Q4: Can convulsive epilepsy be diagnosed at first level care by a non-specialist health care provider in low and middle income country settings?

Background

Epilepsy affects 50 million people in the world, accounting for 0.5% of the global burden of disease (WHO, 2006). It is estimated, albeit from few studies with significant variability, that more than 80% of the global burden of epilepsy is found in the low and middle income countries (LAMIC) (WHO, 2006). Up to 61.8% to 88% of seizures are convulsive, of which 17% to 44% are secondarily generalized (Wang et al, 2006; Ndoye et al, 2005; Placencia et al, 1994; Sander et al, 1990). The diagnosis of epilepsy relies on history alone, and although investigations can determine the cause, these are not necessary for the case definition. Seizures are classified into generalized or partial seizures. The epilepsies can be divided into symptomatic (the cause is identified and usually manifest as partial seizures), or epilepsies of unknown aetiology (ILAE, 1993). Convulsive epilepsies are often reported in studies, particularly those from LAMIC, since convulsions are more conspicuous and are associated with the local terms for epilepsy. Furthermore these types of epilepsy are associated with greater stigma (Baker et al, 2000) and mortality (Lhatoo et al, 2001) than non-convulsive epilepsies.

In LAMICs, neurologists are not available. Overall the prevalence and incidence of epilepsy across the world is variable. Some of the reasons for this variation could be due to differences in screening tools or definition, the types of epilepsy identified, diagnostic accuracy, or real differences in the prevalence. Most studies in the West are hospital-based and utilize medical records. In LAMICs, however, routine health care statistics are underdeveloped and many people with epilepsy (PWE) do not access health care facilities, and thus reliance on these methods under-estimates the burden of epilepsy. Those that do access these facilities are seen at peripheral clinics, or outpatient clinics in District Hospitals, sometimes seen by psychiatric nurses, although often by health care staff with little specialist training.

The need for more research on the primary care of PWE, particularly those in LAMICs and rural areas has been highlighted 6 years ago (Krishnamoorthy et al, 2003), but few studies have been reported since then.

Population/Intervention(s)/Comparison/Outcome(s) (PICO)

Population: individuals with probable epilepsy

Interventions: diagnosis by a non-specialist health care provider

Diagnosis of convulsive epilepsy by non-specialist health care providers

Comparison: diagnosis by a specialist

Outcomes: appropriate diagnosis

Search strategy

Table 1: Search strategy and output

Main question: Can (1) convulsive epilepsy be (2) diagnosed at (3) first level care by a (4) non-specialist health care provider?

Additional information: (first level care refers to (5) health workers such as (6) nurses, doctors or other non-specialist health care provider working in a (7) health centre with (8) an outpatient facility)

Database	Boolean Search	Limits	Total
Pubmed	((convulsive) OR (convul*) AND (epilepsy) OR (epilep*)) AND ((first level care) OR (primary healthcare) OR (primary care) OR (nonspecialist healthcare provider) OR (healthcare provider) OR (health care provider) OR (health personnel) OR (primary care provider) OR (health workers) OR (doctors) OR (primary care doctors) OR (nurses) OR (primary care nurses) OR (health centre) OR (out-patient facility) OR (outpatient facility))	humans, from unspecified and until 2009/01/3. Please note, the best outcome for the Boolean search was with the removal of 'diagnosed' and 'diagnosis' and words 3 – 8 were grouped together and linked with OR.	3182
Cochrane	(convulsive) AND (epilepsy) AND (diagnosis) AND (primary healthcare) AND (health personnel) AND (health workers) AND (primary care doctors) AND (primary care nurses) AND (health centre) AND (outpatient facility)	Unable to specify limits and there was a need to simplify and reduce the Boolean search	1
PsychInfo	http://www.apa.org/publications/results.html?cx=004712435678442832158%3Abzq2f8t6h2i&cof=FORID%3A11&q=epilepsy&na.x=3&na.y=11&na=GO#969	Unable to specify limits or perform Boolean with database. No results for 'convulsive'. Total here is for 'epilepsy'	10
Medline Plus	((convulsive) OR (convul*)) AND ((epilepsy) OR (epilep*)) AND ((diagnosed) OR (diagnosis)) AND ((first level care) OR (primary healthcare) OR (primary health care) OR (primary care)) AND ((nonspecialist healthcare provider) OR (healthcare provider) OR (health care provider) OR (health personnel) OR (primary care	Search would not allow limit specification and there were no results for Boolean search after 'out-patient facility' or 'outpatient facility' were included.	1

