

Myanmar Epilepsy Initiative

Piloting the WHO Programme on reducing the
epilepsy treatment gap 2013-2017



**World Health
Organization**
Myanmar

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Myanmar

Epilepsy Initiative

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Foreword

Epilepsy affects more than 50 million people worldwide. Although it is a treatable condition, almost three quarters of affected people in low- and middle-income countries do not receive treatment. Many health professionals do not have the training to recognize, diagnose and treat epilepsy, and medicines are often unavailable or unaffordable. In many parts of the world, people living with epilepsy and their families experience stigma and discrimination in their communities.

To defeat epilepsy and tackle the burden of disease, the WHO Programme on reducing the epilepsy treatment gap has been implemented in the South-East Asian and African regions. In a collaboration between the World Health Organization and the Ministry of Health and Sports, the Myanmar Epilepsy Initiative was launched in 2013. Over the past 5 years of the project's implementation, the Myanmar Epilepsy Initiative has been gradually scaled up to cover 12 townships across seven states/regions by the close of 2017, reaching a total population of 2.9 million people.

Since its inception, 2315 health care providers have been trained and 1709 new cases of epilepsy identified and treated in the community. A great achievement of the pilot project has been increasing the coverage in implementing areas from 2% to 47%. The project's advocacy efforts have proved successful – evidenced by the launch of the Five-year Strategic Plan for Epilepsy (2016–2020) and the National Framework for Epilepsy Care in Myanmar.

The Myanmar Epilepsy Initiative has demonstrated a model that is effective in reducing the epilepsy treatment gap. With a population of 53.8 million, successful nationwide scale up for epilepsy care in Myanmar will only be possible through an innovative, decentralized model that is integrated within existing primary care health services, to reach people living with epilepsy close to home.

The efforts between World Health Organization and the Ministry of Health and Sports generated evidence and lessons learned that will now be applied in a scale up programme to ensure long-term sustainability of accessible, affordable and quality care for epilepsy in Myanmar. The scale up programme will reach 85 townships in nine states/regions by the end of 2021, with full coverage of all townships in five states/regions. It will offer an opportunity to test the model's effectiveness in responding to the burden of epilepsy and improving the quality of life for people living with epilepsy in Myanmar.

MH
 26.10.18

Dr. Myint Htwe
 Union Minister, Ministry of Health and Sports

Abbreviations

BHS	basic health staff	VHW	voluntary health workers
CT	computerized axial tomography	WHA	World Health Assembly
DALYs	disability-adjusted life years	WHO	World Health Organization
EEG	electroencephalography		
GCAE	Global Campaign Against Epilepsy		
GP	general practitioner		
HMIS	Health Management Information System		
IBE	International Bureau for Epilepsy		
ILAE	International League Against Epilepsy		
KAP	knowledge, attitude and practices		
LMIC	low- and middle-income countries		
M&E	monitoring and evaluation		
mhGAP	mental health Gap Action Programme		
mhGAP-IG	mental health Gap Action Programme Intervention Guide		
MO	medical officers		
MoHS	Ministry of Health and Sports		
MRI	magnetic resonance imaging		
NCD	noncommunicable disease		
NGO	nongovernmental organization		
PCC	project coordination committee		
QoL	quality of Life		
RHC	rural health centre		
ToTS	training of trainers and supervisors		

Executive summary

Epilepsy is a major public health problem: it is a chronic noncommunicable disease of the brain that affects more than 50 million people worldwide. Epilepsy accounts for 0.5% of the global burden of disease and is associated with stigma, physical and psychiatric comorbidity, and high economic costs. Nearly 80% of people living with epilepsy reside in low- and middle-income countries, and 75% do not receive the treatment they need.

Over half of the people living with epilepsy worldwide are estimated to live in Asia. In comparison with Africa, Asia has more untreated patients, with greater treatment costs and possibly higher premature mortality. According to the WHO Atlas: country resources for neurological disorders (second edition), the median number of neurologists is extremely low in South-East Asia (0.1 per 100 000 population) and the Western Pacific (1.2) – far fewer than the ratio in Europe (6.6).

In Myanmar, it is estimated that around 500 000 people live with epilepsy, a prevalence of 1.1 per 1000 population. An estimated 95% of people living with epilepsy do not receive the care required. The main reasons for this include the limited number of health care providers trained to provide care and support to people living with epilepsy, the limited access to anti-seizure medications, and a lack of awareness and health education about epilepsy.

For more than 20 years, the WHO has led the global movement against epilepsy. Within the framework of the Global Campaign Against Epilepsy, WHO aims to bring epilepsy “out of the shadows”, encouraging countries to prioritize epilepsy in public health planning, as well as raise awareness of the disease among health care providers and the general public.

The WHO Programme on reducing the epilepsy treatment gap seeks to achieve these goals in pilot locations in Myanmar, Ghana, Mozambique and Viet Nam, which can be used as a model for scale up in other countries. The Programme offers an innovative community-based model focused on expanding the skills of nonspecialist health care providers to diagnose, treat and follow up people living with epilepsy.

Epilepsy is included as a priority condition in the WHO mental health Gap Action Programme (mhGAP). It's evidence-based guidelines facilitate delivery of interventions by nonspecialist health care providers and is used in the WHO Programme on reducing the epilepsy treatment gap to strengthen care provided for people living with epilepsy and their families. The Programme also includes strengthening of health systems to increase sustainable access to anti-seizure medications, reinforcing referral systems, ensuring better monitoring of epilepsy in health information systems, and raising awareness to support people living with epilepsy and their families.

The Myanmar Epilepsy Initiative was launched in 2013 in a phased approach. In 2013, the project was initiated in the two townships of Hlegu and Hmawbi and then subsequently scaled up to Lewe, Kawhmu and Thalyinin in 2014; Nyaundon, Thaton and Kyaikhto in 2015; Sagaing and Taunggyi in 2016, and Nyaunglebin and Pantanaw in 2017. The project gradually expanded to 12 townships, from seven states/regions, covering 2.9 million people.

In 2013 and 2014, situation analyses and baseline surveys were carried out in the first five project townships to better understand the existing needs and resources. The prevalence of epilepsy ranged from 0.83 to 1.9 per 1000 population in the surveyed townships, with an average prevalence of 1.4 per 1000 population that was used to estimate the number of people living with epilepsy in other townships for planning purposes.

A survey of knowledge, attitude and practices... showed that most health care providers did not have experience or confidence in treating epilepsy.

A survey of knowledge, attitude and practices carried out in five townships showed that most health care providers did not have experience or confidence in treating epilepsy. More than 80% of health care providers had never attended any training on epilepsy. Surveys with community members revealed high levels of stigma and discrimination, as well as a lack of knowledge in how to care for people living with epilepsy.

Early stakeholder engagement with a variety of experts in public health, neurology, the Ministry of Health and Sports, nongovernmental organizations and research were key to the achievement of several project goals. A project coordination committee was established to lead and advise on project implementation. Due to this successful advocacy, the following policies were approved by the Ministry of Health and Sports:

- Five-year Strategic Plan for Epilepsy (2016–2020)
- National Framework for Epilepsy Care in Myanmar
- nationwide scaling up proposal for epilepsy.

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). During the project implementation period (2014–2017) a total of 2231 health care providers and 84 specialists were trained:

- 237 medical officers
- 1023 basic health workers

- 971 voluntary health workers
- 84 specialists who provided training and supervision
- Refresher trainings were provided to 828 health care providers.

Community awareness was raised through multiple channels. Locally developed information, education and communication materials, such as comic books for children, a video and song, and posters in health clinics, reached a variety of audiences. The project galvanized the support of national celebrities to spread messages about epilepsy and reduce stigma. 21 336 health education talks were held between 2014–2017 that reached over 285 000 people. A national support group was established for people living with epilepsy and their families. These efforts not only raised awareness and reduced stigma, but they also led to an increase in the number of people living with epilepsy seeking treatment and care.

Contact coverage increased from 2% to 47% in 4 years of data collection.

Major achievements of the project included ensuring treatment and care for epilepsy in 12 townships covering a population of 2.9 million. Contact coverage increased from 2% to 47% in the 4 years of data collection.

- A total of 1709 new cases of epilepsy were identified in the project townships and 18 028 follow-up consultations conducted to ensure continued care.
- A reduction in seizures (by at least 50%) was observed in follow-up visits in most project townships.
- A significant improvement in subjective quality of life was reported for people who received epilepsy treatment.

The availability of anti-seizure medication improved substantially in all project townships.

The project was successful in ensuring the adequate and sustainable availability of medicines, of anti-seizure medications via the government procurement system. Approval for the use of phenobarbital (a controlled medicine included in narcotic psychotropic substances) by basic health staff to be used for the treatment of epilepsy was also obtained.

A comprehensive monitoring and evaluation system was established to provide a clear understanding of the availability of anti-seizure medication in rural health centres, the use of epilepsy services, and patient outcomes. The project has planned for future integration with the existing health management information system so that epilepsy indicators will be collected routinely nationwide.

The Myanmar Epilepsy Initiative demonstrates that epilepsy care can be feasibly and cost-effectively integrated into the primary health system in a low-resource setting. The many lessons learned will be used to scale up services to 85 townships, covering all townships in five states/regions over the next 4 years.

Epilepsy: a public health problem

The global problem

The treatment gap

- Workforce shortages
- Accessibility, affordability and availability of anti-seizure medication
- The economic and social impact of epilepsy

The global response

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

Epilepsy in Myanmar

- The health care system
- Mental health and neurological services

Approximately 50 million people have epilepsy, making it one of the most common neurological conditions globally (1,2).

It is estimated that 80% of persons with epilepsy live in low- and middle-income countries (LMIC), where they have limited access to treatment (3).

The global problem

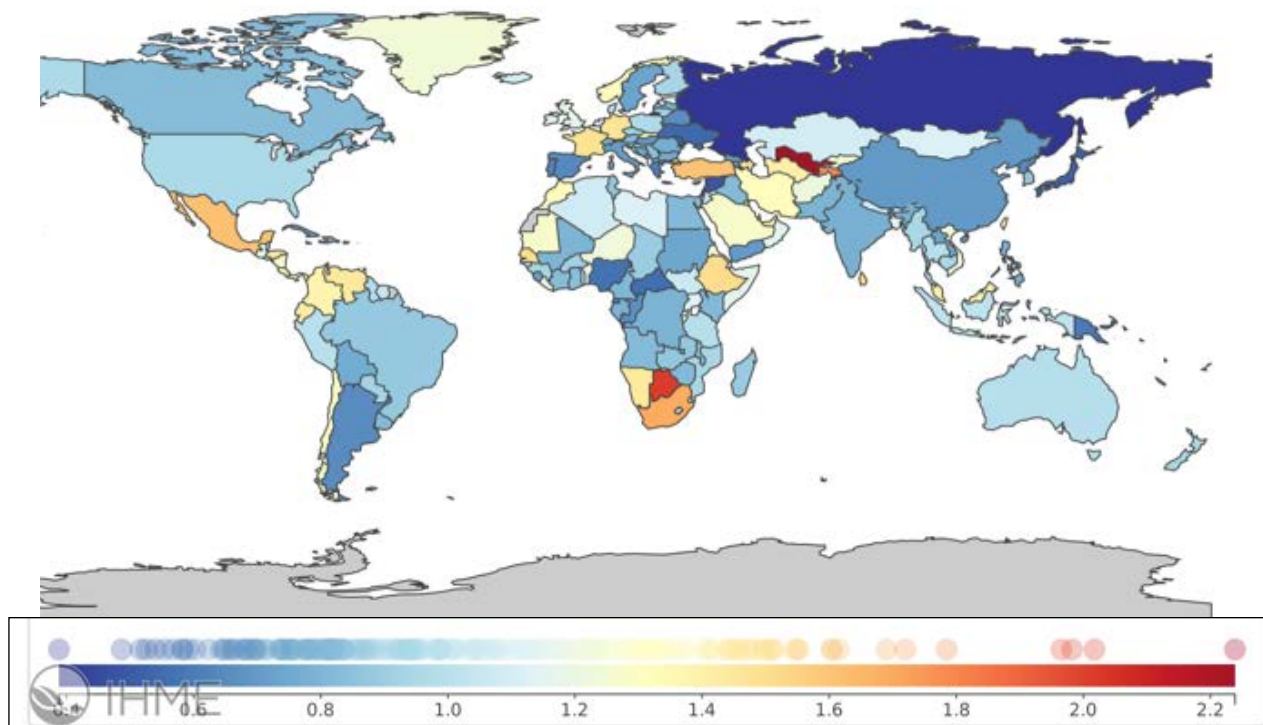
Approximately 50 million people have epilepsy, making it one of the most common neurological conditions globally (1,2). It is estimated that 80% of persons with epilepsy live in low- and middle-income countries (LMIC), where they have limited access to treatment (3).

The prevalence of epilepsy is reported to vary substantially between countries: estimated as 5.8 per 1000 persons in high-income countries, and 15.4 per 1000 persons in rural and 10.3 in urban populations of LMIC (4). 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 adults in LMIC (5). The higher prevalence and incidence of epilepsy in LMIC is partly explained by some risk factors such as head trauma, perinatal injury and central nervous system infections, which are more common in low-resource settings, especially in rural areas.

When classified together, neurological conditions were one of the leading causes of disability-adjusted life years (DALYs) in 2015 (250.7 million, comprising 10.2% of global DALYs) and the second-leading cause group of deaths (9.4 million, comprising 16.8% of global deaths) (6). DALYs are the sum of two components: years of life lost due to premature mortality and years lived with disability. One DALY is equivalent to one healthy life-year lost and a particularly useful metric to quantify the burden of noncommunicable diseases (NCDs) (e.g. epilepsy) that often result in long-term disability for survivors (Fig. 1).

