Ghana’s Fight Against Epilepsy Initiative (FAEI)

Multi-Country Workshop, Africa 15 – 16 September 2015

Meeting Brief

Background

Policymakers, experts, people living with epilepsy, nongovernmental organizations (NGOs) and other key stakeholders from 17 countries attended Ghana’s Multi-Country Epilepsy Workshop, held in Accra on the 15 – 16 September 2015.

Country representation included Benin, Burkina Faso, Burundi, Democratic Republic of the Congo, Ethiopia, Ghana, Mozambique, Myanmar, Nigeria, Senegal, South Africa, South Sudan, Togo, Uganda, Viet Nam, Zambia, and Zimbabwe. Over 150 people were in attendance across the two days, including the Ghana Minister of Health, Honorable Alex Segbefia; Dr Ebenezer Appiah–Denkyira, Director-General of the Ghana Health Service; and Dr Prosper Tumusiime, Ghana’s WHO Representative. The Workshop was organized by WHO HQ, WHO AFRO and Ghana WCO, in collaboration with Ghana Ministry of Health and Ghana Health Services.

Workshop Objectives

The two main objectives of the Workshop were to:

1. Share Ghana’s progress, including achievements and challenges, regarding their implementation of Ghana’s ‘Fight Against Epilepsy Initiative’ and consider strategies for nationwide scale up.

2. Share other country experiences and challenges of implementing epilepsy and/or mental health projects, and to develop common understandings and goals for addressing epilepsy care across the African Region, in accordance with WHA68.20 recommendations.

Other goals of the Workshop were to:

- Highlight evidence relating to the global and regional burden of epilepsy and its impact on health and socio-economic outcomes;

- Summarize the World Health Assembly’s (2015) adoption of the epilepsy resolution WHA68.20 and the opportunity this historical mandate presents for improving epilepsy care worldwide;

- Gain further understandings from persons’ living with epilepsy and their perspective;

- Examine the challenges that exist regarding epilepsy care, including lack of resources and access to antiepileptic medications;

- Emphasize the need for increased investment in epilepsy and related research;
• Encourage governments to take action to prevent epilepsy and improve care services, based on current scientific knowledge, available evidence and global experience.

The format was both didactic and interactive, including presentations, panel discussions and rotating group work.

Presentation and Discussion Themes

Day 1 of the meeting set the stage for discussions regarding Ghana’s experience implementing Ghana’s Fight Against Epilepsy Initiative, a non-specialist community based epilepsy healthcare package that aims to improve access to epilepsy care at the grassroots level. This included:

• The Ghana Minister of Health, Honorable Alex Segbefia, delivering a keynote address and citing political commitment towards continuing the demonstration project.

• Hearing the perspectives of persons living with epilepsy and their caregivers.

• Presentations highlighting Ghana’s Fight Against Epilepsy Initiative achievements, challenges and directions moving forward.

The day’s deliberations were completed by an expert panel discussion, including representation from Ghana’s Fight Against Epilepsy Initiative team (national, regional and district levels), other Ghana Ministry of Health officials, NGOs, faith healers, other African country experts and the private sector.

Day 2 focused on the regional burden of epilepsy and the response required. Presentations, discussions and group work focused on:

• The epilepsy resolution, WHA68.20;

• Challenges regarding sustainable access to antiepileptic medications;

• How epilepsy service delivery can be improved, including integration with other community mental health and noncommunicable disease programs;

• Capacity building strategies including the concept of centralized health worker training processes, the use of mhGAP resources and integration with pre-existing training curriculums;

• The importance of health information surveillance systems;

• Stigma and discrimination and the need for increasing public awareness and educative material dissemination;

• The importance of engagement with persons living with epilepsy, traditional healers and other community groups;

• Current NGO work in the field and the importance of fostering these relationships and pursuing collaborations.
Key Workshop Outcomes

1. Ghana Fight Against Epilepsy Initiative – Experience and Scaling Up Plan

An overview on how the project was executed and its many achievements were discussed. Key points that emerged were:

- The demonstration project was successful regarding the development of a model of epilepsy care in Ghana that can be scaled up;
- It is feasible to reduce epilepsy treatment gaps via training non-specialist health care workers at the primary care level;
- Collaborations are vital. In particular, with NGOs and faith and traditional healers. These have resulted in the development of tandem, non-competitive approaches to epilepsy care including better referral pathways;
- Challenges, including inadequate supplies of antiepileptic medication and distribution obstacles at regional and district levels, lack of health system resources, social stigma and misinformation continue;
- Identification of strategies on how Ghana’s project can be scaled up nationwide. Over-arching principles included:
  