	provider)) AND ((health workers)) AND ((doctors) OR (primary care doctors)) AND ((nurses) OR (primary care nurses))		
WHO Africa Index Medicus		Unable to specify limits. Boolean results were incomplete. Final search was based on 'convulsive' and 'epilepsy' totals	'convulsive' = 1 'epilepsy' = 29
WHO Eastern Mediterranean		Unable to specify limits. Database used was EMRO / IMEMR to avoid defaulting to Virtual Health Library or using sub-database, EMCAT. Boolean results were incomplete. Final search was based on 'convulsive' and 'epilepsy' totals	'convulsive' = 38 'epilepsy' = 429
WHO Europe	(convulsive) AND (epilepsy) AND ((diagnosed) OR (diagnosis)) AND ((first level care) OR (primary healthcare) OR (primary care)) AND ((nonspecialist healthcare provider) OR (healthcare provider) OR (health care provider) OR (health personnel) OR (primary care provider))	Unable to specify limits. Stopped Boolean at the end of main question that included words numbered 1 – 4.	2
WHO Latin American & Caribbean	((convulsive) OR (convul*)) AND ((epilepsy) OR epilep*))	Unable to specify limits. Database search defaulted to Virtual Health Library. Had to specify LILACS. Boolean provided no results beyond this point.	1777
WHO South East Asia	((convulsive) OR (convul*)) AND ((epilepsy) OR (epilep*)) AND ((diagnosed) OR (diagnosis)) AND ((first level care) OR (primary healthcare) OR (primary care))	Unable to specify limits. Boolean provided no results beyond this point. Suggested that search concentrate on 'convulsive epilepsy' and 'epilepsy'	'convulsive' = 13 'epilepsy' = 251 Total = 2
WHO Western Pacific		Unable to specify limits. Boolean provided no results. WPRO defaulted to Global Health Library that was under	'epilepsy' = 686

		construction. This result was from the Regional Index.	
Articles chosen out of all database searches performed			Total
Pubmed, WHO African Index Medicus & WHO East Mediterranean			705
			Total accessed
Pubmed, WHO articles pending			575

Inclusion and exclusion criteria

Studies that compare the detection of convulsive epilepsy by primary care workers with an epilepsy specialist. For the purposes of this review, primary care workers refers to health workers such as nurses, doctors or other non-specialist health care provider working in a health centre with an outpatient facility. Similarly, for the purposes of this review, epilepsy specialists are considered specialist neurologists or psychiatrists, although they may not have sub-specialist training in epilepsy.

Narrative description of the studies that went into the analysis

There were no reports with strong (GRADE 1) recommendation and high quality evidence (Guyatt et al, 2006) about the diagnosis of convulsive epilepsy by primary health care workers. In particular, no studies that directly compared the diagnosis of convulsive epilepsy by primary care worker and epilepsy specialists were identified. A few studies examined the effect of training primary care workers in the diagnosis of epilepsy, but these were pre- and post-studies and did not specifically address the diagnosis of convulsive epilepsy.

Since the diagnosis of epilepsy is made on history alone, the diagnosis of seizures and seizure types is often reliant on the histories of other observers. In a recent study only 75% of observers correctly identified generalized tonic-clonic seizures (GTCS) when compared to video recordings of the seizures (Heo et al, 2008).

Diagnosis of convulsive epilepsy by non-specialist health care providers

The studies that compared the skills of a primary care worker and an epilepsy specialist were mainly from the West, and involved the capability of a general practitioner to diagnose epilepsy with that of a neurologist. Studies focusing on epilepsy nurse specialists did not provide any data on the diagnosis of epilepsy, but reported an increase in knowledge about epilepsy amongst PWE (Appleton and Sweeney, 1995; Mills et al, 1999) and better adherence (Mills et al, 1999).