Fig. 1. Global burden of epilepsy as the percentage of total DALYs (both sexes, all ages, 2016)



Source: GBD Compare (7)

Overall, epilepsy contributed more than 12 million DALYs (0.5% of the worldwide burden of disease or 5% of the burden of neurological conditions) to the global burden of disease in 2015 (6). It ranked second only to stroke among selected neurological conditions in terms of years of potential life lost.

The profound physical, psychological and social consequences of epilepsy impose significant burdens on people living with epilepsy and their families (8). People living with epilepsy tend to have more physical problems, such as fractures and bruising from injuries related to seizures, and a higher prevalence of mental health conditions, such as depression, anxiety and psychosis, compared with the general population (9,10). These comorbidities are associated with poorer health outcomes, increased health care needs, decreased quality of life (QoL) and higher mortality.

More than 70% of children with epilepsy have some level of disability affecting their daily life.

More than 70% of children with epilepsy have some level of disability affecting their daily life (11). Neurological comorbidities in children with epilepsy vary, including intellectual disability, language impairment, migraines and sleep problems. The most common mental health conditions among children who have epilepsy include attention-deficit hyperactivity disorder, depression and anxiety disorders (12).

People living with epilepsy are at an overall increased risk of premature death.

People living with epilepsy are at an overall increased risk of premature death (13,14). Mortality in people living with epilepsy in LMIC is estimated to be 2.6 times higher than in the general populations of those countries and significantly higher than in high-income countries (15). This is likely to be due to the higher incidence of preventable causes such as road traffic injuries, drowning, burns and birth-related injuries; and variations in medical infrastructure. Epilepsy resulting from infection is a major cause of morbidity and mortality in low-income countries and the most preventable cause of epilepsy worldwide (16). Premature mortality imposes a significant public health burden, and many of the specific causes of death are potentially preventable.



Treatment gap

The epilepsy treatment gap is defined as the proportion of the population who require but have not received treatment for epilepsy (17). It is a useful parameter to compare access to care for epilepsy across populations; and an important indicator for policy-makers. The treatment gap is estimated to be over 75% in low-income countries and over 50% in most

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middle-income countries (17). Even in high-income countries, where the treatment gap is under 10%, there are disparities in rural versus urban settings (Fig. 2). In Asian countries, the treatment gap is estimated between 29% and 98%, with values for most countries between 50% and 95% (18,19).

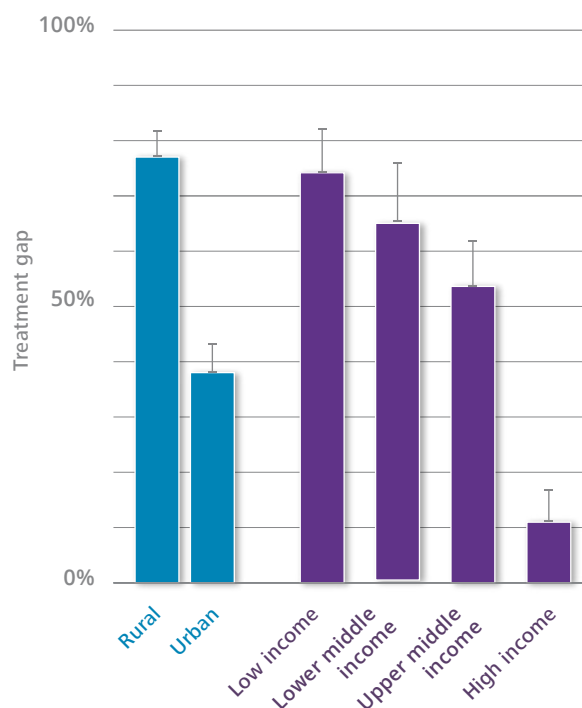
The causes for this lack of access to treatment are multifaceted and complex, involving financial, educational and social factors. These include, but are not limited to:

- the low public health 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 health care providers;
- inadequate and inconsistent access to affordable medicines;
- social misconceptions; and
- poverty (20).

It is estimated that 70–80% of people living with epilepsy could lead normal lives if properly diagnosed and treated (21). However, despite the cost-effectiveness of anti-seizure medications, at as little as US\$ 5 per year (22), the majority of affected individuals in low-resource settings do not receive treatment. Left untreated, people living with epilepsy face devastating social consequences, including stigma and discrimination, human rights violations and premature mortality.

Fig. 2. Disparities in the epilepsy treatment gap



Source: adapted from Meyer et al (2010) (17)

Workforce shortages

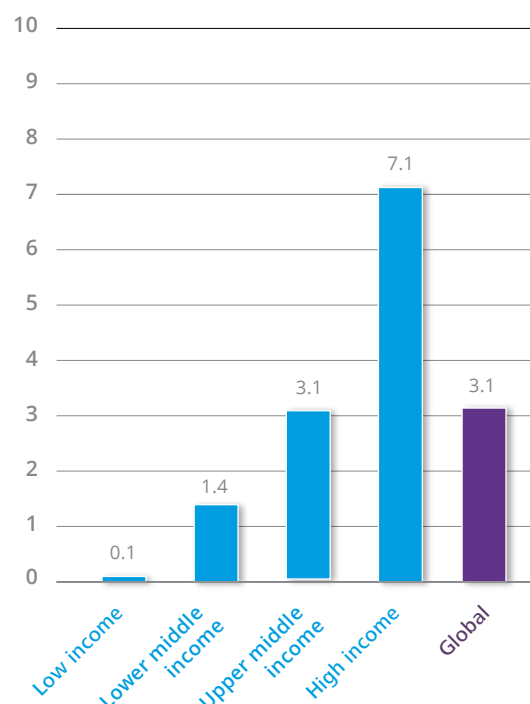
Delivery of efficacious interventions in low-resource settings can only be achieved if people living with epilepsy are correctly identified and assessed. In high-income countries misdiagnosis occurs in 5–30% of cases, and in LMIC this is likely to be higher (23). The shortage of trained professionals in the health workforce to assess and manage epilepsy in primary care is a key factor affecting the treatment gap. Results from WHO Atlas: country resources for neurological disorders (24) showed that the global median of the neurological workforce (defined as the total number of neurologists, neurosurgeons and child neurologists) is 3.1 per 100 000 population. This total figure does not reflect the significant discrepancy between low- and high-income countries which reported median neurological workforce figures of 0.1 and 7.1 per 100 000 population, respectively (Fig. 3).

Accessibility, affordability and availability of anti-seizure medication

The accessibility, affordability, availability and poor quality of medicines are also key factors affecting access to epilepsy treatment. Although effective anti-seizure medications are on the WHO Model List of Essential Medicines (25) and are purportedly available in all countries (26), distribution and quality of medicines are inconsistent, thus limiting access to treatment. Phenobarbital is the least expensive anti-seizure medication (22), but its distribution has been restricted due to its classification as a controlled substance in some countries (27).

The median cost of first-line anti-seizure medications varies across regions and is higher in low and middle-income countries than in high-income countries (28). In general, the cost of phenobarbital in South-East Asia

Fig. 3. Median neurological workforce per 100 000 population, by World Bank income group



Source: adapted from WHO (2017) (24)

is 2.7 times higher than in Europe, and two to six times higher than in sub-Saharan Africa (28). A study of the availability and prices of anti-seizure medications in southern Viet Nam showed that less than 60% of pharmacies had anti-seizure medications available and monthly treatment costs ranged from US\$ 3.30 for carbamazepine (200 mg) to US\$ 22.50 for valproic acid (200 mg) (29). Because epilepsy management requires sustained treatment with anti-seizure medications to avoid seizures and other health and social problems, the low availability and affordability are public health issues and important barriers to universal health coverage.



Misunderstandings about epilepsy play an important role in preventing people from accessing treatment and care, in addition to furthering stigma.



The economic and social impact of epilepsy

The high health care costs related to assessment and treatment for epilepsy, as well as lost employment, income and household work, are well recognized. A systematic review of 322 studies assessing the economic impact of epilepsy found the total costs associated with epilepsy varied significantly in relation to the duration and severity of the condition, response to treatment, length of time since diagnosis and health care setting (30). Out-of-pocket costs and productivity losses were found to create substantial burdens on households. People living with epilepsy have also been shown to utilize more health resources than those with other chronic health conditions (31).

In many parts of the world, people living with epilepsy and their families suffer from stigma and discrimination because of ignorance, misconceptions and negative attitudes surrounding the disease (3). They face serious difficulties in, for example, education, employment,

marriage, obtaining a driving licence, and reduced access to health and life insurance. In some countries epilepsy is viewed as a demonic curse or the result of spiritual possession and seizures thought to be contagious (32).

In Asia, there exist strong cultural perceptions of epilepsy that rely on nonscientific explanations (33). Many people seek treatment from alternative systems of medicine, such as Ayurveda in India and Sri Lanka, and acupuncture in Thailand (19). In the Republic of Korea, the name for epilepsy was recently changed from a stigmatizing term to a neutral and scientific term meaning “cerebroelectric disorder” (34), in an effort to reduce the stigma by understanding epilepsy as a neurologic disease. Misunderstandings about epilepsy play an important role in preventing people from accessing treatment and care, in addition to furthering stigma.



The global response

Global Campaign Against Epilepsy

For more than 20 years, WHO, with the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE), have led the Global Campaign Against Epilepsy (GCAE), a movement to bring epilepsy “out of the shadows” and raise awareness of the disease among health care providers and the general public (35). The GCAE has made substantial progress in encouraging countries to prioritize epilepsy, which resulted in WHO regional declarations in all six WHO regions and the successful completion of a number of demonstration projects (3).

Demonstration projects were conducted in China, Senegal, Zimbabwe and Brazil, among others. These were designed to identify people living with epilepsy and to reduce the treatment gap through the education of health care providers, dispelling stigma, eradicating preventable causes of epilepsy and integrating epilepsy care in public health systems. The project in China estimated the number of people living with epilepsy in the country to be around 9 million, with a treatment gap of 63% (36). The project successfully implemented training of health care providers to diagnose and manage epilepsy in nonspecialized settings, significantly reducing the treatment gap by about 13%, and was shown to be cost-effective.

WHO Programme on reducing the epilepsy treatment gap

In 2012, the WHO launched the Programme on reducing the epilepsy treatment gap to build on the activities of the GCAE and to provide epilepsy care and services using a community-based model. This model combines several innovative strategies such as extending the skills of nonspecialist primary health care providers to diagnose, treat and follow up people living with epilepsy; mobilizing nongovernmental organizations (NGOs), community groups and volunteers to raise awareness and support people living with epilepsy and their families; and strengthening health systems to ensure sustainable access to anti-seizure medications, reinforce referral systems, and ensure better monitoring of epilepsy in health information systems. Pilot projects for the Programme were initiated in four countries: Ghana (37), Mozambique, Myanmar and Viet Nam.

The Programme works in synergy with other WHO resources, including the mental health Gap Action Programme (mhGAP) and the mhGAP Intervention Guide (mhGAP-IG). mhGAP-IG is a technical tool that has been developed through a systematic review of evidence followed by an international consultative and participatory process. It has modules related to epilepsy and its treatment, including emergency treatment of seizures. Countries implementing the WHO Programme on reducing the epilepsy treatment gap have translated and adapted the mhGAP-IG to local contexts, provided training of health care providers, and successfully integrated mhGAP into national plans and strategies. mhGAP has made a great contribution to scaling up epilepsy services worldwide (38).

At the political level, WHO and its partners have long recognized that epilepsy is a major public health concern. This was reflected in 2015, when the World Health Assembly (WHA) approved unanimously a resolution on the global burden of epilepsy, which urges Member States to implement a coordinated action against epilepsy and its consequences (see Box on right).

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

In 2015, the WHA adopted a resolution on the global burden of epilepsy and the need for coordinated action at country level to address its health, social and public knowledge implications. 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 nonspecialist health care providers in order to reduce the epilepsy treatment gap. It recognizes the essential role of increasing access to epilepsy care in achieving better health for all people.

The resolution calls on the 194 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.

To accomplish these actions, political commitment by governments is vitally important, as shown by previous successful GCAE projects in a number of LMICs (37). The Myanmar Epilepsy Initiative is an example of how the recommendations in WHA68.20 can be put into action at a national level.

Almost 20 years after the establishment of the GCAE, the WHA resolution is a landmark, creating new opportunities in the long-standing collaboration between the WHO, ILAE and IBE to address the needs of people living with epilepsy (3).

For more information, please see:

http://www.who.int/mental_health/neurology/epilepsy/resolution_68_20/en/



Epilepsy in Myanmar

Epilepsy is a serious public health issue that imposes an enormous physical, psychological, social and economic burden on individuals, families and the country due to misconceptions, fear and stigma. It is estimated that there might be 500 000 people living with epilepsy in Myanmar. There is an absence of nationwide statistics regarding the prevalence of epilepsy in the country, but a survey on generalized tonic-clonic seizures (major fits) conducted in one township (Nyaungdon) estimated the prevalence at 1.1 per 1000 population (19). Limited data from annual hospital statistics (39) showed that among the neurological diseases treated in private and public hospitals, epilepsy ranked second in both males and females.

It is estimated that there might be 500 000 people living with epilepsy in Myanmar.

Myanmar, located in South-East Asia, is bordered by Bangladesh, India, China, the Lao People's Democratic Republic and Thailand, with a long coastline on the Bay of Bengal and Andaman Sea. Myanmar's population of 53.8 million is made up of many ethnic groups, the largest being Bamar (Burman), constituting about 68% of population. In this heterogeneous society, there are many obstacles to the provision of health services to the whole nation (40).