  1. Expand coverage to include more districts within the five regions already involved, with the aim of having project activities and services accessible in all the districts/district clinics within these five regions.
  2. Once this is achieved across all five regions, consider expansion into additional regions of Ghana with the aim of complete national coverage (all 10 regions), one additional region at a time.
  3. Access to antiepileptic medications and their effective distribution would be a crucial determinant with regards to the success of this scale up.
  4. Continuing collaboration with various actors is recommended. This would include NGOs and private industry, traditional/faith healer and religious groups, schools and colleges, persons living with epilepsy and their care-givers, and media organizations.

2. Regional Experiences and Challenges – Towards a Regional Framework for Action

Many of the challenges highlighted were shared across most African countries. Based on this, the Workshop discussed key strategies for improving epilepsy care across the Region. Solutions were related to the core domains of:

i. Government leadership and partnership
ii. Policies and planning
iii. Capacity building
iv. Access to antiepileptic medications, and
v. Reducing stigma and discrimination
A broad framework was drafted, which provides steps to assist accelerate implementation of existing international, regional and national commitments on epilepsy. Its formulation provided an opportunity for the Region to identify broad priorities, identify strategic actions, and determine responsibilities among different stakeholders. It also ensures that activities on improving epilepsy care are not seen as standalone efforts, but rather recognizes that many of the most effective actions necessary to tackle the epilepsy burden lie outside of the health sector, such as tackling stigma and discrimination.

The Regional framework on epilepsy focuses on six key stakeholder levels:

1) Regional
2) National
3) Civil society
4) Private industry (including media)
5) Academic institutions, and
6) Community

Some of the suggested actions are simple and can be taken at the individual level, whereas others require collective involvement. When undertaken, all the actions reflect a commitment to treating and defeating epilepsy, and reducing epilepsy treatment gaps.

Regional

a. WHO to continue leading, coordinating and supporting in order to identify, summarize and integrate the relevant best practices with a view to making this information widely available. This includes supporting epilepsy demonstration projects, providing care packages and resources, such as those related to mhGAP.
b. WHO to continue jointly with the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE) to provide the overall coordination of the Global Campaign against Epilepsy (GCAE).
c. ILAE and IBE, together with regional associations, to contribute towards to development of a ‘Regional Epilepsy Resource Hub’ (RERH), which could include ‘Master Trainers and Supervisors’ (MTAS) for inter-country capacity building, as well as a repository to share materials related to training and community awareness.
d. The organization of regular Regional Workshops to reevaluate current work within the Region and share experiences regarding epilepsy policy and project implementation. This would include continued advocacy ensuring access to antiepileptic medications and their effective distribution; review and evaluation of epilepsy projects and research within the Region and the promotion of further investment in these areas.
e. Advocate for International Epilepsy Day to be celebrated by all African countries.

National

a. Governments to facilitate prioritization and larger resource allocation towards epilepsy care.
b. Governments to introduce and implement, in accordance with international human rights norms and standards, national health care plans for epilepsy management.
c. Governments to promote policies which reduce stigma and discrimination, including the facilitation of societal care for persons living with epilepsy, including access to entitlements and employment.
d. Consideration of integrating epilepsy care with mental health and other noncommunicable disease programmes, particularly focusing on improving access to epilepsy care at the non-specialized community healthcare level.
e. Identify a national focal person for epilepsy associated with the Ministry of Health.
f. Undertake information, education and communication (IEC) activities on a large scale to generate awareness of epilepsy, service delivery and removal of stigma.

g. Establish a National Epilepsy Day to assist raise awareness for epilepsy annually.

h. Improve accessibility to and promote affordability of safe, effective and quality-assured antiepileptic medicines, and include essential antiepileptic medicines into national lists of essential medicines and health budgets.

i. Consider health insurance schemes and civil/corporate partnering to assist costs associated with epilepsy care, in particular the cost of antiepileptic medications.

j. Promote actions to prevent the causes of epilepsy, using evidence-based interventions, within the health sector and in other sectors outside health.

k. Support the training of personnel and the maintenance of health information systems related to epilepsy at the district and national level.

l. Improve investment into epilepsy training and research.