Misdiagnosis of epilepsy in the primary care setting

Misdiagnosis of epilepsy is common (van Donselaar et al, 2006), despite that most studies have been conducted in specialized epilepsy clinics (Chowdhury et al, 2008). In the primary care setting in the United Kingdom, 21-23% of people diagnosed with epilepsy by general practitioners did not have epilepsy on review by neurologists (Sander et al, 1990; Scheepers et al, 1998). None of the studies reviewed differentiated between convulsive and non-convulsive seizures or epilepsy. One finding indicated that the difference between partial and generalized onset seizures can be reliably identified with structured interviews by lay people (Ottman et al, 1993).

Questionnaires to aid diagnosis by primary health care workers

Two studies examined the use of questionnaires to aid the diagnosis of epilepsy by primary health care workers. In India, a questionnaire was developed for the identification of GTCS by community based health care providers (Anand et al, 2005). The development of the questionnaire went through three phases, starting with a 14-item structured interview, ending with 6 questions (Box).

Diagnosis of Generalized Tonic-Clonic Seizures (Anand et al, 2005)

A history of two or more episodes of jerking or rigidity of limbs, plus 4 or more of the following features:

1. Did s/he pass urine or stool in his/her clothes during the episode?
2. Did s/he ever injure himself/herself or bite his/her tongue/cheek during the episode?
3. Was there any frothing from the mouth during the episode?
4. Did s/he have such an episode whilst asleep?
5. Was the patient completely unconscious during the episode?
6. Has the episode ever occurred without preceding emotional/stressful events?

Diagnosis of convulsive epilepsy by non-specialist health care providers

In phase 3, the 2-stem questions (episodes of jerking or rigidity of limbs) and 6 other questions were tested on 223 patients attending psychiatric outpatients in Bhutan, Myanmar, Nepal, Sri Lanka and Thailand. Neurologists or psychiatrists administered this abbreviated questionnaire. Positive answers to at least 4 of the 6 questions had a sensitivity of 72% (95%CI 65-78%) and a specificity of 100% (95%CI 84-100%) (Anand et al, 2005). Unfortunately this use of this questionnaire was not tested by primary health care workers, nor was a comparison between the primary health care workers and specialists performed; but it does represent one of the few attempts to develop tools for use by this group.

In Ecuador, a diagnostic questionnaire was developed for establishing the diagnosis of epilepsy in children (1 to 10 years old) and for classifying their epileptic seizures to be administered in primary healthcare services (Carpio et al, 2006). This questionnaire was tested by medical students on 204 children (102 with epilepsy and 102 without epilepsy) selected from a regional epilepsy centre by non-medical practitioners and was found to have 95.1% sensitivity (95% CI: 94.58%–95.61%) and 97.1% specificity (95% CI: 96.6%–97.6%), with a positive predictive value of 97.0% (95% CI: 96.5%–97.5%) and a negative predictive value of 95.2% (95% CI: 94.7%–95.7%). The agreement in the classification of the generalized epileptic seizures between the neurologists and medical students was satisfactory (kappa = 0.67), whilst that between the specialists (kappa = 0.80) and the paediatricians (kappa = 0.80) was better (Carpio et al, 2006).

In a Demonstration Project carried out in China, 80-85% of people referred by trained primary care physician's and confirmed by secondary care specialists / hospital specialists were found to have convulsive epilepsies (Wang et al, 2006). This study did not formally set out to examine the reliability of the diagnosis of convulsive epilepsy by non-specialists, but rather recruited patients to a project to demonstrate the reduction in the treatment gap. Furthermore, these results may have been influenced by the vigorous publicity campaign that was part of this project. This project used a questionnaire based upon the WHO screening questionnaire and had a sensitivity of 78.5% and specificity of 100% (Wang et al, 2006). This questionnaire was used in the Senegalese Demonstration Project, but the sensitivity and specificity were not measured. The Brazilian Demonstration Project used a validated questionnaire (Li et al, 2007) which had sensitivity 95.8% and specificity 97.8%.

Many epidemiological surveys have used questionnaires to detect epilepsy, but the questions are often study specific, administered by specially trained non-medical staff and are not designed for use in the primary care setting. Some of these projects used questionnaires that may be useful by non-specialist health care providers, although they often are not designed for convulsive epilepsy. In an Ecuadorian study, the questionnaire had sensitivity of 98% and specificity of 92% (Placencia et al, 1992c). In Georgia, an adapted Epilepsy Epidemiological Study Screening Questionnaire (IBE/ILAE/WHO) based on the "ICBERG Screening Instrument 11, previously used in China, had a sensitivity 98.8% and specificity 87.0% for the diagnosis of epilepsy (JW Sander, personal communication).