In Myanmar, an estimated 95% of people living with epilepsy do not receive the care required.

The health care system

Myanmar transitioned to a civilian government in March 2011. Since then, the health care system has evolved with the changing political and administrative systems. However, problems remain in access to health care services and quality of services, particularly in the areas of maternal and child health, nutrition, and infectious disease controls (40).

Health care is organized, funded and delivered by both public and private providers. National and international NGOs and community-based organizations support health care. As hospital statistics by the government cover only public facilities, the information on private facilities is limited. According to World health statistics 2018 (41), the number of doctors per 100 000 population in Myanmar was 61, and 100 nurses and midwives; while in South-East Asia as a whole, there were 59 and 153, respectively. Despite recent increases in the health workforce, there is an uneven spread of skilled health care providers between urban and rural areas.

About 70% of the population resides in rural areas. Basic health staff (BHS) are the main health care providers for people living in rural areas and are based in rural and sub-rural health centres (RHC). **Fig. 4** provides an overview of the health service structure in Myanmar. Overseen by medical officers (MO), the BHS are responsible for disease surveillance and control, treatment of common illnesses, referral services, immunization and nutrition programmes, and training of volunteer health workers (VHW), including community health workers and auxiliary

midwives. These health workers face many challenges in their efforts to reach out to remote villages, with minimal resources and support.

Mental health and neurological services

There is a limited infrastructure and a shortage of skilled human resources for mental health, including neurology, in Myanmar. The country has two psychiatric hospitals, 25 outpatient mental health facilities, and 17 community-based psychiatric inpatient units. However, 87% of government mental health expenditure goes to the hospitals (42). Mental health expenditure comprises 0.3% of total health care expenditure. The total number of mental health professionals (in public and private sector) is 627; at a rate of 1.20 per 100 000 population (43).

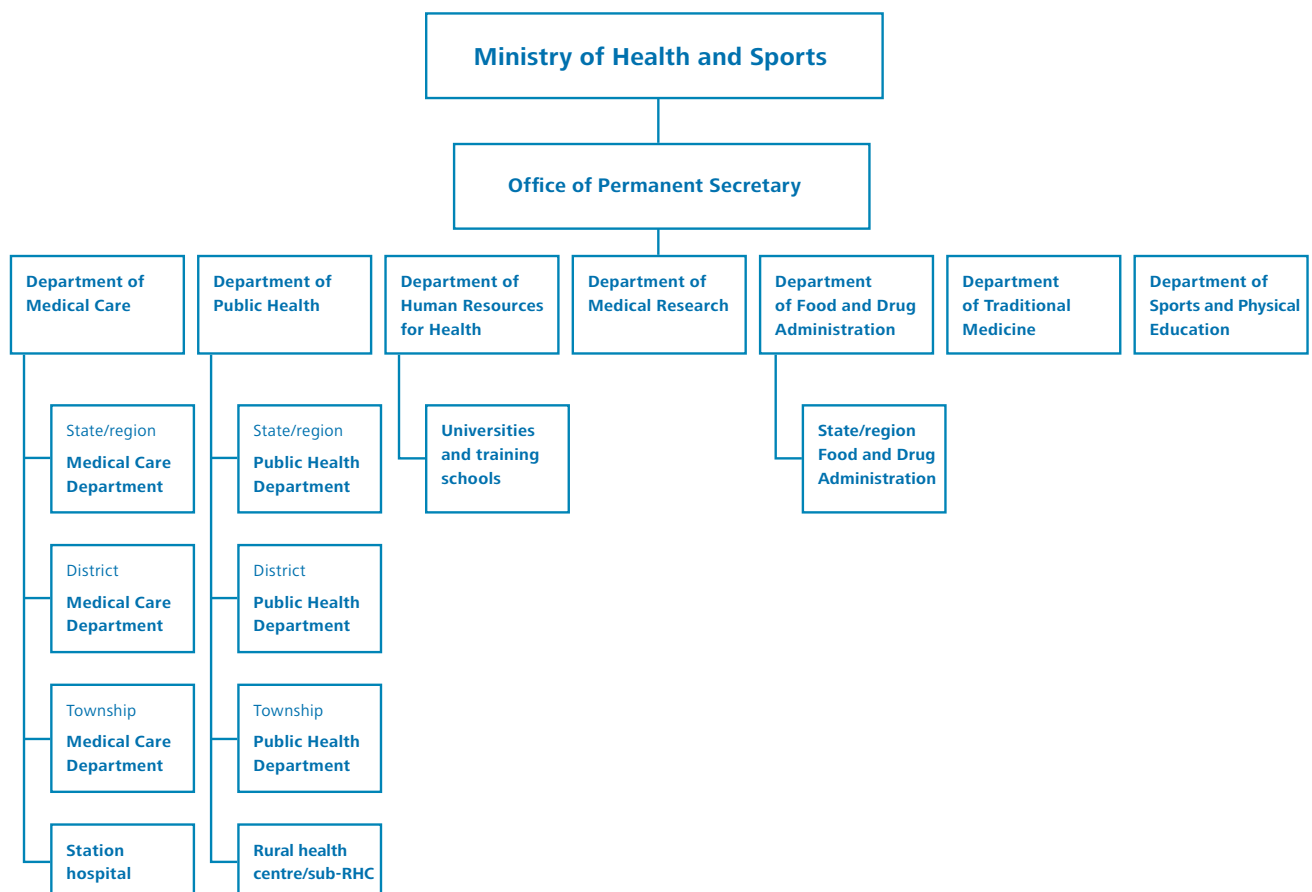
Most of the population in Myanmar has no medical insurance. Those who can afford it consult neurologists in private practice while the rest rely on government hospitals for their care, from either neurologists or primary care workers (44). The country has 25 neurologists (18 in public health services) and 19 neurosurgeons (15 in public health services). All four neurological centres have computerized axial tomography (CT), magnetic resonance imaging (MRI) and electroencephalography (EEG), and one has electromyography. Training programmes for neurologists are available in Yangon General Hospital, Mandalay General Hospital and North Okkalapa General Hospital. The Myanmar Neurology Society was founded in 2000 and is affiliated to World Federation of Neurology, the ASEAN (Association of Southeast Asian Nations) Neurological Association and the ILAE.



In Myanmar, an estimated 95% of people living with epilepsy do not receive the care required (19). The main reasons for this include the limited number of health care personnel trained to provide care and

support to people living with epilepsy, the limited access to anti-seizure medications and the lack of awareness and health education about epilepsy.

Fig. 4. Health service structure in Myanmar



Myanmar Epilepsy Initiative



Project goals

Methods

- Develop a strategy for delivering epilepsy care
- Capacity building of health care providers
- Awareness raising
- Provision of nonspecialized care for epilepsy
- Monitoring and evaluating the initiative

In 2013, the Myanmar Epilepsy Initiative was launched to address the epilepsy treatment gap by improving access to quality care for people living with epilepsy in communities. Within the framework of the WHO Programme on reducing the epilepsy treatment gap, the pilot project was rolled out in a phased approach, gradually expanding to 12 townships in five regions and two states, covering a population of 2.9 million. Considerable successes have been achieved and valuable experience gained during the implementation.

Project goals

The main goal of the 5-year project was to improve the care and services at the primary health care level to reduce the epilepsy treatment gap. Specific objectives of the Myanmar Epilepsy Initiative were to:

- 1** Develop a strategy to deliver epilepsy care to ensure accessibility to proper treatment and care for people living with epilepsy down to the rural communities.
- 2** Promote training of health care providers, making them competent in assessing and treating epilepsy.
- 3** Develop epilepsy information, education and communication (IEC) materials to improve awareness of public and community groups through widespread health education activities.
- 4** Integrate provision of care and services for epilepsy into the primary health care system for long-term sustainability.
- 5** Enhance capacity to monitor and evaluate the project and disseminate the knowledge.

1 Develop a strategy for delivering epilepsy care

Strengthening of services to deliver epilepsy treatment and care is an ongoing process, involving various aspects of formative planning for modification and refinement within the existing health system. For this reason, a phased approach to implementation was developed. The first year of the Myanmar Epilepsy Initiative focused on initial planning, where the necessary approval from the Ministry of Health and Sports (MoHS) was obtained and the project leadership was established. Effective coordination with engaged and committed stakeholders was required to implement the project.

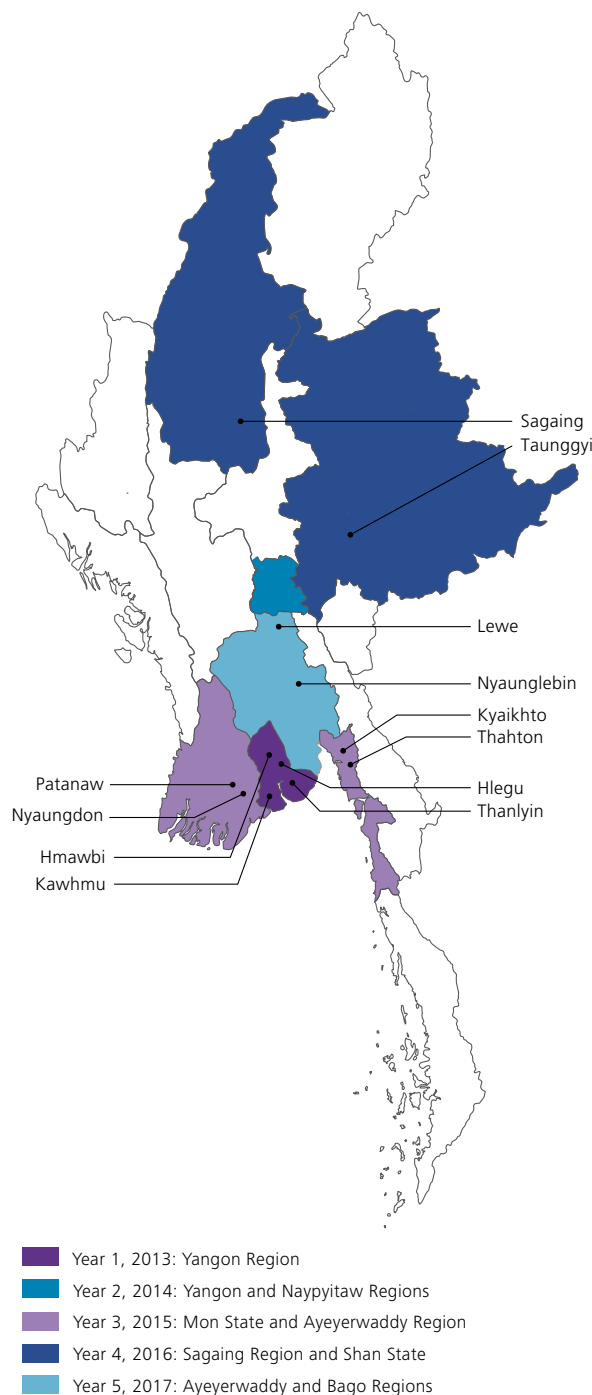
In 2013, baseline surveys to assess the situation of epilepsy treatment and care in primary health services was conducted in two townships in Yangon Region following which implementation commenced and was gradually expanded to 12 townships in seven states/regions (Fig. 5).

Establishment of project leadership

Implementation of project activities requires a variety of skills, knowledge of the local health system and public health priorities, and leadership from multiple disciplines. In July 2013, a project coordination committee (PCC) was established. The PCC consisted of high level experts in disciplines of public health, neurology, paediatrics, medical care, academia, epidemiology, mental health, as well as epilepsy specialists. Representatives from the WHO also facilitated the process of project coordination.

Leadership by the PCC was essential to advocate for the Myanmar Epilepsy Initiative across service levels. The PCC helped the project team to coordinate with township and state/regional level health department officials to procure anti-seizure medications in the government system, organize training, supervision, and monitoring and evaluation (M&E) visits (Fig. 6). The project team met monthly to discuss any problems or constraints encountered and identify solutions.

Fig. 5. Phased approach to piloting the project across states/regions and townships in Myanmar



“Since we now have gained knowledge on epilepsy as a result of this meeting, we can include the topic of epilepsy in our health education sessions in the community.”

Member of Myanmar Maternal and Child Welfare Association attending the advocacy meeting in Nyaunglebin

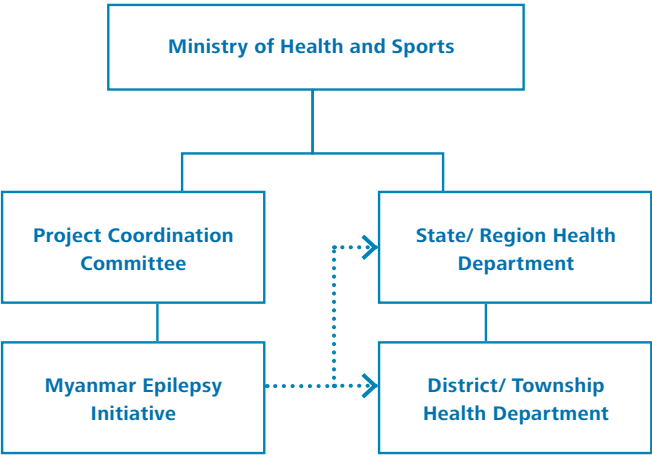
Stakeholder collaboration

Engaging with a variety of stakeholders was key to the success of the project and achievement of several project goals. For example, in the MoHS, the Director General of the Food and Drug Administration played a pivotal role regarding the procurement of anti-seizure medications and the Deputy Director of Health Education was involved in the development and production of IEC materials for awareness raising. Patient and family groups also participated in the development of the materials. Neurologists and professors from university departments of medicine and public health in Yangon, Magwe and Mandalay were consulted on the design and implementation of project activities.