Civil society

a. Pursue and partner with government, and assist with the implementation of epilepsy care programmes.

b. Mobilize public opinion and commitment of policy-makers for the epilepsy cause.

c. Assist in care provision and dissemination of epilepsy best practices.

d. Assist human resource training and filling the resource gap in public spending on epilepsy.

e. Network with similar organizations within the region and worldwide.

f. Facilitate the creation of an 'epilepsy champion' involved in community awareness strategies who can assist the reduction of stigma and discrimination.

Private industry

a. Encourage corporate services and responsibility (CSR) activities to be focused on epilepsy, including financial support of epilepsy projects.

b. Make affordable medications for epilepsy, including consideration of government partnerships and drug banks.

c. Include insurance for epilepsy in health insurance schemes.

d. No discrimination policy vis-à-vis persons with epilepsy.

e. Regularly liaise with media groups to promote time and space for highlighting epilepsy issues and solutions, including television, radio and newspaper press.

Community members (including users and care-givers)

a. Play an active role in awareness creation and de-stigmatization.

b. Organize self-health groups of people living with epilepsy and care-givers of persons with epilepsy.

c. Suitably train traditional/religious/faith healers and teachers to be aware of and identify epilepsy syndromes.

d. Provision of learning materials about epilepsy to communities, including faith groups and schools.

e. Promote a no discrimination policy vis-à-vis students with epilepsy.

Academic and research institutions

a. Facilitate improvements in training healthcare personnel on epilepsy diagnosis, management and treatment.

b. Promote further research into epilepsy aetiology and epidemiology.
The Workshop’s activities were captured in the media and published by Ghana News Agency and Ghana Web:

http://www.ghananewsagency.org/health/ghana-rolls-interventions-to-manage-epilepsy-95025

The Workshop was also featured in the Ghana WHO country office newsletter:
http://whoghana-whoafroccmaster.newsweaver.com/9l2xuny5ancix5afii1j3o?email=true&a=11&p=49310524

For more information on how you can reduce the epilepsy treatment gap, visit:
http://www.who.int/mental_health/neurology/epilepsy/en/

Meeting Brief Compilation and Editing

This brief was compiled and authored by Dr Tarun Dua and Dr Brooke Short. Special thanks are extended to Mrs Edith Andrews Annan, Dr Nkomo Sebastiana and Mrs Grazia Motturi for their reviews and edits.

We would like to acknowledge the contribution of all presenters and participants who attended the Workshop. Particular thanks to colleagues who facilitated group work and/or moderated sessions (in alphabetical order): Dr. Albert Akpalu, Dr Daniel Gerard, Dr Truong Le Van Ngoc, Dr Raquel Maguele, Dr Sheila Ndyanabangi, Dr Sammy Ohene, Dr Akwasi Osei, Prof Win Min Thit and Mr Peter Yaro.
## Appendix 1 - Regional Activity Framework

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<td><strong>Regional Level</strong></td>
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| Development of a Regional Epilepsy Resource Hub (RERH)                           | 1. Develop a spreadsheet with data for regional use including:   
   i. Directory of neurologists
   ii. Directory of NGOs working in the area of epilepsy
2. Disseminate:   
   i. Documents addressing burden of epilepsy & recommendations
   ii. Available training tools
   iii. Awareness raising and education materials
3. Foster capacity building, networking and collaborations                          | ILAE (lead) IBE WHO                                                            | 1. Spreadsheet available and disseminated to all African Region countries.  
2. Repository of resources that can be accessed via an internet/cloud folder     | 2015 - 2016                    |
| Development of Master Trainers and Supervisors (MTAS)                           | 1. Each country to identify at least one person with suitable training to be a part of the RERH group | ILAE (lead) WHO      | 1. Directory available and disseminated to all African Region countries.    | 2016             |
| Regular Regional Workshops                                                       | 1. Development of an annual Regional workshop on epilepsy, supported by governments and NGOs | WHO (lead) ILAE IBE Other NGOs Governments | 1. Regional epilepsy workshop calendar                                      | 2016             |
| The establishment of International Epilepsy Day across the Region               | 1. Endorsement of International Epilepsy Day (second Monday of February each year) within each African country to increase community awareness and education | IBE (lead) ILAE WHO Other NGOs Governments | 1. All African Region countries to celebrate International Epilepsy Day     | 2018             |
Appendix 2 – List of Participants