In Ecuador, of 881 with definite epilepsy, 298 had secondarily generalized seizures and 378 had GTCS (plus a further 27 had more than 1 type of generalized seizure - not stated how many of these had convulsive seizures). Thus of 676 (76.7%) with convulsive seizures, 298 (44.08%) were secondarily generalized (Placencia et al, 1994).

Diagnosis of convulsive epilepsy by non-specialist health care providers

In **National General Practice Study of Epilepsy and Epileptic Seizures in UK,** 198 (35%) GTCS, 14 (2%) mixed generalized, 151 (27%) secondarily generalized. 349/564 (61.8%) minimum of people with definite epilepsy had convulsive seizures of which 43.3% were secondarily generalized (Sander et al, 1990).

Primary Health Care led clinics

There are a number of reports of primary health care led clinics for epilepsy in Cameroon (Kengne et al, 2008), Ethiopia (Berhanu et al, 2009), Kenya (Feksi et al, 1991), Saudi Arabia (al-Shammari et al, 1996), and Zimbabwe (Adamolekun et al, 1999; Adamolekun et al, 2000), often part of mental health programs in Guinea Bissau (de-Jong, 1996) or chronic diseases such as those in Tanzania (Unwin et al, 1999) and South Africa (Coleman et al, 1998). Most of these studies demonstrated an increase in the attendance of PWE to health clinics, but did not formally assess the quality of diagnosis. An increase in attendance can be improved by community leaders, although in one Zimbabwean study, there was no increase in newly diagnosed patients (Ball et al, 2000). Training of staff members at primary care clinics has led to a decrease in seizure frequency (Kengne et al, 2008; Li et al, 2007) and improved health status (Li et al, 2007).

Causes of epilepsy treatment gap

In a systematic review of the magnitude, causes, and intervention strategies for the epilepsy treatment gap in developing countries (Mbuba et al, 2008), Eight studies investigated causes of the treatment gap. All the eight studies reported that the cost associated with seeking epilepsy care contributed to the treatment gap. The highest median (70%) was associated with inadequate skilled manpower, and the lowest median (18.5%) was associated with long distances to health facilities. Non-adherence to antiepileptic drugs, a factor that also contributes to epilepsy treatment gap was investigated in two studies.

Table 1. Epilepsy prevalence studies in LMIC where a screening questionnaire was validated

Citation	Sampled population size (numerical)	Sampling strategy	Response Rate	Method of Case Ascertainment	Validation of Case Ascertainment	Other Comments
Almu S et al (2006). The prevalence of epilepsy in the Zay Society, Ethiopia--an area of high prevalence. *Seizure,* 15(3):211-3.	1154	door-to-door		1. every resident was visited by a trained enumerator using a questionnaire w/ epilepsy questions 2. Suspected cases (answered yes to any epilepsy Item, n=82) underwent detailed evaluation by a doctor experienced in epilepsy.	questionnaire including epilepsy questions from a WHO screening instrument (Tekle-Haimanot et al, 1990b) translated into Zayigna by local doctors & piloted in two Zay villages	Population selected for high rates of epilepsy and isolation from rest of pop.