It was important to advocate with township level stakeholders early on in the project’s implementation. Prior to rolling out the project in a new township, advocacy meetings were held with local Myanmar Medical Association branches, and township, ward and village level administrative personnel. In addition, all international and national NGOs involved in health care delivery, representatives from local community-based organizations and community leaders were involved (e.g. Myanmar Red Cross Society, Myanmar Maternal and Child Welfare Association).

Teachers and state/regional level education officers participated in advocacy meetings and learned about the issues that children with epilepsy encounter in school. Particular emphasis was placed on the acceptance for enrolment of children with epilepsy into schools, to reduce stigma and discrimination. Question and answer sessions were held and IEC materials about epilepsy and the project were distributed.

Fig. 6. Project organization



Baseline situation analysis

A situation analysis is an assessment of the baseline situation in the potential study sites, used to identify the services and resources available in nonspecialized health care settings. It is an essential first step for informed decision-making and was used in planning the implementation of the project.

National and state/regional level situation analyses were completed in 2013. Results helped to inform project planning as they collected data on the state of epilepsy services, policies, programmes and government expenditure for mental health, and stocks of anti-seizure medication.

A household survey, to determine the prevalence of epilepsy in the implementing townships, was carried out across five townships between 2013–2014. For one township, Nyaungdon, the prevalence data from a 2005 survey were used. Based on these findings, the prevalence in the remaining townships was estimated using census population data and an average prevalence in six survey townships at 1.4 per 1000 population ([Table 1](#)).

The situation analysis in Hlegu and Hmawbi townships showed that more than 97% of community members surveyed wanted the epilepsy project in their townships. On the other hand, the analysis revealed strong negative attitudes and enormous stigma attached to epilepsy among community members:

- 22–42% did not want their children to play with other children living with epilepsy;
- 83–89% did not want their offspring to marry persons with epilepsy; and
- 80–89% disagreed to employ a person with epilepsy.

A knowledge, attitude and practices (KAP) survey was carried out in 2014 in the next three implementation townships of Thanlyin, Kawhmu and Lewe. The goal was to determine help-seeking patterns for epilepsy care among health care providers and community members.

The KAP survey revealed that most nonspecialized health care providers in the townships surveyed did not have any experience in treating epilepsy and that most

Among the health care providers surveyed, more than 80% had never attended training on epilepsy and 95% said they wanted training on epilepsy.

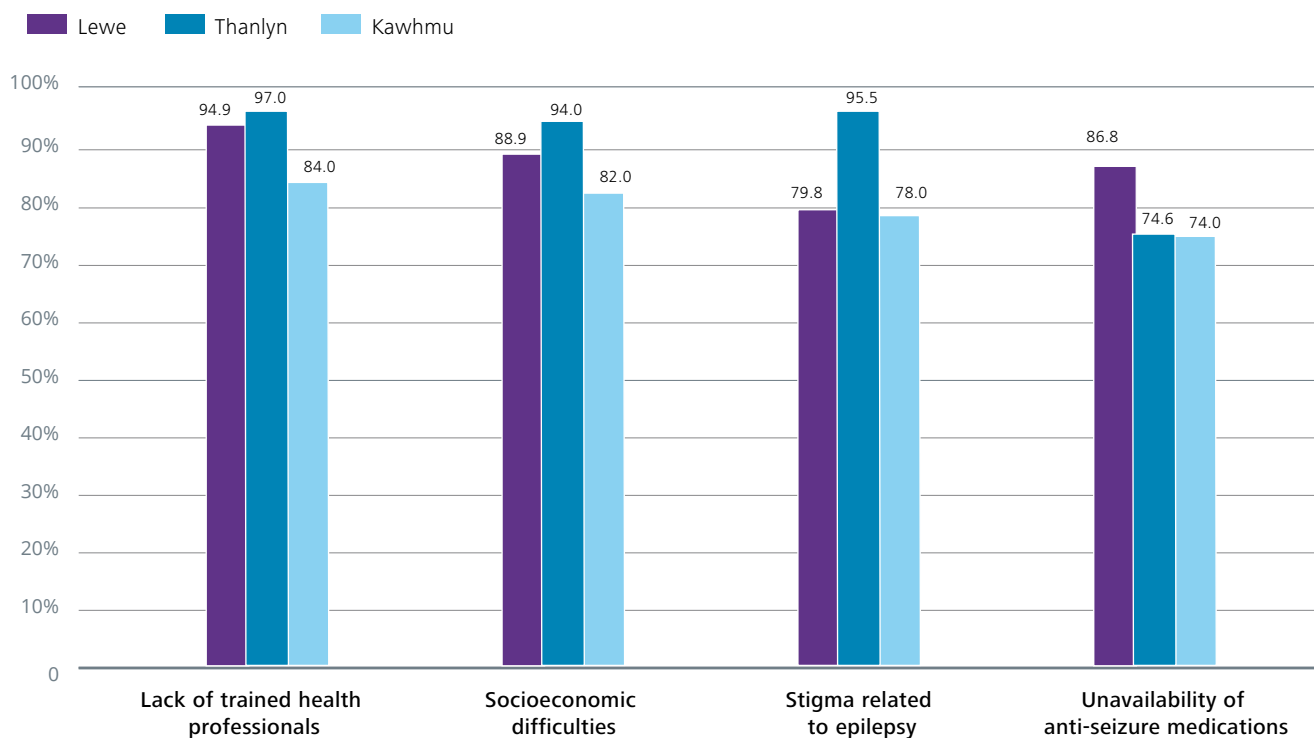
lacked confidence in doing so. Among the health care providers surveyed, more than 80% had never attended training on epilepsy and 95% said they wanted training on epilepsy. Community members also lacked information on epilepsy, with people recommending placing an object into the person's mouth during a seizure to prevent tongue biting – an action that is not recommended by clinical guidelines (mhGAP-IG). As detailed in [Fig. 7](#), many barriers to accessing care for epilepsy were identified by health care providers and community members, with “the lack of trained health professionals” mentioned across the townships (mean 92.0%).



Table 1. Prevalence of convulsive epilepsy in project townships

District	Total population	Estimated no. of epilepsy cases	Prevalence (per 1000 population)
Hlegu	214 967	335.8	1.6
Hmawbi	199 993	377.2	1.9
Kawhmu	127 246	148.2	1.2
Lewe	287 024	460.7	1.6
Thanlyin	232 437	194.0	0.8
Kyaikhto	169 454	237.2	1.4*
Nyaungdon	226 967	249.7	1.1
Thahton	265 737	372.0	1.4*
Sagaing	300 900	421.3	1.4*
Taunggyi	382 534	535.6	1.4*
Nyaunglebin	202 199	283.1	1.4*
Pantanaw	265 002	371.0	1.4*
Total	2 874 460	3985.8	1.38

* Estimated prevalence, an average of the prevalence in six surveyed townships.

Fig. 7. Key barriers identified to accessing care for epilepsy in three townships



2 Capacity building of health care providers

The workforce is the most valuable asset of a health system but the shortage of health care providers in Myanmar was found to be a key barrier to strengthening services. Therefore, capacity building of a nonspecialized workforce was deemed the most viable strategy for increasing access to epilepsy care.

Training of health care providers was based on adapted mhGAP materials, which are designed to be used in-service (i.e. continuing education). This broadens the

...the shortage of health care providers in Myanmar was found to be a key barrier to strengthening services. Therefore, capacity building of a nonspecialized workforce was deemed the most viable strategy for increasing access to epilepsy care.

existing attitudes, knowledge and skills of health care providers, and requires coordination with specialists to ensure optimum delivery and continued support and supervision. A cascade model of training was introduced, where specialists were trained as trainers and supervisors, then various cadres of the workforce in Myanmar were trained to provide epilepsy treatment and care.

Adaptation of generic training materials and tools

Adaptation involves making changes to components of the training package to ensure the content and delivery is meaningful and helpful to the cultural context. Prior to the commencement of training, mhGAP training manuals for trainers and supervisors were adapted for the cultural context using local case studies and role plays. The manuals for MO, BHS and VHW were also adapted to fit in with the Myanmar health care system.

The manuals for MO were developed in English and for the BHS and VHW in Myanmar language. Video presentations of the various types of epilepsy were developed and found to be very effective in training. Materials were further revised following feedback from participants at the training sessions. It was decided to give more attention to case scenarios in the training, which help participants (especially medical doctors) deal with various situations encountered in managing epilepsy cases. Practical case presentations of people living with epilepsy not only enable understanding of the clinical and management aspects but also the impact of epilepsy on the person and the family. Revisions to the training materials were again carried out in 2017 using the updated version of mhGAP-IG 2.0.

Training health care providers

During the project implementation period a total of 84 specialists were trained as trainers and supervisors, and 2231 health care providers were trained: 237 MO, 1023 BHS and 971 VHW. Refresher training sessions were held between 2016 and 2017 for 828 health care providers, as displayed in [Table 2](#).

"I did not know that it was wrong to put something into the mouth while having seizures. We always did that before."

Table 2. Number of health workers trained

District	Year	Initial training			Refresher training		Total
		MO	BHS	VHS	MO	BHS	
Hlegu	2013	21	97	74	11	107	310
Hmawbi		20	65	85	20	67	257
Kawhmu	2014	5	48	91	3	94	241
Lewe		20	100	65	17	101	303
Thanlyin		47	61	65	30	77	280
Kyaikhto	2015	15	67	63	5	76	226
Nyaungdon		15	68	177	4	106	370
Thahton		18	68	62	16	94	258
Sagaing	2016	22	88	54	–	–	164
Taunggyi		29	102	60	–	–	191
Nyaunglebin	2017	15	138	73	–	–	226
Pantanaw		10	121	102	–	–	233
Total		237	1023	971	106	722	3059

Training of trainers and supervisors: 84 specialists (e.g. neurologists, physicians, paediatricians and psychiatrists) were trained as trainers and supervisors in four sessions during 2015 and 2017. This training of trainers and supervisors (ToTS) aimed to build the skills of specialists in training methodologies such as preparing and presenting training sessions, facilitation of role plays and group work, time management, and giving individual feedback.

Training of medical officers: Between 2014–2017, 12 new training sessions were conducted where a total of 237 MO were trained. Eight refresher training sessions were held for 106 MO. The training of MO included the following topics: definition, classification and types of seizures and epilepsy; epilepsy in children; assessment, management and follow up of convulsive epilepsy; emergency management of acute seizures; principles of treatment and care including psychosocial support; referral pathways; data collection and reporting.

During training of MO, general practitioners (GPs) were encouraged to attend; in total, 40 GPs were trained. The participation of GPs was higher in townships further

**...a total of
237 medical officers
were trained.**

away from Yangon than those near the country's largest city. This is possibly due to the working schedule of GPs near Yangon who are in government services during the day and private practice in the evenings.

“I find that using the case demonstration (with actual epilepsy cases) is very effective and now we are more confident in diagnosis of epilepsy, classifying management of epilepsy.”

A general practitioner from Pantanaw township in 2017 training

Training of nonspecialist basic health staff: Health assistants, lady health visitors, public health supervisors and midwives are among BHS. Throughout the 5 years of the project, a total of 1023 BHS were trained in 12 sessions, and 722 received refresher training. Compared with the training of MO, the training of BHS put more emphasis on: definition of epilepsy; assessment and management acute seizure including first aid measures; timely referral of people living with epileptic seizure to medical doctors or specialists; ensuring treatment compliance and understanding of the side-effects of anti-seizure medications and regular follow up; providing psychosocial support; health education to people living with epilepsy and their families and combating myths and misconceptions; epilepsy with

special conditions and epilepsy in children; use of diazepam in acute emergencies and indication for urgent referrals; data collection and reporting.

Training of voluntary health workers: Auxiliary midwives and community health workers make up the VHW. 12 new training sessions were conducted for 971 VHW. The training sessions included participants from local NGOs such as members of the Red Cross Society, Myanmar Maternal and Child Welfare Association, and the Myanmar Women’s Affairs Federation. Members of the auxiliary fire brigade were also provided with training in the project townships with the aim of disseminating information about epilepsy and identifying suspected cases for referral to the health facilities, especially in hard-to-reach areas.

As a result of the training, the health care providers were equipped with the knowledge and skills to manage epilepsy cases in their respective townships at the community level. Pre-test and post-test training surveys were carried out to test knowledge about epilepsy (**Table 3**). Paired t-tests were carried out to evaluate the difference in scores from pre- to post-test for each training group; these were found to be highly significant. The participation of traditional medicine practitioners and faith leaders in the training was minimal and mobilizing this group in the epilepsy project is an area for improvement in the future scale up.



Table 3. Results of pre- and post-training evaluations by workforce cadre (2014–2017)

Category of health provider	Number of participants	Pre-test*	Post-test*	% improvement	Paired t-test value	P-value
MO	237	54.4	83.9	54.2%	11.81	< 0.001
BHS	1023	77.2	92.0	19.2%	20.46	< 0.001
VHW	971	65.7	84.0	27.9%	13.59	< 0.001
Total	2231	65.8	86.6	31.7%		

* Scores are calculated based on a maximum score of 100.

3 Awareness raising

One of the key objectives of the Myanmar Epilepsy Initiative was to develop and disseminate epilepsy IEC materials to improve awareness among public and community groups. The communication strategy included using multiple channels to disseminate key messages on epilepsy and impart information to raise awareness and encourage people living with epilepsy to seek treatment.

