

Guidance on use of epilepsy clinic registers and filing

1. EPILEPSY NEW PATIENT FORM

One copy of this register shall be used at a time, until the depletion of its pages.

If, following the assessment, the patient is deemed not to have epilepsy / NS and so s/he is not enrolled for treatment, the outcome of this assessment shall be clearly written under section 10 – Diagnosis and the entire page shall be crossed.

→ As a rule, no cell shall be left blank. If the information / answer / value is not available / applicable, please indicate: “N.A”, or “NO”, or “NONE”, or “/”, as appropriate.

Element	Comment	Required action
1. Socio-demographic information		
DOB/Age	Either Date Of Birth (DOB) or Age can be inserted.	Do not leave blank – try to get the best approximation possible and insert it.
Date of first visit	Coincides with the “date” at the top of the form	
File No./Reg. No.	This is assigned by CUAMM. Numbering the new patients has proven a tricky exercise. This File No./Reg. No. will eventually have to match with the one indicated in the epilepsy notebook.	Check the File No./Reg. No. assigned to the patient recorded in the previous form (e.g., 64). The new patient shall be assigned the subsequent number (e.g., 65). If the previous form was crossed, look for the latest uncrossed form and resume counting from there.
Position of the child in the family	With “child” is meant “patient”.	Count from the oldest member of the family to the youngest and insert the patient’s position within this order.
No. of siblings	Siblings = brothers and sisters (dead + alive)	Insert the number of brothers and sisters
No. alive		Insert the number of brothers and sisters who are currently alive
No. dead		Insert the number of brothers and sisters who passed away
Birth order	Applicable if the patient is a child or a youth	E.g. if the patient is the 3 rd born among his/her siblings, indicate “3”
Address		Indicate the village and, if possible, the closest landmark
Payam & Boma	Very important to specify the Boma. If the patient does not know, try to get as much information as possible on the location. Precise boma location is necessary for referring the patient for follow-up, if need be.	Insert available information.

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Distance from health facility	This can be approximated by the patient.	Please insert both KM and HRS, if possible, otherwise just the number of HRS.
2. Seizure/epilepsy related history		
Type of epilepsy	This has been deemed to be optional.	Tick focal, generalized, combined generalized and focal, or unknown.
Aetiology of symptomatic epilepsy	Do not leave blank.	If the epilepsy is not symptomatic, indicate "N.A." If the epilepsy is symptomatic, tick one option.
Type of seizures	Choose between (a), (b) and (c) and then select the type within the chosen category of epilepsy.	Tick the relevant type.
Age at seizures onset	Very important information for the NSA project / for disease surveillance purposes. If the patient does not recall the age/date, the clinician can use references to past public and well-known events to understand whether the seizures started before or after that event.	Fill it even if approximated.
Seizure frequency		Tick one option – do not leave blank.
Seizure description	Very important to corroborate final diagnosis.	Fill it with as many details as possible.
Past antiepileptic treatment history	It refers to antiepileptic treatment prior to the last year	If no history of treatment, indicate "none"
Present antiepileptic treatment	It refers to antiepileptic treatment over last 12 months	If no ongoing treatment, indicate "none"
Epilepsy in the family		Indicate the number of family members who also suffer from epilepsy / NS (excluding the patient)
Other relevant medical history		Indicate any other relevant information pertaining the patient's medical history
4. Physical examination		
All variables	Do not leave blank. If the information / answer / value is not available / applicable, please indicate: "N.A", or "NO", or "NONE", or "/", as appropriate.	
MUAC	An incorrect use of the MUAC measurement has been noticed. This measurement determines the diagnosis of MAM & SAM (section 7. Nutritional Assessment)	Comply with standard utilization of the MUAC tape.
6. Assessment for nodding syndrome/Classification for nodding syndrome		
Head Nodding		Tick:

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		<ul style="list-style-type: none"> · “<i>Reported</i>” if the head nodding is simply reported by the patient or his/her caretaker; · “<i>Videotaped</i>” if the patient provides video documentation of the head nodding (e.g., on phone); · “<i>Observed by HW</i>” if the head nodding was witnessed a health worker ahead of today’s visit to the clinic by the patient.
Frequency of nodding 5 to 20 per minute	It means that the patient nods > than 5 times (and less that < than 20 times) every minute. Which means 1 nod of the head ever 3 to 12 seconds.	
Clustering in space or time with similar cases	With “clustering in space and time” we mean: within recent times and / or within the village and its surroundings have there been other cases of NS?	
Probable case?	Follow the NS diagnostic algorithm and determine if the patient is a PROBABLE case of NS or not.	
Documented nodding episode	<p>This serves to conclude if a PROBABLE case of NS can be CONFIRMED.</p> <p>If none of the options is ticked, then the PROBABLE case of NS is not a CONFIRMED case of NS.</p>	<p>Tick “YES” and specify:</p> <ul style="list-style-type: none"> · “<i>Observed by a trained health worker</i>” if the head nodding is witnessed by the health worker at the clinic. · “<i>Videotaped</i>” if the patient is videotaped by the HW at the clinic while nodding (e.g., on phone); · “<i>EEG / EMG</i>” if Nodding is confirmed through an EEG /EMG examination. <p>If none of the above, then tick “NO”</p>
7. Nutritional assessment		
Nutritional assessment	It appears that cases of MAM and SAM have been overestimated	Answer on the basis of the MUAC measurement taken, if applicable
8. Laboratory findings		
All variables	This section is sometimes left blank	Do not leave blank. If the information / answer / value is not available / applicable, please indicate: “N.A”, or “NO”, or “NONE”, or “/”, as appropriate.
9. Referral pathway / Referred by		
a., b., c.	Sometimes this section is left blank	Tick one (no more) of the possible answers
If (c), Client Code	This applies when the patient was referred to the clinic by a Community Health Worker, Community-Based Rehabilitation	If (c) was ticked for the previous question, indicate the Client Code assigned to the patient by the CHW (or BHW, or CBRW). For

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	Worker, Boma Health Worker or any community volunteer of this sort.	instance the CBRWs of SEM assign Client Codes such as “EL126”
Referral Form SN	This applies when the patient was referred to the clinic by a Community Health Worker, Community-Based Rehabilitation Worker, Boma Health Worker or any community volunteer of this sort.	Most times the patient referred by a CHW/BHW/CBRW comes to the clinic with a Referral Form, which has a unique serial number. If so, indicate the Referral Form SN; if not, indicate “N.A.”
CHW/CBRW Name	This applies when the patient was referred to the clinic by a Community Health Worker, Community-Based Rehabilitation Worker, Boma Health Worker or any community volunteer of this sort.	Most times the patient referred by a CHW/BHW/CBRW comes to the clinic with a Referral Form, which indicates the volunteer who referred the patient. If so, indicate the name of the volunteer; if not, indicate “N.A.”
Organization	This applies when the patient was referred to the clinic by a Community Health Worker, Community-Based Rehabilitation Worker, Boma Health Worker or any community volunteer of this sort.	Most times the patient referred by a CHW/BHW/CBRW comes to the clinic with a Referral Form, which indicates the organization that is referring the patient. If so, indicate the name of the organization; if not, indicate “N.A.”
10. Diagnosis		
Diagnosis	<p>Sometimes this value is missing. The diagnosis is formulated on the basis of the answers given under sections 2 and 6.</p> <p>If the diagnosis is “Nodding Syndrome”, clearly indicate if it is a case of PROBABLE NS or CONFIRMED NS.</p> <p>If the diagnosis is “Epilepsy”, please indicate the type of epilepsy.</p>	<p>Clearly indicate the diagnosis.</p> <p>IF THE PATIENT IS NOT DIAGNOSED WITH EPILEPSY:</p> <ul style="list-style-type: none"> - CLEARLY INDICATE “NO EPILEPSY” - LEAVE THE REST OF THE SECTIONS EMPTY - CROSS THE ENTIRE PAGE - SIGN THE PAGE AT THE BOTTOM
11. Treatment initiated		
Treatment initiated	Sometimes this section is incomplete.	<p>Indicate <u>ALL</u> the below:</p> <ul style="list-style-type: none"> • type of AED • dosage & times per day • quantity of pills given (i.e. 30 days – not more) • any other treatment prescribed and provided (e.g. supplements, etc.)
14. Referred for follow-up?		
Yes / No	<p>Sometimes this section is left blank.</p> <p>Each Epilepsy Clinic has its own list of contacts for BHW/HHP/CHWs and CBRWs and shall refer to it when</p>	<p>If the patient is already followed up at home by a BHW (supported by Amref) or by a CBRW (of SEM), indicate “NO” as the patient does not need to be referred.</p>