Birbeck GL, Kalichi EM (2004). Epilepsy prevalence in rural Zambia: a door-to-door survey. *Tropical Medicine & International Health,* 9(1):92-5.	55000	door-to-door: each of 33 staff were required to interview 340 households within assigned subdivisions of planning zones over 5 months.		1. Questionnaire administered by community health workers with household heads. 2. Suspected cases referred for physician assessment, but prevalence rates based on questionnaire only.	9-item questionnaire previously validated (Placencia et al, 1992c); pilot testing revealed low specificity among children, so 3 questions were added. Blinded neurologist assessed a random subset (100 pos; 50 neg). Adapted questionnaire exhibited 86% specificity & 92% positive predictive value in this population. All 50 who screened negative were determined not to have epilepsy by neurologist.	questionnaire best able to detect generalized tonic clonic seizures, so absence or myoclonic epilepsy likely under recognized. Also bias due to stigma
Edwards T et al (2008). Active convulsive epilepsy in a rural district of Kenya: a study of prevalence and possible risk factors. *Lancet Neurology,* 7(1):50-6. Mung'ala-Odera V et al (2008). Prevalence, incidence and risk factors of epilepsy in older children in rural Kenya. *Seizure,* 17(5):396-404.	151408	door-to-door, 3-phase study	phase 1 identified 2348, 19% refused to participate further. Phase 2 identified 614, 15% refused to participate further. 4 more had poor recall of time since last seizure and were excluded 77% response rate	1. Census team (field workers) asked heads of every household 2 questions about every person in household to identify those who had had seizures. 2. "epilepsy field team" (field workers) visited all individual identified in phase 1 and interviewed them or their guardians 3. suspected cases invited for formal assessment and diagnosis by a clinician at Kilifi District hospital w/in one week. Detailed medical history was used to make diagnosis and record freq. and description of seizures.	1. Question 2 was shown to be 100% sensitive in a previous study in this area for id'ing active epil. (Mung'ala-Odera V et al, 2004 - Ten Questions). 3. A panel of neurologists (the study authors) reviewed case notes to confirm diagnoses. In this study, of 1283 participants deemed negative after phase 2, 1174 were re-interviewed w/ 70 reclassified as positive, from these 24 were identified as having active epilepsy who were originally phase 2 negative. Sensitivity and specificity estimates were 94.8% (442/466) & 52.3% (46/88).	Mung'ala Odera study breaks out active epilepsy into one year intervals from 6-9

Tekle-Haimanot R et al (1990b). Community-based study of neurological disorders in rural central Ethiopia. *Neuroepidemiology*, 9(5):263-77. Tekle-Haimanot R, Forsgren L, Ekstedt J (1997). Incidence of epilepsy in rural central Ethiopia. *Epilepsia,* 38(5):541-6. Tekle-Haimanot R,et al (1990a). Clinical and electroencephalographic characteristics of epilepsy in rural Ethiopia: a community-based study. *Epilepsy Research,* 7(3):230-9.	60820	door-to-door; 30% random sample	95-100%	1. lay health-workers did door-to-door interviews with a questionnaire to screen for neurological disorders (Haimanot et al, 1990) conducted with head of household or his wife for each member of the family. A second form for epilepsy administered for those with unconsciousness fits or jerky movements of the body. 2. examination by neurologists for final diagnosis 3. EEG for persons fulfilling criteria for active epilepsy.	Pretested the screening questionnaire for a 91% sensitivity and an 85% specificity for detection of epilepsy.	
Koul R, Razdan S, Motta A (1988). Prevalence and pattern of epilepsy (Lath/Mirgi/Laran) in rural Kashmir, India. *Epilepsia,* 29(2):116-22. Razdan S,et al (1994). Prevalence and pattern of major neurological disorders in rural Kashmir (India) in 1986. *Neuroepidemiology,* 13(3):113-9.	63645	door-to-door		1. WHO questionnaire 2. Neurological evaluation for those who screen positive.	pilot study in population among 9,000 individuals	
Duron R et al (1997). Las epilepsias en Salama, Honduras: Primera fase de un estudio epidemiologico. *Revista Hondurena de Neurociencias*, 1:38247. Medina MT et al (2005). Prevalence, incidence, and etiology of epilepsies in rural Honduras: the Salama Study. *Epilepsia,* 46(1):124-31.	6473	door-to-door;	88% of residents	1. Screen questionnaire - talked with multiple family members about each patient (ILAE classifications for seizures, 1993); use of 10-min video-EEG to identify seizure types witnessed. 2. Neurological exam for all suspected cases as well as CT & EEG	modification of questionnaire used by Aziz, 1994 from WHO 1981 with >90% sensitivity reported & 50% specificity In this population, sensitivity and specificity 99.2% & 75%, respectively	

[Diagnosis of convulsive epilepsy by non-specialist health care providers]