Public education and promotional materials developed

A diverse range of IEC materials were developed for the project targeting the general public to raise awareness about epilepsy and the services available in the community. These included:

- One video feature on generalized tonic-clonic epilepsy targeting the general population on epilepsy, symptoms, do's and don'ts, and first aid measures (2014).
- Short public service announcements mainly comprised of overarching key messages on epilepsy targeted at the general population aired since 2014.
- Two posters – one general information poster and one on first aid targeting the general population and also family members and teachers including the message against stigma and discrimination.
- Three pamphlets – one on general facts about epilepsy, one on first aid directed at the general population and one on epilepsy in women and children targeting women, children and the general population.
- A song on epilepsy targeting the general population that contains key messages about epilepsy performed by a nationally recognized singer.
- A comic book for middle and high school children providing information on epilepsy developed in 2016.

The IEC materials were produced at the beginning of the project in 2014 during a multistakeholder workshop that gathered 37 participants, including five TV programmers, two FM radio station staff, and eight journalists. Private FM radio stations and TV channels such as MRTV 5 and Sky Net channels provided assistance in filming and airing news relating to epilepsy training sessions and workshops and interviews with senior project staff.

In addition, advocacy materials, such as T-shirts, bags, key chains and logo tags, were produced, which were distributed during the advocacy sessions in all the project townships and at the workshops during the project period. At the township level, the Myanmar Red Cross Society, Myanmar Maternal and Child Welfare Association, Myanmar Women's Affairs Federation and other local NGOs participated in the VHW training and regularly disseminated IEC on epilepsy in their respective townships. The Myanmar Medical Association chapters in townships agreed to disseminate information on epilepsy project activities among people living with epilepsy, family members, department of education personnel especially school teachers, and the general community.

In 2016, an educational video was developed and aired by government as well as private TV stations providing education on epilepsy.

In 2016, an educational video (with famous actors and actresses) was developed and aired by government as well as private TV stations providing education on epilepsy, aimed particularly at reducing stigma and discrimination. The Health Education Bureau, under the MoHS, closely collaborated with the project in development and pre-testing of IEC materials and obtaining approval from various departments, as well as ensuring the video could be aired on national TV free of charge.



Information, education and communication activities

Activities were arranged throughout the project's implementation to raise awareness of epilepsy and enhance access to services. The activities aimed to better support people living with epilepsy and their families, for example, by organizing a support group. Members of the general public were also targeted to share information on epilepsy and reduce stigma and discrimination.

Community awareness events: International Epilepsy Day was commemorated annually between 2015–2017. Every year on the second Monday of February people joined together to celebrate and highlight the problems faced by people living with epilepsy and their families. In Myanmar, a wide spectrum of stakeholders from members of parliament, directors of regional and township health departments, village level administrators, local and international NGOs, members of community-based organizations, civil society members, media personnel and the general public participated. These events included health education talks, video presentations and mini-exhibitions. Approximately 930 people attended the events over the 3 years.

The service sector was acknowledged as an important place to identify and respond to the needs of people living with epilepsy. In 2017, a health education session on epilepsy was carried out in Kawhmu township at the Hospitality and Catering Training Academy, where staff and 120 students, as well as headmistresses from five primary schools, four middle schools and three high schools, attended the health education session and viewed a mini-exhibition on epilepsy IEC materials.

Formulation of an epilepsy support group: In 2017, a mass community awareness-raising event in Yangon aimed to educate the public on epilepsy. The event was attended by people living with epilepsy and their families and offered an opportunity to mobilize them to join the epilepsy awareness and support group.

Members of the general public were also targeted to share information on epilepsy and reduce stigma and discrimination.



Prior to the event, the Epilepsy Support Group was formed with the parent of a child with epilepsy as chair and secretary. During the event, flyers were distributed with information on where to access services and asking for people to join the support group. A famous film star/singer was recruited to serve as an ambassador for combating stigma and discrimination against people living with epilepsy.

The Epilepsy Support Group aims to promote a brighter future for people living with epilepsy in Myanmar with the following objectives:

- To increase understanding of epilepsy and reduce stigma and discrimination through awareness campaigns and education programmes.
- To increase access to treatment and care by providing support, referral information, assistance in obtaining access to anti-seizure medications, counselling and advice to people living with epilepsy and their families.
- To advocate for the rights of people living with epilepsy and to campaign to eliminate all discriminatory practices and policies affecting them, especially in relation to education/schooling, employment, driving etc.

Health education talks: Regular health education talks are held by BHS as part of their outreach service delivery missions. In the project townships, epilepsy was added to the list of routine topics covered by these health education talks. Over the 5-year project, a total of 21 336 health talks were conducted and 286 218 persons were reached (**Table 4**).

Table 4. Total number of health talks given by BHS

District	Total number of health talks	Estimated number of persons reached
Hlegu	2470	35 277
Hmawbi	810	9972
Kawhmu	522	6087
Lewe	3715	82 721
Thanlyin	2897	44 717
Kyaikhto	489	16 859
Nyaungdon	652	6980
Thahton	8251	47 218
Sagaing	760	14 937
Taunggyi	19	1331
Nyaunglebin	751	20 119
Pantanaw*	0	0
Total	21 336	286 218

* This township received training in December 2017 and therefore did not have time during the course of the pilot project to implement the awareness raising activities.

“Most of the people with epilepsy are not taking proper treatment or they are taking irregular treatment because the drugs are also expensive. It will be of great help to the patients if drugs are provided free by the health department.”



4 Provision of nonspecialized care for epilepsy

The epilepsy project activities were integrated into the three levels of the primary health system in Myanmar. At each level, innovative approaches were used to maximize the limited health care workforce and improve access to treatment for people living with epilepsy.

- At the township level (i.e. township health department facilities and hospitals), outpatient departments where MO provide services, a specific time and day was designated for people living with epilepsy to access routine care.
- At the RHC level, health assistants were allowed to initiate treatment.
- At sub-RHC level, to ensure uninterrupted supply of anti-seizure medications, midwives were given a supply of anti-seizure medications to provide follow-up treatment. Midwives provide community-based health care, conduct health education sessions on epilepsy, case finding, follow-up treatment, reporting and referral of epilepsy cases.

These changes meant that epilepsy services could be provided in the community, closer to people living with epilepsy, rather than solely at the township hospital level. This is significant, as prior to the project, many people living with epilepsy were unable to travel to township hospitals for treatment because of the distance and transportation costs.

Procurement, distribution and use of essential anti-seizure medications

In order for people living with epilepsy to have access to effective treatment, adequate stocks of anti-seizure medications are essential. The project team coordinated across levels of the health system, with the MoHS,

regional health directors and the township MO for inclusion of available anti-seizure medications in Myanmar (i.e. sodium valproate and carbamazepine) in their biannual procurement plans in all the project townships.

The project made the process of anti-seizure medications procurement more sustainable by providing townships with initial 6-month to 1-year supplies of available medicines and gradually built up mechanisms for the township health departments to procure medicines from the government system themselves before stopping provision from the project. This mechanism has been implemented in 10 townships (excluding the two townships trained at the end of 2017).

In 2016, phenobarbital, sodium valproate and carbamazepine were designated as first-line anti-seizure medications in the Myanmar National List of Essential Medicines. Throughout much of the project implementation period, phenobarbital was not registered or available in Myanmar and could not be obtained by local procurement, thus, it

...prior to the project, many people living with epilepsy were unable to travel to township hospitals for treatment because of the distance and transportation costs.

was procured by WHO to ensure an uninterrupted supply in project townships. Due to advocacy efforts of the project team, the Department of Public Health agreed to purchase phenobarbital locally from the Myanmar Pharmaceutical Enterprise starting in 2018. The project team, Department of Food and Drug Administration and the Department of Public Health negotiated the price for phenobarbital at 26 Kyats (US\$ 0.02) per tablet.



At the end of the pilot project in 2017, none of the health facilities across the project townships reported stock outs of anti-seizure medications. Between supply from the project and that received through government procurement, anti-seizure medications supply is sufficient to serve the number of people requiring epilepsy treatment.

Integration of epilepsy service provision with outreach care

The cascade model of training ensured a multidisciplinary and collaborative model of service provision was rolled out in the project townships. In order for epilepsy care to reach people in rural communities that previously did not have access to services, BHS were trained to provide epilepsy care during routine health outreach visits to villages. When BHS consult people living with epilepsy during these outreach visits, they provide follow-up care, health education, psychosocial support, and counselling regarding the importance of medication adherence and potential side-effects.

A total of 84 874 outreach visits were conducted in project townships, reaching 2715 people living with epilepsy.

A total of 84 874 outreach visits were conducted in project townships, reaching 2715 people living with epilepsy. From 2016 to 2017 the total number of outreach visits increased by 62% (Table 5) and the number of people living with epilepsy seen on these outreach visits rose four-fold. This is partly due to epilepsy care becoming increasingly embedded in the routine primary health care delivery, more health education sessions to raise awareness, and an emphasis on regular follow up by health care providers at the refresher trainings.

Ensuring regular supervision of nonspecialists

The model of service provision also required consistent, supportive supervision by the township level health personnel. This included the township and station MO, township health officers and nurses providing supervision to the RHC staff, health assistants and lady health visitors, who in turn supervised midwives at sub-RHC, BHS and VHW in the community.

Table 5. Total number of health outreach visits by BHS in 2017

District	2014	2015	2016	2017	Total
Hlegu	156	567	1321	1442	3486
Hmawbi	470	3971	3868	3053	11 362
Kawhmu		55	212	245	512
Lewe		2	3252	3458	6712
Thanlyin		0	2339	7758	10 097
Kyaikhto		2134	5416	10 499	18 049
Nyaungdon			3557	1229	4786
Thahton		36	5375	5260	10 671
Sagaing			0	5697	5697
Taunggyi			0	12 440	12 440
Nyaunglebin				1062	1062
Pantanaw				0	0
Total	626	6765	25 340	52 143	84 874

* Where data were unavailable, training had not taken place during these years or was too late to be part of the reporting period.

The central level project team also conducted quarterly supervision at the project townships (Table 6). In 2015, a total of 35 visits were carried out by the central level project staff: 13 were M&E supervision visits and 22 were supportive technical supervision visits. In 2016, a total of 56 supervisory visits were carried out (18 technical, 38 M&E), which represented an important increase compared with 2015. In 2017, 33 supportive supervisions were conducted by the M&E officer and the township level health department staff covering both technical and administrative matters. It was found that data entry and submission had improved over previous years and data reporting was more regular and timely.

In 2016, a total of 56 supervisory visits were carried out...

During each supervision visit the following issues were reviewed and solutions discussed:

- Attrition of trained health care personnel (which remains a problem in many townships) required the addition of five refresher training sessions in 2017.
- Improvements in data recording and reporting were observed and need to be maintained through the review of new patient forms, follow-up registers and monthly reports.

- Review of treatment provided to some epilepsy patients, leading to the project developing a national framework for epilepsy care in Myanmar which was endorsed by the MoHS.
- Review of stocks of anti-seizure medications at health facilities, requisition of anti-seizure medications through the government procurement system, and addressing issues of adherence among people living with epilepsy.
- Administrative/management problems, such as townships that need to improve decentralization of epilepsy treatment to rural health facilities (e.g. Thanlyin, Nyaungdon and Taunggyi that have only decentralized to station hospital level).

Care pathways and referrals strengthened

Care pathways are the routes by which people living with epilepsy access treatment and care. They influence the organization of services and comprise a collaborative system of care, at multiple levels of care and across cadres of the workforce. The project measured referrals from participating facilities to tertiary providers in monthly township report forms to monitor the care pathways for people living with epilepsy in each township.

In 2015, there were two referrals to secondary and tertiary levels. By 2016 there were 53 referrals and in 2017 the referrals had increased to 61. These referrals were for management of seizures that could not be controlled by treatment at the township level and some of the cases were paediatric cases.



Table 6. Total number of supervision sessions

	2014	2015	2016	2017	Total
Supervision sessions by central level project team	14	35	56	33	138
Number of monitoring visit by township level supervisory team	8	81	147	225	461
Total	22	116	203	258	599

5 Monitoring and evaluating the initiative

The Myanmar Epilepsy Initiative M&E plan included a pragmatic list of indicators to not only monitor inputs and processes but also coverage and outcomes for people using services. The plan included a management protocol to assess and manage people living with epilepsy, new patient forms, follow-up patient forms, monthly facility forms and a follow-up register (see Annexes 1-3 for more information). These forms were printed and distributed at the beginning of March 2015. A M&E officer was recruited for the project in October 2015, this helped to ensure quality data collection and analyses.

The number of primary health care facilities involved in the project that were trained in the use of the management protocol up to 2017 is shown in [Table 7](#). The M&E officer coordinated data collection with the staff in these health facilities and improved the recording of patient and facility level data.

To further integrate epilepsy treatment and care in the government system, it is important to establish epilepsy indicators in routine data collection. A major success of the Myanmar Epilepsy Initiative was coordination with relevant departments under the MoHS for the definitions of epilepsy to be revised and the four minimal indicators for epilepsy to be collected by the routine health management information system (HMIS). Collection of four indicators, (old and new cases, total number of consultations, and referrals to specialists) is feasible at a health facility level and can be used to monitor epilepsy care nationwide.

A major success of the Myanmar Epilepsy Initiative was coordination with relevant departments under the MoHS for the definitions of epilepsy to be revised and the four minimal indicators for epilepsy to be collected...

