </ul> Private: <ul style="list-style-type: none"> <li>• 2 hospitals</li> <li>• 4 clinics</li> </ul>
<b>West Akim</b>	<ul style="list-style-type: none"> <li>• 112 037 population</li> <li>• 65% rural</li> <li>• Reasonable roads but large areas isolated by floods in rainy season</li> <li>• Inadequate Internet services</li> <li>• Radio and TV network intact</li> <li>• Mobile phone network adequate</li> <li>• Mobile communications van</li> </ul>	642	None	Public: <ul style="list-style-type: none"> <li>• 1 district hospital</li> <li>• 1 health centre</li> <li>• 28 health post (CHPS)</li> </ul> Private: <ul style="list-style-type: none"> <li>• 2 clinics</li> </ul>
<b>Birim Central</b>	<ul style="list-style-type: none"> <li>• 157 427 population</li> <li>• 55% rural</li> <li>• Reasonable roads</li> <li>• Inadequate Internet services</li> <li>• Radio and TV network intact</li> <li>• Mobile phone network adequate</li> <li>• Mobile communications van</li> </ul>	No data	None	Public: <ul style="list-style-type: none"> <li>• 1 district hospital</li> <li>• 1 health centre</li> <li>• 19 health posts (CHPS)</li> </ul> Private: <ul style="list-style-type: none"> <li>• 2 hospitals</li> <li>• 4 clinics</li> </ul>
<b>Kpando</b>	<ul style="list-style-type: none"> <li>• 609 275 population</li> <li>• 70% rural</li> <li>• Reasonable roads but large areas isolated by floods in rainy season</li> <li>• Inadequate Internet services</li> <li>• Radio and TV network intact</li> <li>• Inadequate mobile phone network</li> </ul>	No data	None	Public: <ul style="list-style-type: none"> <li>• 5 health centres</li> <li>• 6 health posts (CHPS)</li> </ul> Private: <ul style="list-style-type: none"> <li>• 2 hospitals</li> </ul>

\* Other relevant information: BasicNeeds Ghana provide medication back-up, training, a treatment handbook and public education. They run a quarterly outpatient clinic in Ashiedu Kete district with a psychiatrist who provides medicines.