Gourie-Devi M et al (1996). Neuro-epidemiological pilot survey of an urban population in a developing country. A study in Bangalore, south India. *Neuroepidemiology*, 15(6):313-20.	3040	door-to-door; random sampling: 4 blocks of 131 randomly selected and all available individuals who have been residents longer than 6mo included in study	93.6% of selected households participated	1. Survey (modified WHO questionnaire, 1981) 2. Possible cases underwent neurological exam.	200 persons randomly recaptured, questionnaires re-administered & clinical exam undertaken. Individuals age 7+ sensitivity: 95% specificity: 98% Individuals <7yrs sensitivity: 100% specificity: 99%	
Das SK et al (2008). Prevalence of major neurological disorders among geriatric population in the metropolitan city of Kolkata. *Journal of the Association of Physicians of India,* 56:175-81. Das SK, et al (2006). A random sample survey for prevalence of major neurological disorders in Kolkata. *Indian Journal of Medical Research,* 124(2):163-72.	52377	door-to-door; random sampling: 166 blocks across the city randomly sampled via an SES stratified plan	98.39% of selected households participated	1. Survey (questionnaire used by the National Institute of Mental Health and Neuro Sciences (NIMHANS) Bangalore, Gourie-Devi et al, 1996) + cognitive questionnaire for persons over 50yrs 2. Neurological exam for possible cases	first 3041 subjects used to validate- all screened by neurologist again. Neurologist also examined 10% of negative sample regularly in each block. sensitivity: 84% specificity: 99.9%	
Gourie-Devi M et al (2004). Prevalence of neurological disorders in Bangalore, India: a community-based study with a comparison between urban and rural areas. *Neuroepidemiology*, 23 (6):261-8.	102557	door-to-door; random sampling		1. Survey (modified WHO questionnaire, 1981) 2. Possible cases underwent neurological exam.	validated in prior study (Gourie-Devi 1996) in this pop. >7yrs sensitivity: 95% specificity: 98% <7yrs sensitivity: 100% specificity: 99%	
Das SK, Sanyal K (1996). Neuroepidemiology of major neurological disorders in rural Bengal. *Neurology India*, 44(2):47-58.	37286	door-to-door	inferred all	1. Survey (modified WHO questionnaire, 1981) 2. Possible cases underwent further interview with study authors (**are they doctors?)	not sure of their validation- whether they are citing the pilot study or recapture, but they claim: sensitivity: 90% specificity: 86%	

Basch EM et al (1997). Prevalence of epilepsy in a migrant population near Quito, Ecuador. *Neuroepidemiology,*16(2):94-8.	221	door-to-door Rotary Club census used to obtain list of names	all	1. screen using WHO protocol (WHO 1981) with 3 questions & simple tasks. 2. Neurological exam	pre-test with individuals with neurological disorders and healthy individuals, 96% sensitivity 37 negative respondents examined further to check for false-positives. **no mention of finding any	
Placencia M et al (1992c). Validation of a screening questionnaire for the detection of epileptic seizures in epidemiological studies. *Brain*, 115 (Pt 3):783-794. Placencia M et al (1992b). Epileptic seizures in an Andean region of Ecuador. Incidence and prevalence and regional variation. *Brain*, 115(Pt 3):771-782. Placencia M, et al (1992a). A large-scale study of epilepsy in Ecuador: Methodological aspects. *Neuroepidemiology,* 11(2):74-84.	72121	door-to-door	96.20%	1. piloted and validated screening instrument 2. possible cases examined by a rural doctor 3. cases seen by a specialist neurologist, including standardized neurological interview and exam for clinical detail 4. Panel of international neurologist reviews and defines probable and definite cases Incidence calculated from 12 months of retrospective data	sensitivity 79.3%** specificity 92.9% **not a mistake, its what it says in the text. Also examined 1.4% of all negatives & 4.6% of all false positives from step 2. Found 4 more cases from negatives & 4 more cases from false-positives.	
Diagana M et al (2006)..[Depistage de l'epilepsie en zones tropicales: validation d'un questionnaire en Mauritanie]. *Bulletin de la Société de pathologie exotique,* 99(2):103-7.	236			1. brief neurological exam & 5 screening questions, parents interviewed for patients under 5yrs 2. Re-examination by neurologist to confirm diagnoses	validity of questionnaire evaluated: 95.1% sensitivity and 65.6% specificity for answering one question "yes"	
not listed - Mohammadi 2006 - Prevalence of epilepsy and comorbidity of psychiatric disorders in Iran	25180	door-to-door; random cluster sampling	90.00%	1. epilepsy questionnaire and completion of the Schedule for Affective Disorders and Schizophrenia	validation in 100 individuals (50 pos and 50 neg) assessed by a blinded psychiatrist: sensitivity 78.5%, specificity 90%	
Haimanot RT et al (1990). Community-based study of neurological disorders in Ethiopia: development of a screening instrument. *Ethiopian Medical Journal,*28(3):123-37.	2747	door-to-door;	92.00%	1. town was mapped and houses were numbered with chalk 2. door-to-door interview with household heads asking about a pre-made list of each person within the household to determine those with neurological syndromes. 3. all possible cases examined by neurologist	20 consecutive households with disease and 20 households without disease re-sampled after being seen by neurologist to validate: for epilepsy, sensitivity 93% & specificity 90%.	this is a pilot study for the next Haimanot study (also published 1990)