Table 7. Health care facilities involved in the project

Township	State/region/ district/township hospital	Station hospital	Rural health centre	Sub-rural health centre	Maternal child health
Hlegu	1	3	8	35	1
Hmawbi	1	3	4	27	1
Kawhmu	1	3	4	27	1
Lewe	1	2	7	28	1
Thanlyin	1	2	8	63	1
Kyaikhto	1	1	6	34	1
Nyaungdon	1	1	5	28	1
Thahton	1	1	5	22	1
Sagaing	1	4	7	40	1
Taunggyi	2	4	4	23	2
Nyaunglebin	1	3	6	32	2
Pantanaw	1	4	7	53	1
Total	13	31	71	412	14



Review & next steps

Results:

- Coverage in all 12 townships
- Adequate follow-up
- Reduction in seizures
- Improvement in quality of life

Lessons learned

Moving forward:

- Commitment from policy-makers
- Moving toward universal coverage for epilepsy

Results

The results of the Myanmar Epilepsy Initiative have not only been evaluated on the activities carried out by the team, but also in terms of coverage in project townships. The phased approach to implementing the project in townships, states/regions over the 5-year period and advocacy by the project leadership led to a gradual increase in the number of health facilities providing quality epilepsy care, better awareness in the community, improved M&E across implementation sites and growing political commitment to improve epilepsy treatment and care.

Coverage in all 12 townships

Service coverage is a comprehensive concept expressing the ability of a health service to interact with the target population who should benefit from the service (45). The process to improve service coverage includes a variety of factors, such as availability of resources and workforce, distribution of facilities, supply logistics, and people's attitudes toward health care. Improving service coverage is essential for scaling up effective, equitable services for people living with epilepsy and can guide quality improvement of existing services (46). However, estimating service coverage requires substantial technical, human and financial resources, which are not necessarily available within routine health information systems. Estimates of service coverage should include data on new and follow-up cases, but because some health information systems do not provide this information, coverage for epilepsy is often underestimated.

Contact and effective coverage are two important dimensions of service coverage (45). 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. Routine data collected by a programme can sometimes be used to calculate contact coverage, but determining effective coverage requires further information on patient health and functioning outcomes (46).

The project was successful at increasing contact coverage (by new cases) in the 12 implementing townships, from 2% at baseline to 47% in 2017.

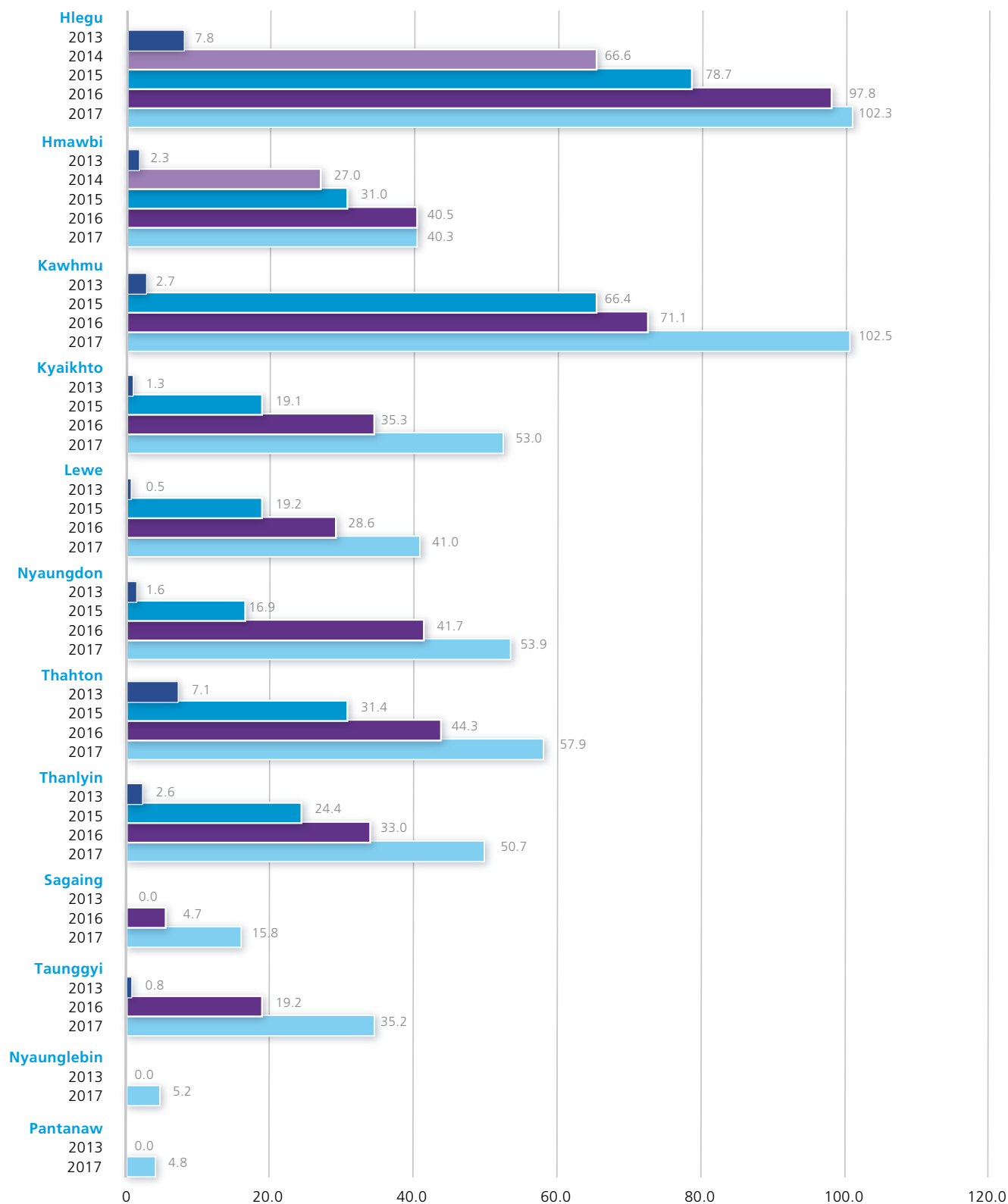
The first coverage indicator that was routinely monitored by the Myanmar Epilepsy Initiative was contact with epilepsy services. In the absence of population-representative surveys in all project townships, prevalence data were estimated from surveys conducted in six townships and data were extrapolated on the number of epilepsy cases which might be in need of services. **Table 8** shows the coverage of epilepsy care estimated from the number of new cases that gained access to care since the project inception. The project was successful at increasing contact coverage in the 12 implementing townships, from 2% at baseline to 47% in 2017.



Table 8. Contact coverage by year of the project

Contact coverage (new cases)	2013	2014	2015	2016	2017
Average*	2.2	46.8	35.9	41.6	46.9

* Measured as the proportion of people who accessed services in project townships based on the estimated prevalence of epilepsy in the township population (see Table 1 for more information on estimated prevalence).

Fig. 8. Percentage of contact coverage (by new cases) – by year and township

The project was implemented in townships gradually in a phased approach, and contact coverage data based on new cases are presented in [Fig. 8](#). The population data used to calculate coverage are based on the annually produced township health profiles. The population has increased in some townships, thus reducing the estimated coverage (e.g. Hwambi). Coverage was lower in Sagaing township due to its geographic location and difficulty in accessing health facilities. An unusual finding is that the coverage exceeded 100% in Hlegu and Kawhmu in 2017. This may be explained by the mobile population in Hlegu. In Kawhmu, people living with epilepsy from the neighbouring townships of Twante, Kungyankone and Dedaye sought free services in Kawhmu.

[Fig. 9](#) presents the number of new epilepsy cases and follow-up consultations conducted annually under the Myanmar Epilepsy Initiative. Continued care for people living with epilepsy is important, so that health care providers can monitor their progress in terms of seizure reduction and adherence to medicine. This shows the project has been

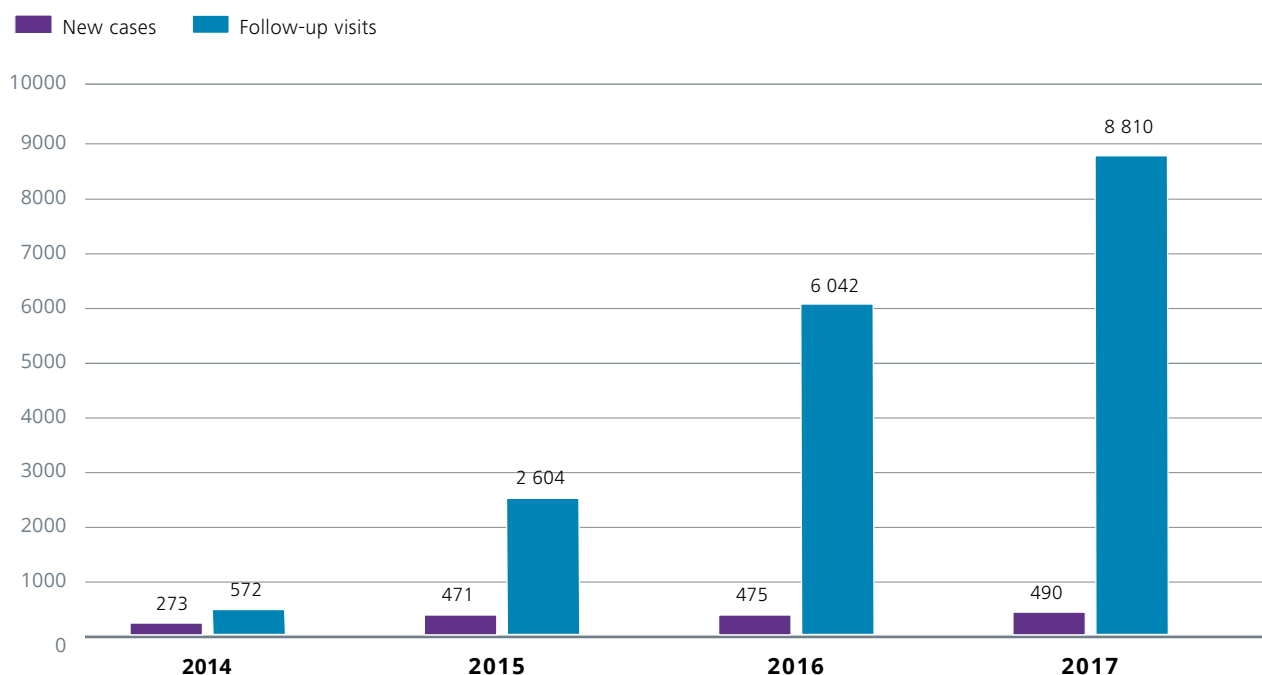
successful in improving access to treatment and continued care for people living with epilepsy.

When comparing data across townships (Annex 4), an increase in new cases identified was observed in some townships during the first year of implementation, as activities such as training of health care providers and awareness raising were implemented. In some townships, decreases in subsequent years of the project can be explained by most new cases having been identified. In Hmawbi, a township near the main city of Yangon and with the military hospital in its jurisdiction, new cases reduced in 2017 because a higher number of people living with epilepsy were being treated by specialists in private practice.

Follow-up consultations increased each year of the project, as shown in Annex 4. Training in Nyaunglebin and Pantanaw townships was conducted in late 2017 and therefore the number of new cases is lower, and follow-up consultation data were unavailable.



Fig. 9. Total number of new cases and follow-up consultations 2014-2017



Living with epilepsy in Myanmar

When Ma Shwe Zin Moe, a 16-year-old female adolescent, went to the RHC, it was noticed that she had impaired physical and mental development. She had a history of seizures starting at the age of three, which was then accompanied by fever. She exhibited slow growth, dysphasia, was unable to walk without support and suffered from three to four seizures per month (unprovoked). Her attention wandered and she was hyperactive. Clinically, she had weakness in her lower left limb and she was significantly disabled. Ma Shwe Zin Moe's parents had taken her to several traditional medicine practitioners, both in her village and nearby, and also conducted rituals as instructed by various

nat-ka-daw (similar to faith healers) and astrologers to please the "spirits causing the ailment".

When her parents took her to the RHC involved in the project, she was diagnosed with epilepsy (childhood onset) probably due to a central nervous system infection. She was started on phenobarbital 30 mg hs. After about 3 months of regular treatment her seizures were reduced by more than half and her general condition improved (i.e. she had less hyperactivity and was more attentive). This is an example of how the project is helping to provide services for people living with epilepsy and support their families to access quality treatment and care.



Table 9. Number of new cases and follow-up consultations by age and sex 2014-2017

	Age categories				Total
	0–12	13–18	19–60	>60	
New cases					1709
Male	184	109	589	39	921
Female	145	113	500	30	788
Follow-up consultations					18 028
Male	1470	1141	6378	438	9427
Female	1188	1216	5812	385	8601

Table 10. Adequate follow-up in Hlegu, Thanlyin, Kawhmu and Kyaikhto townships

Township	Estimated cases of epilepsy	New cases	Follow-up cases in 1-year period	Number of cases with 75% follow-up	Rate of adequate follow-up
Hlegu	335	352	175	85	49%
Thanlyin	193	97	72	36	50%
Kawhmu	148	154	97	61	63%
Kyaikhto	237	129	78	44	56%

The total number of new and follow-up cases are shown in **Table 9**, by age group and sex. The project identified 1709 new cases of epilepsy. There was a slightly higher number of males and a majority of cases were in the adult age category of 19–60 years old.

Effective coverage is a measure of the impact of a project on patient outcomes, i.e. the proportion of the target population who receive appropriate, effective care that benefits people living with epilepsy. The impact of the project for people living with epilepsy can be seen in key indicators such as: adequate follow-up, reduction of seizures and improved QoL.

Adequate follow-up

Adherence to medication is defined as taking the exact prescribed amount of medicine at the precise times of every day for an extended period of time (47). This is important because medications will only work if they are taken regularly. When doses are missed or the medicine is taken irregularly, people living with epilepsy are at greater risk of having seizures and adverse effects. However, medication

adherence is difficult to measure in routine consultations and therefore the project team adopted adequate follow-up as a proxy indicator for adherence. The operational definition required that a person with epilepsy returned to the health facility for follow-up treatment at least nine times within a 12-month period.