Human resources, including psychiatrists and neurologists	Availability of antiepileptic medication and medical equipment	Epilepsy care guideline	Health and epilepsy information systems	Stigmatization and awareness-raising campaigns
<ul style="list-style-type: none"> <li>• 10 general practitioners</li> <li>• 40 nurses</li> <li>• 38 CHWs</li> <li>• 1 mental health specialist</li> </ul>	<ul style="list-style-type: none"> <li>• Carbamazepine 200 mg;</li> <li>• phenobarbital 60 mg, 30 mg;</li> <li>• phenytoin 100 mg</li> <li>• Serious medication stock-outs</li> <li>• CT scanner 2 km from district</li> </ul>	No	<ul style="list-style-type: none"> <li>• Exists and covers some indicators</li> <li>• No epilepsy system</li> <li>• CPN writes quarterly report on all cases seen</li> </ul>	<ul style="list-style-type: none"> <li>• High stigmatization, with discrimination for marriage, education and employment</li> <li>• People with epilepsy isolated from the community</li> <li>• No education programmes</li> </ul>
<ul style="list-style-type: none"> <li>• 1 doctor</li> <li>• 3 medical assistants</li> <li>• 61 nurses (all types)</li> <li>• 12 CHWs</li> <li>• 1 CPN</li> <li>• CPN and CHWs trained in epilepsy care</li> </ul>	<ul style="list-style-type: none"> <li>• Carbamazepine 200 mg;</li> <li>• phenobarbital 60 mg, 30 mg;</li> <li>• phenytoin 100 mg</li> <li>• Available at one health centre only</li> <li>• Medication shortages reported</li> <li>• Only one, privately owned CT scanner</li> </ul>	No	<ul style="list-style-type: none"> <li>• Excel spreadsheets</li> <li>• No epilepsy system</li> <li>• CPN writes a quarterly report on all cases seen</li> </ul>	<ul style="list-style-type: none"> <li>• High stigmatization with discrimination for marriage, education and employment</li> <li>• No regular campaigns, but stigmatization improved after brochures disseminated by BasicNeeds Ghana</li> </ul>
<ul style="list-style-type: none"> <li>• No doctor</li> <li>• 19 nurses (all types)</li> <li>• 73 CHWs</li> <li>• Nurses trained in epilepsy management</li> </ul>	<ul style="list-style-type: none"> <li>• No stocks in sub-district: patients must go to municipal or regional hospitals</li> <li>• No scanning equipment</li> </ul>	No	<ul style="list-style-type: none"> <li>• Outpatient morbidity form</li> <li>• Monthly epilepsy management form in facilities</li> </ul>	<ul style="list-style-type: none"> <li>• High stigmatization</li> </ul>
<ul style="list-style-type: none"> <li>• 1 doctor</li> <li>• 6 medical assistants</li> <li>• 163 nurses (all types)</li> <li>• 1 CPN</li> </ul>	<ul style="list-style-type: none"> <li>• Carbamazepine 200 mg;</li> <li>• phenobarbital 60 mg, 30mg;</li> <li>• phenytoin 100 mg</li> <li>• Available only at hospital</li> <li>• Medication shortages reported</li> <li>• No scanning equipment</li> </ul>	No	<ul style="list-style-type: none"> <li>• DHIS II software</li> <li>• CPN reports on epilepsy quarterly</li> </ul>	<ul style="list-style-type: none"> <li>• High stigmatization with discrimination for marriage, education and employment</li> <li>• No regular campaigns but some TV and radio spots</li> </ul>
<ul style="list-style-type: none"> <li>• 4 general practitioners</li> <li>• 185 nurses (all types)</li> <li>• 66 CHWs</li> <li>• 1 CPN</li> <li>• 2 psychiatric assistants</li> </ul>	<ul style="list-style-type: none"> <li>• Carbamazepine 200 mg;</li> <li>• phenobarbital 60 mg, 30 mg;</li> <li>• phenytoin 100 mg</li> <li>• No scanning equipment</li> </ul>	No, but a guide book is used	<ul style="list-style-type: none"> <li>• Excel spreadsheets</li> <li>• No epilepsy-specific system</li> <li>• CPN keeps a record of all cases at district hospital</li> </ul>	<ul style="list-style-type: none"> <li>• High stigmatization with discrimination for marriage and education</li> <li>• People believe epilepsy is a spiritual problem and do not attend health services</li> <li>• No regular education programmes</li> </ul>
<ul style="list-style-type: none"> <li>• 3 doctors</li> <li>• 6 medical assistants</li> <li>• 142 nurses (all types)</li> <li>• 55 CHWs</li> <li>• 2 CPNs</li> <li>• CPNs and CHWs trained in epilepsy care</li> </ul>	<ul style="list-style-type: none"> <li>• Carbamazepine 200 mg;</li> <li>• phenobarbital 60 mg, 30 mg;</li> <li>• phenytoin 100 mg</li> <li>• Available in hospitals</li> <li>• Medication shortages reported</li> </ul>	No	<ul style="list-style-type: none"> <li>• No epilepsy-specific system</li> <li>• CPN writes quarterly report on all cases seen</li> </ul>	<ul style="list-style-type: none"> <li>• High stigmatization with discrimination for marriage, education and employment</li> </ul>
<ul style="list-style-type: none"> <li>• 3 doctors</li> <li>• 7 medical assistants</li> <li>• 89 nurses (all types)</li> <li>• 70 CHWs</li> <li>• 3 CPN</li> <li>• CPNs and CHWs trained in epilepsy care</li> </ul>	<ul style="list-style-type: none"> <li>• Carbamazepine 200 mg;</li> <li>• phenobarbital 60 mg, 30 mg;</li> <li>• phenytoin 100 mg</li> <li>• Available in hospitals</li> <li>• Medication shortages reported</li> </ul>	No	<ul style="list-style-type: none"> <li>• No epilepsy-specific system</li> <li>• CPN writes quarterly report on all cases seen</li> </ul>	<ul style="list-style-type: none"> <li>• High stigmatization with discrimination for marriage, education and employment</li> </ul>
<ul style="list-style-type: none"> <li>• 3 doctors</li> <li>• 6 medical assistants</li> <li>• 115 nurses (all types)</li> <li>• 80 CHWs</li> <li>• 4 CPNs</li> <li>• CPNs and CHWs trained in epilepsy care</li> </ul>	<ul style="list-style-type: none"> <li>• Carbamazepine 200 mg;</li> <li>• phenobarbital 60 mg, 30 mg;</li> <li>• phenytoin 100 mg</li> <li>• Available in hospitals</li> <li>• Medication shortages reported</li> </ul>	No	<ul style="list-style-type: none"> <li>• CPN writes quarterly report on all cases seen</li> </ul>	<ul style="list-style-type: none"> <li>• High stigmatization with discrimination for marriage, education and employment</li> </ul>
<ul style="list-style-type: none"> <li>• 8 doctors</li> <li>• 6 medical assistants</li> <li>• 106 nurses (all types)</li> <li>• 37 CHWs</li> <li>• 3 CPNs</li> <li>• CPNs and CHWs trained in epilepsy care</li> </ul>	<ul style="list-style-type: none"> <li>• Carbamazepine 200 mg;</li> <li>• phenobarbital 60 mg, 30 mg;</li> <li>• phenytoin 100 mg</li> <li>• Available in hospitals</li> <li>• Medication shortages reported</li> </ul>		<ul style="list-style-type: none"> <li>• No epilepsy-specific system</li> <li>• CPN writes quarterly report on all cases seen</li> </ul>	<ul style="list-style-type: none"> <li>• High stigmatization with discrimination for marriage, education and employment</li> <li>• Care provided only in private mission hospitals</li> </ul>

## Annex 2. The WHO Programme on reducing the epilepsy treatment gap

### The Programme

Building on previous WHO collaborative projects to reduce stigmatization and improve access to treatment, the WHO Programme on reducing the epilepsy treatment gap enhances the skills of non-specialist health care providers to diagnose, treat and follow up people with epilepsy. The Programme also strengthens health systems to increase sustainable access to antiepileptic medicines, reinforce referral systems and ensure better monitoring of epilepsy in health information systems. It mobilizes nongovernmental organizations, community groups and volunteers to raise awareness about epilepsy and to support people with epilepsy and their families among policy-makers, health care providers, people living with epilepsy and their families, nongovernmental organizations and the general public. The model combines several innovative strategies and demonstrates how the requests in World Health Assembly resolution WHA68.20 can be addressed, systematically and effectively, at country level. Pilot projects for the Programme have been initiated in Ghana, Mozambique, Myanmar and Viet Nam.