Mung'ala-Odera V, Meehan R, Njuguna P et al (2006). Prevalence and risk factors of neurological disability and impairment in children living in rural Kenya. *International Journal of Epidemiology,* 35(3):683-88.	10218	door-to-door	89.51%	1. Administered the Ten Questions Questionnaire to parents or guardians 2. Screen pos were referred for a comprehensive clinical and psychological assessment & similar number of screen neg.		
Simms V et al (2008). Prevalence of epilepsy in Rwanda: a national cross-sectional survey. *Tropical Medicine and International Health,* 13(8):1047–53.	6757	door-to-door; probability cluster sampling	80.80%	1. Door-to-door screening for MSI, standardized questionnaire validated elsewhere (Atijosan, 2007), 6 questions. 2. Screen pos examined by physiotherapist using the diagnostic section of the questionnaire. 3. Randomly selected 10% of screen neg to be examined as well.	Atijosan, 2007 none of the 10% of screen neg had epilepsy, 47/51 (92%) of screen pos had epilepsy (i.e. 100% sensitivity, 92% specificity)	
Borges MA, Barros EP, Zanetta DM et al (2002). [Prevalence of epilepsy in Bakairi indians from Mato Grosso State, Brazil]. *Arquivos de Neuro-Psiquiatria,* 60 (1): 80-5.	546	door to door	483(88.46%)	Questionnaire, and resulted in history, exam, EEG	Used modification of Placencia et al, 1992c, Validated in an urban population in Sao Jose do Rio Preto	
Carpio A, Morales J (1986). Prevalencia de epilepsia en la parroquia de Cumbe de la provincia del Azuay, Ecuador. *Rev. Inst. Investig. Salud. Univ. Cuenca*, 1: 10166	5000	random sample of 20% of the households, stratified by sector	all households participated, of 200 sampled, only spoke with 180 because 20 were not registered correctly?	Head of household interviewed, suspicious cases interviewed and examined by medical team		
Debouverie M et al (1993). Epidemiologie de l'epilepsie au Burkina-Faso. *Neurologie Tropicale*, 57-61.	16627	All persons residing in the selected villages		OMS questionnaire, Schoenberg methods; questionnaire administered then positives examined and questioned	informal piloting in a different local population	
Placencia M (1991). Prevalencia de epilepsia en la Sierra Norte ecuatoriana, un trabajo clinico-epidemiologico, 1984-1989. *Metro cienc,* 1(4):4-13. Placencia M (1992). The incidence of epileptic seizures in the highlands of	878			Neuroepidemiology protocol from WHO with additional questions plus neurological exam	validated in hospital population	

Ecuador: An epidemiologic profile. *Revista Ecuatoriana de Neurologia*, 1(2):72-76.						
Goudsmit J, van der Waals F, Gajdusek D (1983). Epilepsy in the Gbawein and Wroughbarth Clan of Gran Bassa County, Liberia: the endemic occurrence of "See-ee" in the native population. *Neuroepidemiology*, 2:24-34. van der Waals F, Goudsmit J, Gajdusek D (1983). Clinical characteristics of highly prevalent seizure disorders in the Gbawein and Wroughbarh Clan Region of Grand Bassa County, Liberia. *Neuroepidemiology,* 2:35-44.	4436	key informant?		standardized physical and neurological examination		
Osuntokun B et al (1982). Research protocol for measuring the prevalence of neurologic disorders in developing countries: results of a pilot study in Nigeria. *Neuroepidemiology*, 1:143-53.	1000	a section of the village	903/1100	questionnaire and screening exam	this was validation study	

Narrative conclusion

No reports were identified that provide data to answer the question “Can convulsive epilepsy be diagnosed at first level care by a non-specialist health care provider?” Data that addresses this question is available, particularly from the epidemiological studies and Demonstration Projects, but it is unclear if these could be incorporated into primary care practice, and whether they would be sufficiently sensitive or specific to be used within a health system.