Data on adequate follow-up was analysed from January 2017 to December 2017 in four townships. The four townships were selected based on two primarily using sodium valproate and carbamazepine (Hlegu – 2014 and Thanlyin – 2015), and two townships which primarily used phenobarbital (Kawhmu – 2015 and Kyaikhto – 2015). Table 10 shows that among the people living with epilepsy coming for follow-up visits over 1 year, those who made at least nine visits or 75% regularly, were considered as having adequate follow-up.

Reduction in seizures

Freedom from seizures is the ultimate goal of epilepsy treatment. It reduces morbidity and mortality, prevents sudden death from epilepsy, and improves QoL.

Calculating seizure freedom rates relative to a comparator is an ideal way to document efficacy of anti-seizure medications and report on the impact of treatment for people living with epilepsy (22). By the end of 2017, data on seizure reduction, measured as at least a 50% reduction during follow-up visits were available in 10 project townships (Fig. 10). Seizure reduction was observed in 36% of follow-up visits across the 10 townships.

Improvement in quality of life

With appropriate treatment, more than three quarters of people living with epilepsy could lead normal lives, free of seizures. This has the potential to improve QoL by helping people to regain employment or attendance in school, reduce their social isolation and enhance independence.

For pragmatic reasons of collecting data in routine consultations, QoL was assessed by one subjective item in the follow-up consultation form asking people living with epilepsy if they felt their QoL had improved since starting treatment. In 2015, the range of people who indicated a positive improvement in QoL ranged from 28.6% (in Kyaikhto) to 98.3% (in Hmawbi). In 2017, improvement of QoL among the people living with epilepsy coming for follow-up visits ranged from 47.8% (Nyaungdon) to 90.8% (Kyaikhto), with an average improvement of 78.2%. The slight reduction seen in Hlegu and Kawhmu is due to the marked increase in number of new cases in these townships.

Additional data was collected in Hlegu township from October to November 2016 for better understanding of issues related to quality of life. All people living with epilepsy who accessed services and received treatment in the township health facilities during this 1-month period were invited to participate in the evaluation. QoL was assessed before taking anti-seizure medication, and 2 weeks after starting treatment.

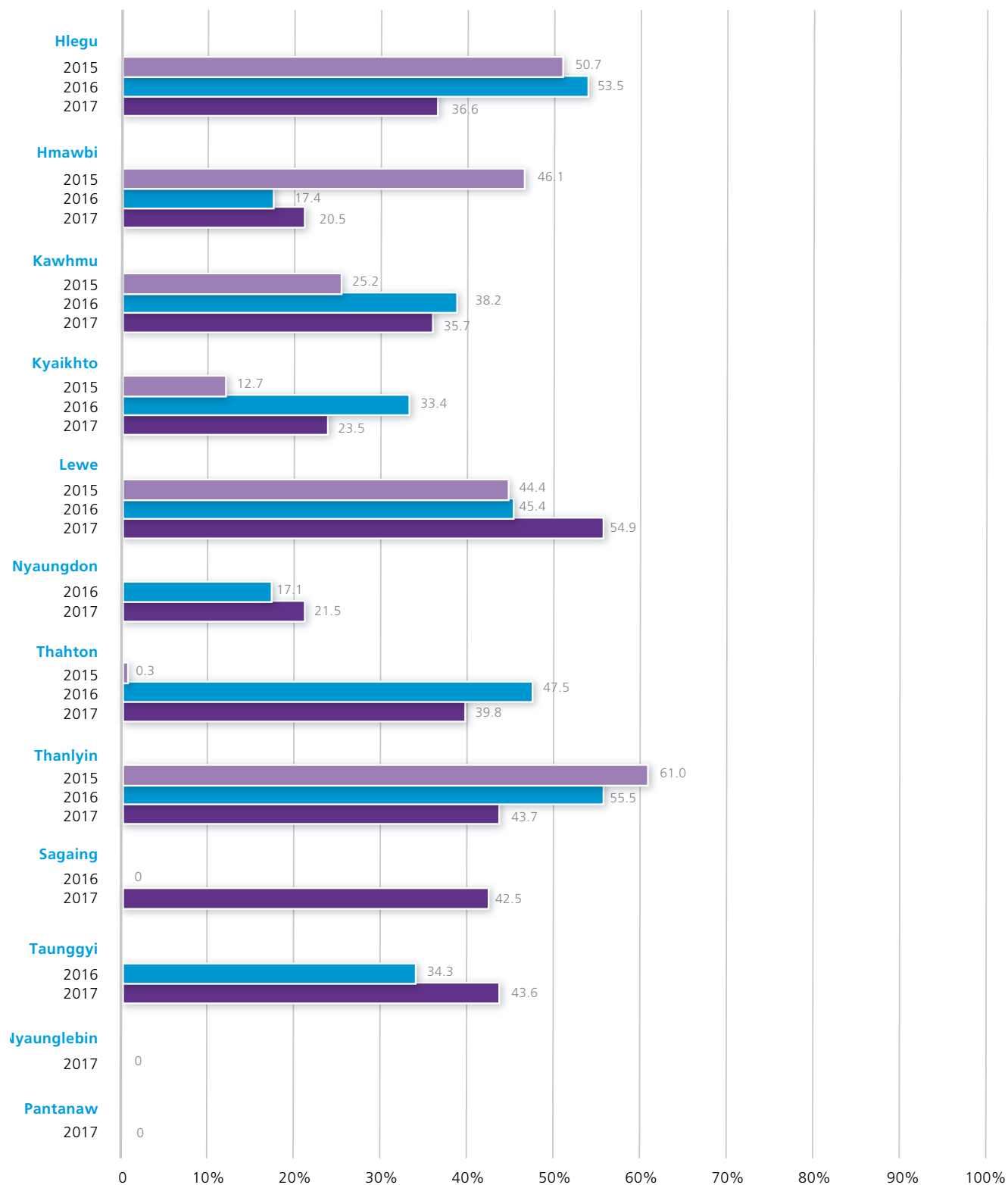
Participants were interviewed using pre-tested, semi-structured questionnaires with health-related QoL items modified from the Quality of Life in Epilepsy Inventory, 40-item scale (48). The adapted questionnaire included items on epilepsy effects (memory, physical effects, cognitive effects of medication) mental health (energy, depressive symptoms, overall quality of life) and social functioning. Trained health assistants from the University of Community Health in Magwe carried out the survey.

The total number of participants in the evaluation was 72. The majority of people were between the ages of 20 and 40 years old, living in rural areas and most were female (56.9%). Most people only had primary level education, which could be possibly related to early drop out from school. The evaluation revealed the following findings:

- QoL scores significantly increased after treatment, showing the effectiveness of the care received. Mean ($\pm$ standard deviation) QoL scores before 31.56 ($\pm$ 14.38) and after 49.29 ($\pm$ 12.89) treatment, ($p < 0.001$).
- Before treatment, people living with epilepsy living in rural areas were found to be five times more likely to have a low QoL score than those living in urban areas; potentially related to the difficulties in accessing care.

The findings of this evaluation are important when considering the impact that epilepsy has on quality of life, particularly for people who may be at risk of social isolation. The results show that with access to treatment, QoL may significantly improve. However, this evaluation assessed QoL in the short term (2 weeks later) and therefore longer-term follow-up evaluations are required to better understand the impact of treatment.

Fig. 10. Percentage of follow-up visits with at least 50% seizure reduction reported



Lessons learned

Stakeholder participation

Engagement by a range of stakeholders was been instrumental to the success of the project. The members of the PCC provided expertise and experience across a variety of disciplines such as neurology, public health, MoHS administration, academia/research. The PCC facilitated coordination across central, state/regional and township levels. This coordination was key to the success of the project in achievements such as model integrated epilepsy care across specialist and nonspecialist cadres of the workforce.

Policy-maker commitment

Commitment from the MoHS was essential both for project implementation and for the long-term sustainability of epilepsy care in Myanmar. During project implementation, the MoHS facilitated the process of anti-seizure medications supply through the government procurement system, thus enabling townships to provide free medication to people living with epilepsy in the community. Key policy achievements resulting from the project were the inclusion of epilepsy in the Myanmar National Health Plan 2017–2021, as part of the NCD programme, and the publication of the National Framework for Epilepsy Care in Myanmar, adopted in 2017.

Care in nonspecialized settings

A key success of this project has been in training workers across several categories of the health system. This included specialists as trainers and supervisors; MO to provide regular diagnosis and treatment in townships;

BHS for identification of convulsive seizures and epilepsy; health assistants trained to initiate treatment with phenobarbital starting in 2016; and VHWs to recognize symptoms, disseminate health education on epilepsy, provide first aid and refer for treatment.

Attrition of trained health care providers remained a problem in many townships throughout the project. Activities to mitigate this risk included refresher training sessions to address staff turnover in implementing health facilities, as well as training workers outside the facilities, for example, those based in communities, such as auxiliary midwives.

A key success of this project has been in training workers across several categories of the health system.

The culturally adapted mhGAP training materials enhanced various categories of health workers' understanding and ability to care for people living with epilepsy. These materials are an important resource both in Myanmar and may be adaptable to other countries.

Phased and flexible approach

People living with epilepsy in Myanmar face geographic and economic challenges to accessing services (e.g. living in hard-to-reach areas and the cost of transportation). Poor adherence to anti-seizure medication also resulted from



difficulties in accessing services. This was addressed by using a community-based approach to service delivery that was gradually rolled out across the 12 townships. The approach reached township health facilities and RHC/ sub-RHC. By training health assistants and midwives who also provided outreach care, the project made epilepsy services more accessible and affordable.

Multi-pronged model of awareness raising

The widespread awareness raising activities, from township to RHC level, was implemented concurrently with improvements in service provision, thus increasing the number of people accessing treatment and care. The project successfully involved school teachers, local administrative bodies, NGOs, the service sector and even national celebrities to mobilize the community around epilepsy and break down stigma. The formation of the epilepsy support group aims to further improve the social participation and QoL of people living with epilepsy.

Supervision, monitoring and evaluation

Supportive supervision and regular M&E were essential to the success of the project. Both clinical and administrative logistics need to be monitored to ensure an adequate supply of medicines and the quality of the services provided. In some townships, treatment guidelines were not properly followed and multi-drug therapy was prescribed. Thus, more technical support and supervision was organized. The project also developed the National Framework for Epilepsy Care in Myanmar which has been endorsed by the MoHS.

The success of these activities was reflected in the improvement of data collection at the health facility level and its integration with government HMIS. The achievement of routinely collecting data on epilepsy indicators will inform the future scale up of services and reduce the burden that limited health care places on providing quality treatment and care.



Moving forward

Commitment from policy-makers

Successful advocacy during the Myanmar Epilepsy Initiative resulted in the inclusion of epilepsy under the neurological disorders as one of the NCDs in the National Health Plan (2017–2021). This major milestone represents a commitment by the MoHS to ensure implementation of epilepsy services.

The Myanmar Epilepsy Initiative demonstrated a model that was effective in reducing the epilepsy treatment gap.

The Public Health Department and the PCC coordinated with the Myanmar Pharmaceutical Industry for local production and purchase of phenobarbital. Phenobarbital, sodium valproate and carbamazepine are classified as first-line medicines under Myanmar's National List of Essential Medicines (2016). The project was also able to institutionalize the procurement of anti-seizure medications by township health departments in their biannual procurement system, thereby ensuring a sustainable supply within communities. Political commitment has been strong; as a result, the MoHS has procured sufficient quantities of anti-seizure medications for 2018.

The National Framework for Epilepsy Care in Myanmar has been approved by the MoHS. This framework provides a model of epilepsy care for the country at

all levels of the health care system. It can be applied in other states/regions and townships outside the project sites to enhance the quality of services. To develop the national framework a core group from the Department of Neurology and other public health experts were selected to draft and revise. An initial workshop in August 2016 was conducted in Nay Pyi Taw, the capital, to engage with policy-makers and present the draft. The final version was launched in December 2017.

Since 2014, the subject of epilepsy has been included in the undergraduate medical curriculum of University of Nursing, Yangon. Epilepsy has also been included in the in-service township medical training course conducted at the training school in Lewe. Coordination was done with the Rector of the University of Community Health in Magwe in 2016, to insert epilepsy in the health assistant training curriculum beginning in 2017.

Moving toward universal coverage for epilepsy

The Myanmar Epilepsy Initiative demonstrated a model that was effective in reducing the epilepsy treatment gap and expanding coverage. WHO and the MoHS are committed to building on the lessons learned and evidence generated from the pilot project, which will now be applied in a scale up programme to ensure the long-term sustainability of accessible, affordable and quality care for epilepsy in Myanmar.

The approach to scaling up epilepsy care in Myanmar will translate the policy and decentralized service achievements from the pilot project into meaningful and sustainable gains toward universal health coverage. At a scale of 12 townships, the pilot project improved epilepsy coverage from 2% to 47% in just 4 years of data collection. Over the next 4 years, the scale up programme will be gradually phased to cover all townships in five states/regions of the country (an additional 73 townships). The programme will also continue to monitor and evaluate the pilot townships in an additional four states/regions for a total of 85 townships reached by the end of 2021.



Universal health coverage means that all people receive the quality, essential health services they need, without being exposed to financial hardship (49). This requires an efficient health system that provides the population with access to good quality services, trained health care providers, medicines and technologies, while at the same time reducing out-of-pocket costs. In order to achieve universal health coverage for epilepsy in Myanmar, the following priorities will be strengthened:

- **Affordability** – a system for ensuring health services reach people in rural communities so they do not suffer financial hardship when accessing care for epilepsy.
- **Availability** of essential anti-seizure medications and technologies to diagnose and treat epilepsy.
- **Sufficient numbers** of well-trained, motivated health workers to provide good quality epilepsy services to meet people's needs based on the best available evidence.
- **Actions** to address the social impact of epilepsy by raising awareness and knowledge of epilepsy among the general public, and reducing the social exclusion of people living with epilepsy and their families.