Member States

Benin
Dr Dismand Houinato, Coordinator Programme National Contre les MNT

Burkina Faso
Mr Pale Koffi Leonard, Point Focal Santé Mentale
Dr Yacoub Ahmedou, WHO IST WA

Burundi
Dr Kamwenubusa Godefroid, Directeur Prog. National Intégré MNT

Ethiopia
Prof Redda Teklehaimanot, Neurologist, Addis Ababa University
Dr Hermon Amare, The Federal Ministry of Health of Ethiopia

Ghana
Honorable Alex Segbefia, Ghana Minister for Health
Mrs Martha Gyansa Lutterodt, Chief Pharmacist, Ghana Ministry of Health
Dr Cynthia Sottie, Medical Officer, Ghana Ministry of Health
Dr Akwasi Osei, Head, Ghana Mental Health Authority
Dr Albert Akpalu, Korle-Bu Teaching Hospital
Dr Patrick Adjei, Korle-Bu Teaching Hospital
Mr Chief Asiam Coker, Accra Psychiatric Hospital
Mr Daniel Asiedu, Ghana Health Service
Mr Samuel Boateng, Ghana Health Service
Mr Cephas Anorku, Ghana Health Service
Ms Philomina Nkansah, Ghana Health Service
Mr Theophilus Gaisie, Ghana Health Service
Ms Confidence Brown, Ghana Health Service
Mr Issah Musah, Ghana Health Service
Mr Bukari Adams, Ghana Health Service
Mr Charles Vigbedor, Ghana Health Service
Ms Justina Awaworyi, Ghana Health Service
Mr Fiifi Ayetey, Christian Health Association of Ghana
Mr Humphrey Kofie, Mental Health Association of Ghana

Mozambique
Dr Paulo Adrassone, Mozambique Ministry of Health
Dr Eugenia Teodoro, Mozambique Ministry of Health

Myanmar
Dr San Oo, Myanmar Ministry of Health
Prof Win Win Min Thit, Myanmar Ministry of Health
Nigeria

Dr Ezeala-Adikaibe Birinus Adikaibe, Department of Medicine UNTH
Mr Donald Ordu, Deputy Director, NCD Division
Dr Bernard Bene, Acting Focal Person for Epilepsy

South Sudan

Prof Mohamedi Boy Sebit, Neuropsychiatrist and Dean of the School of Medicine, Juba

Togo

Prof Belo Mofou, Professeur de Neurologie au CHU Sylvanus Olympio de Lomé

Uganda

Dr Sheila Ndyanabangi, Principal Medical Officer, Mental Health Division, Ministry of Health, Uganda
Dr Hafsa Lukwata Sentongo, Senior Medical Officer, Ministry of Health, Uganda

Viet Nam

Dr Truong Le Van Ngoc, Medical Officer, Viet Nam Ministry of Health

Zambia

Dr Evans Mpabalwani, Consultant Physician

Zimbabwe

Dr Maxwell G. M. Hove, Acting Principal Director Curative Services
Mrs Dorcas S. Sithole, Deputy Director Mental Health Services

Nongovernmental Organizations

BasicNeeds - Ghana

Mr Peter Yaro, Executive Director of BasicNeeds-Ghana

International Bureau for Epilepsy

Marina Clarke, South Africa IBE Branch

International League Against Epilepsy

Dr Sammy Ohene, Ghana ILAE Branch

Private industry

The Sanofi Espoir Foundation

Dr Caty Forget, Managing Director of the Sanofi Espoir Foundation
Dr Daniel Gerard, Associate Vice President Chronic Diseases, Access to Medicines Department
Mr Philip Tagboto, Sanofi Country Manager of Ghana
Mr Dimeji Agbolade, Head of Public Affairs in Nigeria-Ghana
UCB

Dr Dirk Teuwen, Vice President of Corporate Societal Responsibility and Project Leader

Persons Living with Epilepsy

Mrs Francisca Aba Larbie
Mr Thomas Papa Nil Larbie
Mrs Grace Kumah
Mr Eugene Doe

WHO Offices

WHO African Regional Office

Dr Nkomo Sebastiana, MVI/NCD
Mrs Gobo-Mboulion Gisèle, SEC/NCD

WHO Ghana

Dr Prosper Tumusiime, Ghana WHO Representative
Mrs Edith Andrews Annan, Technical Officer
Dr Sally-Ann Ohene, Technical Officer

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