Reports from the high income countries suggest that there is substantial mis-diagnosis of epilepsy by general practitioners, but these reports do not specifically address convulsive epilepsy. Questionnaires have been developed for the use of primary health care workers in India and Brazil, but these have not been adequately assessed in the primary care setting.

There is a need for further studies to address this question, but the tools need to take into account the differences in health facilities, experience and training of primary health care workers and the community's perception of epilepsy.**Reference List**

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al-Shammari SA, Khoja TA, Rajeh SA (1996). Role of primary care physicians in the care of epileptic patients. *Public Health,* 110: 47-8.

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Appleton RE, Sweeney A (1995). The management of epilepsy in children: the role of the clinical nurse specialist. *Seizure,* 4:287-291.

Atijosan O et al (2007). Musculoskeletal impairment survey in Rwanda: design of survey tool, survey methodology, and results of the pilot study (a cross sectional survey). *BMC Musculoskeletal Disorders,* 8:30.

Aziz H et al (1994). Epilepsy in Pakistan: a population-based epidemiologic study. *Epilepsia,* 35:950-8.

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From evidence to recommendations

Factor	Explanation
Narrative summary of the evidence base	There is no evidence that provides clear answer to the question as no study that directly compared the diagnosis of convulsive epilepsy by primary care worker and epilepsy specialists. There is indirect evidence from a number of studies carried out in LAMIC that diagnosis initially made by a non-specialist health worker for convulsive forms of epilepsy is feasible. Good sensitivity and specificity of epilepsy diagnosis by non-specialists compared with neurologists has been reported from demonstration projects. The successful use of screening tools for epilepsy used in research projects assessing the epidemiology of the condition is indirect data supporting that given the appropriate instruments, this cadre of workers have some diagnostic capacity.
Summary of the quality of evidence	Very low
Balance of benefits versus harms	Convulsive forms of epilepsy carry a high burden, physical and psychosocial and should be diagnosed at first opportunity and existing evidence suggests the feasibility of diagnosis of convulsive epilepsy by non-specialists. Reports from the high income countries suggest that there can be mis-diagnosis of epilepsy by general practitioners, but these reports do not specifically address convulsive epilepsy and moreover the sample was also biased. Studies suggest that convulsive forms of epilepsy can be reliably diagnosed by non-specialist care providers after training. The consequences of undiagnosed and untreated epilepsy outweigh the risk of non-specialist diagnosis.
Values and preferences including any variability and human rights issues	Convulsive epilepsies are often reported in studies, particularly those from LAMICs, since convulsions are more conspicuous and are associated with the local terms for epilepsy. Furthermore these types of epilepsy are associated with greater stigma and mortality than non-convulsive epilepsies. The treatment gap for epilepsy is more than 75% in many LAMICs and one of the important reason is the high diagnostic gap. No opportunity for epilepsy diagnosis should be lost.

Diagnosis of convulsive epilepsy by non-specialist health care providers

Costs and resource use and any other relevant feasibility issues	In a systematic review of the epilepsy treatment gap in developing countries, for its causes, highest median (70%) was associated with non-availablity of skilled manpower. Non-specialist health care providers should be trained to recognize and diagnose convulsive epilepsy. Criteria for diagnosis should be operationalised.
Final recommendation(s) Non-specialist health care providers can be trained to recognise and diagnose convulsive epilepsy. Such training should be provided. Strength of recommendation: STRONG	
Any additional remarks Non-specialist health care providers differ in countries; they include not only general practitioners, but also clinical officers and nurses as they may be the main person responsible for providing services in that setting.	

Update of the literature search – June 2012

In June 2012 the literature search for this scoping question was updated. No new systematic reviews were found to be relevant.