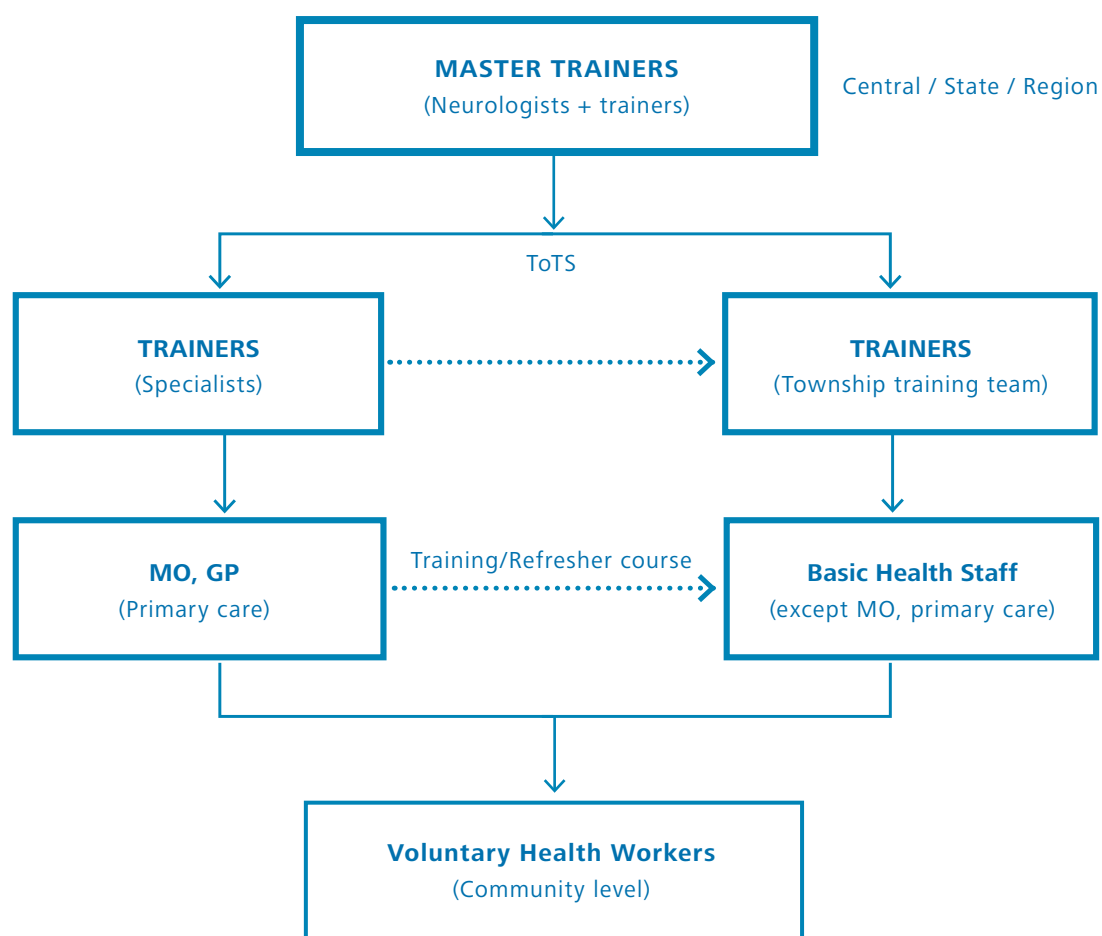
A cascade model of training (**Fig. 11**) will be adopted where the central level will provide training to state/regional level trainers, both in medical care (specialists in hospitals and public health sectors) and NCD focal points at state/regional levels taking responsibility for the implementation. By strengthening and supporting the regional level to roll out and supervise project activities, the scale up programme will ensure local buy-in and ownership. Central level project staff will provide technical support, training, M&E and supportive supervision.

The scale up programme will cover 85 townships across the country. All 12 townships in the pilot project will continue to receive supervision and M&E. The programme will be scaled up to cover all townships in five states/regions, an additional 73 new townships.

- **Year 1:** Mon State (two pilot and eight new townships)
- **Year 2:** Kayin and Kayah States (14 new townships)
- **Year 3:** Bago Region (one pilot and 27 new townships)
- **Year 4:** Ayeyarwaddy Region (two pilot and 24 new townships).

The significant achievements of the initial pilot project in Myanmar led to 47% contact coverage (by new cases) in implementing areas. However, many people living with epilepsy in Myanmar still do not have access to proper and adequate care. Continuing to increase access to quality epilepsy care is therefore essential. Given the size of the country, with a population of 53.8 million, successful nationwide scale up for epilepsy care will only be possible through an innovative, decentralized implementation model. The scale up programme is a unique opportunity to test this model's effectiveness in responding to the burden of epilepsy and improving the QoL for people living with epilepsy in Myanmar. As global attention is shifting toward NCDs and universal health coverage, this programme will also serve to test intermediate nationwide scale up to integrate NCD frameworks into primary care.

Fig. 11. Proposed cascade model of training for epilepsy care



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Annex 1.

Sample new patient data form

Township Name of RHC

Date Patient ID Number (assign now)

1. Name

2. Age

3. Sex

4. Race & Religion

5. Occupation

6. Address

7. Marital status

☐ Unmarried

☐ Divorced / Separated

☐ Married

☐ Widow / Widower

8. Education level and literacy

☐ Illiterate

☐ Can read and write

☐ Primary school

☐ Middle school

☐ High school

☐ Graduate

9. Accompanying person to clinic

Parents / Siblings / Husband / Wife / Relative / Friends / Others

10. Entry Type

☐ Self-referral

☐ By family / friend

☐ As an emergency

☐ By basic health staff

☐ Faith healer

☐ Traditional medicine practitioner

11. Seizure-related history

Age at first seizure

Number of seizures in last 12 months

Date of last seizure

12. Has the patient received treatment in the past for seizures?

☐ Yes

☐ No (If no, proceed to no. 15)

13. Seek treatment from:

☐ Doctor

☐ Traditional medical practitioner

☐ Faith healer

☐ Other

14. Is the patient currently on medication?

☐ Yes

☐ No

Name and dosage of medications

Duration of taking medication.....

15. Family history of epilepsy? ☐ Yes ☐ No

16. Any other neurological conditions? ☐ Yes ☐ No

(e.g. encephalitis, stroke, brain tumor)

17. Head and brain injuries ☐ Yes ☐ No

18. Drinks alcohol? ☐ Yes ☐ No

19. Use narcotics? ☐ Yes ☐ No

20. Past significant medical history

21. Regularly taking medicines

22. Drug allergies

23. Are you able to go to school? ☐ Yes ☐ No

24. Are you able to go to work? ☐ Yes ☐ No

25. Are you able to carry out daily household tasks? ☐ Yes ☐ No

26. Are you satisfied with your life situation? ☐ Yes ☐ No

Relevant supplementary information (e.g. any social support needs, referral to support groups, etc.):

.....

.....

Treatment/ Management Plan

1. Diagnosis

2. Medication prescribed (name of drug, strength, dosage and duration)

.....

.....

3. Referral made ☐ Yes ☐ No

4. Epilepsy education provided during this session? ☐ Yes ☐ No

Prescriber signature

Name

Rank.....

Sample follow-up consultation form

[illegible]

[illegible]

Annex 3.

Sample monthly report form

To be filled in by a facility staff member once a month.

Date: Township: Facility:

Reporting month /year.....

Information on epilepsy cases seen by age and sex:

Age group	New cases		Old / follow up cases*		Total	
	Male	Female	Male	Female	Male	Female
0-12 years						
13-18 years						
19-60 years						
>60 years						
Total						

*the number of patients attending the facility for follow-up care, not the number of follow-up appointments.

1. Total number of patients sent to or referred for management at other facility:
2. Number of seizure free patients:
3. Number of patients with 50% reduction in seizure:
4. Number of patients with side-effects on current medication Yes () No ()
5. Number of patients missed taking medication: No missing dose ()
 < 3 days during 2 weeks ()
 < 3 days during 2 weeks ()
6. Number of patients able to go to work Yes () No ()
7. Number of patients able to go to school Yes () No ()
8. Number of patients able to do housework Yes () No ()
9. Number of patients whose QoL improved since treatment Yes () No ()

Supervision of non-specialist staff

Number of monitoring visits by district (site) coordinator:

Number of monitoring visits by National Coordination Committee representatives:

Outreach provision/home visits

Total number of outreach clinics/services that included epilepsy services:

Total number of patients with epilepsy seen at outreach clinic/services:

Total number of epilepsy related talks given:

Estimated number of audience:

Anti-epileptic medicines

Medicine	Continuously Available*	Female	Old / follow up cases*	Female	Comments (If shortage occurred, no. of days without medicine and why the shortage occurred. If new stock received, details on when and from where)
	Yes/No				
Sodium valproate (200mg)					
Carbamazepine (200mg)					
Phenobarbital (30mg)					
Phenobarbital (60 mg)					
Inj. Diazepam (10mg)					
Other (specify medication and dosage)					

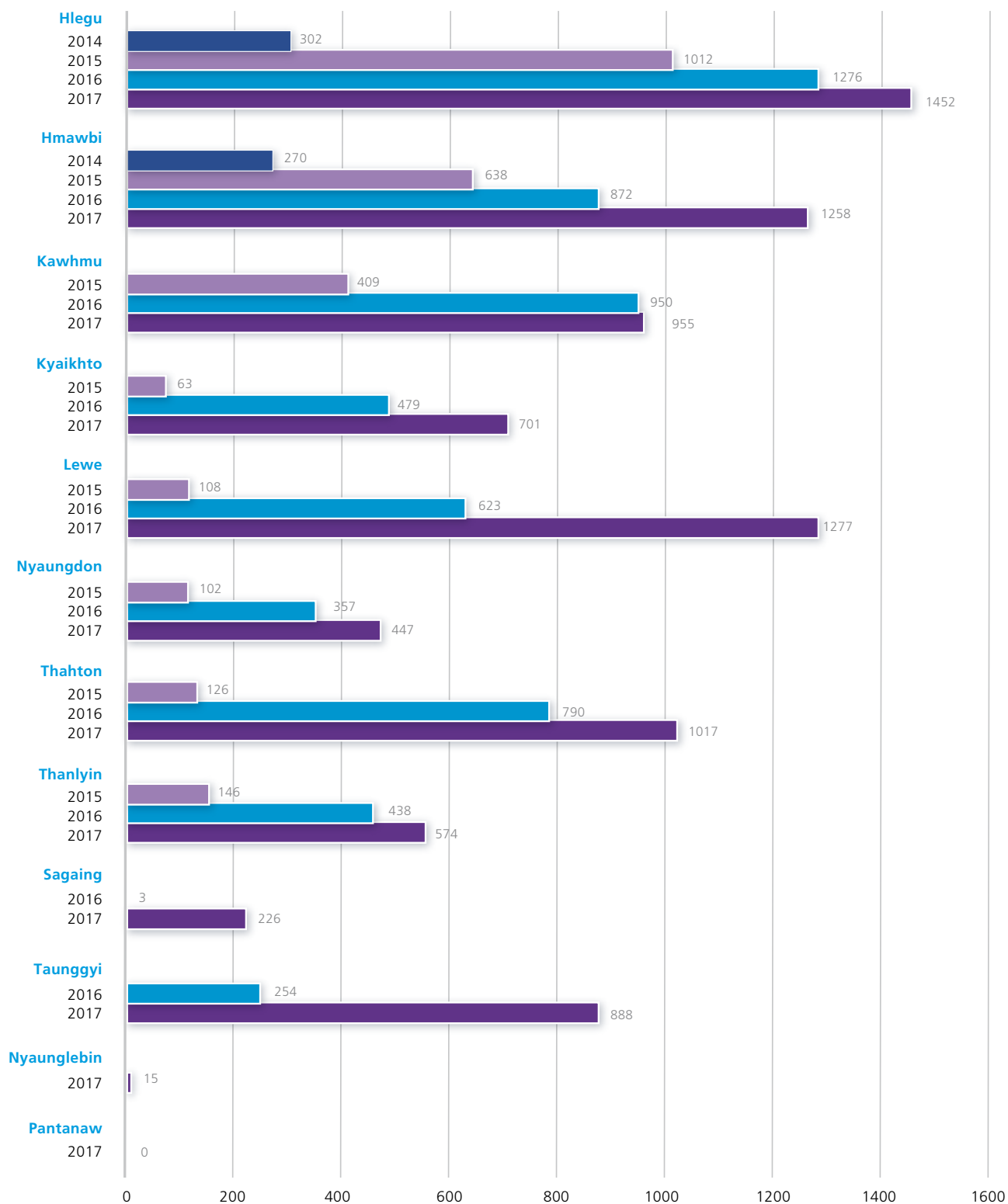
*Continuously available refers to whether a category of medicine was available every day in the month. If there were 1 or more entire days where stock level was zero, then the medicine was not continuously available.

Annex 4.

New cases and follow-up consultations per township



Total number of follow-up consultations per township



Myanmar Epilepsy Initiative

The Myanmar Epilepsy Initiative was implemented through a collaboration between three-levels of WHO--headquarters, South-East Asia Regional Office, the Country Office for Myanmar--and the Ministry of Health and Sports. 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 learned from the Myanmar Epilepsy Initiative and demonstrates the feasibility of scaling up epilepsy services in low-resource settings.



**World Health
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