Epilepsy is treatable with inexpensive, effective medication, and, in most cases, people who receive treatment can lead normal lives. The slogan of the WHO Programme on reducing the epilepsy treatment gap – “Epilepsy: Treat it. Defeat it.”– indicates that the aim is not only to treat the disorder but also to defeat the stigmatization and inaccurate beliefs associated with it. Everyone has a role to play in treating and defeating epilepsy.

### A sustainable model for epilepsy care

#### Five objectives:

1. Develop and engage in a strategy for delivering epilepsy care.
2. Promote training of health care providers to make them competent in assessing and treating epilepsy.
3. Organize information, education and communication campaigns to improve the awareness of the public and community groups.
4. Integrate provision of care and services for epilepsy in the primary health care system.
5. Increase capacity to monitor and evaluate the project and disseminate the information generated.

### Adapting the model to national contexts

Building on previous WHO collaborative projects to reduce stigmatization and improve access to treatment, the WHO Programme on reducing the epilepsy treatment gap enhances the skills of non-specialist health care providers to diagnose, treat and follow up people with epilepsy. The Programme also strengthens health systems to increase sustainable access to antiepileptic medicines, reinforce referral systems and ensure better monitoring of epilepsy in health information systems. It mobilizes nongovernmental organizations, community groups and volunteers to raise awareness about epilepsy and to support people with epilepsy and their families among policy-makers, health care providers, people living with epilepsy and their families, nongovernmental organizations and the general public. The model combines several innovative strategies and demonstrates how the requests in World Health Assembly resolution WHA68.20 can be addressed, systematically and effectively, at country level. Pilot projects for the Programme have been initiated in Ghana, Mozambique, Myanmar and Viet Nam.



The Programme works in synergy with other WHO resources, including mhGAP (1). The mhGAP intervention guide (2) is a tool based on a systematic review of evidence and international consultation and participation. It includes modules on epilepsy and its treatment and also algorithms for management at primary health care level. These materials can be accessed and adapted to suit specific language and/or cultural needs.

For guidance on implementing the WHO Programme on reducing the epilepsy treatment gap, see the WHO Information Kit on Epilepsy (3).

**References**

1. WHO mental health Gap Action Programme (mhGAP) [web site]. Geneva: World Health Organization ([http://www.who.int/mental\\_health/mhgap/en/](http://www.who.int/mental_health/mhgap/en/), accessed 4 November 2016).
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3. WHO information kit on epilepsy. What you can do. Geneva: World Health Organization; 2015:34 ([http://www.who.int/mental\\_health/neurology/epilepsy/information\\_kit\\_epilepsy/en/](http://www.who.int/mental_health/neurology/epilepsy/information_kit_epilepsy/en/)).



**World Health Organization**

**WHAT IS epilepsy?**

A NEUROLOGICAL CONDITION characterized by *recurrent seizures*

Seizures are due to brief disturbances in the electrical functions of the brain

Epilepsy affects people of all ages

**CAUSES**

- NEUROLOGICAL INFECTIONS
- STROKE
- HEAD INJURY
- GENETIC FACTORS
- HEAD TRAUMA
- UNKNOWN CAUSES
- UNKNOWN CAUSES

**What is the IMPACT of epilepsy?**

**50 000 000**  
More than 50 million people are living with epilepsy globally

**3-6 TIMES GREATER RISK OF PREMATURE DEATH**

**80%** Do not receive treatment (in low and middle income countries)

**75%** Do not receive treatment

**CAUSES OF TREATMENT GAP:**

- lack of trained staff
- poor access to anti-epileptic medicines
- societal misconceptions
- poverty
- low prioritization for the treatment of epilepsy

**STIGMA & DISCRIMINATION**

FAMILY, WORK, SOCIAL STANDING

## **“Fight against epilepsy” initiative in Ghana**

The “Fight against epilepsy initiative” was implemented in Ghana through a collaboration between WHO and the Ministry of Health. It is under the framework of the WHO Programme on reducing the epilepsy treatment gap.

This report documents the successes achieved in increasing the epilepsy coverage by improving access to epilepsy care in primary health care services. It presents the lessons learnt from the Fight against epilepsy initiative and demonstrates the feasibility of scaling up epilepsy services in low-resource settings.

For all enquiries:  
The Mental Health Authority,  
Ministry of Health  
P. O. Box LG DTD 20035,  
Tripoli Street, East Legon, Accra

E-mail: [info@mhaghana.com](mailto:info@mhaghana.com)  
Website: <http://www.mhaghana.com>

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