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	referring patients for home-based follow-up.	If the patient is not followed at home, indicate “YES” and refer.
If “YES”, specify: CHW / CBRW name	Each Epilepsy Clinic has its own list of contacts for BHW/HHP/CHWs and CBRWs and shall refer to it when referring patients for home-based follow-up.	<p>Refer:</p> <ul style="list-style-type: none"> i. patients with complications (e.g. physical disabilities) to SEM CBRW: indicate the CBRW’s name & organization (SEM) ii. patients without complications to CHW/BHW/HHPs supported by Amref: indicate the volunteer’s name & organization (Amref) <p>The CO shall give the patient the name and contact number of the CHW/BHW/HHP or CBRW (available in the list of contacts provided by the project to the epilepsy clinic)</p>
Organization		

Each patient comes (or is asked to come) with his/her own notebook. For a new patient, the CO shall write on the first page of the patient’s notebook:

- **Name and surname**
- **File No. / Reg. No. assigned by CUAMM**
- Date
- Diagnosis
- Treatment initiated (for 30 days only) + recommendations
- Date of next appointment (for a new patient the next appoint is always not later than 30 days after the first visit!)
- Other info (at CO’s discretion)

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2. EPILEPSY CLINIC REGISTER / NOTEBOOK

This register is filled with details of the patients diagnosed with epilepsy / NS and enrolled for treatment. This means that this register is filled **AFTER** a “NEW PATIENT REGISTRATION FORM” has been completed.

At any given time, this register shall clearly show the patients who have been enrolled for treatment to date – without duplications, double-counting, etc.

People who came for consultation but were diagnosed with not having epilepsy / NS should not be recorded.

Element	Comment	Required action
Date	It may appear confusing.	Indicate the same date of the first visit of the first patient on the page.
S/NO	This proceeds numerically	Indicate the subsequent number
TREATMENT	This may be changed by the CO, if the patient does not respond (well) to the first treatment prescribed	Indicate the (only) AED prescribed following registration. If treatment is changed at a later stage, this can / should be rectified.
PHONE NUMBER		Indicate the patient’s phone number – or a contact of a close relative
CUAMM File / Reg. No.	This proceeds numerically and SHALL match with the File No./Reg. No. reported in the “EPILEPSY NEW PATIENT FORM”	Indicate the subsequent number
Other ORG Code	This is applicable if the patient is being followed up by SEM, AMREF	If the patient is being followed up by SEM or AMREF, indicate the Client Code assigned to the patient by that organization (copy from Section 9 of the “EPILEPSY NEW PATIENT FORM”). If the patient is not being followed-up, leave it blank.
REFERRED TO (Org & Name)	This is applicable if the patient is not being followed up by SEM, AMREF	Copy from Section 14 of the “EPILEPSY NEW PATIENT FORM”.

This register should show, at any given time, the total number of patients enrolled for treatment at the epilepsy clinic since its inception.

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3. EPILEPSY MONTHLY FOLLOW UP FORM

This form is filled for any patient who had already been registered and who comes for follow-up visits.

→ As a rule, no cell shall be left blank. If the information / answer / value is not available / applicable, please indicate: “N.A”, or “NO”, or “NONE”, or “/”, as appropriate.

Element	Comment	Required action
1. Client information		
File No./Reg. No.	<p>This was assigned by CUAMM at registration. It must match with the one indicated in the “EPILEPSY CLINIC REGISTER / NOTEBOOK” for this specific patient.</p> <p>The File No. / Reg. No. is also recorded on the first page of the personal notebook that the patient carries with him/her to the clinic.</p> <p>Omitting this number makes it hard to properly file the form at the end of the visit.</p>	<p>Indicate the File No. / Reg. No. of the patient.</p> <p>ALSO INDICATE:</p> <ul style="list-style-type: none"> - Sex of the patient - Age of the patient
Missed previous appointment(s)?	The previous appointment was scheduled either 30 days earlier or 60 days earlier (if the patient had received 60 days’ worth of treatment)	Tick “Yes” or “No”
If yes, how many and why?		Indicate the number of missed appointments – and the reason given by the patient for not attending the missed appointments
2. Seizure related information		
Increase or decrease of seizures	Compared to the frequency reported by the patient during the last consultation (not compared to the frequency at the time of registration.	Indicate either “Increase” or “Decrease”
3. Treatment related information		
Current antiepileptic treatment - Name		Indicate the name of AED currently taken by the patient
Current antiepileptic treatment – Dosage		Clearly indicate the dosage in mg
Current antiepileptic treatment – Daily intake		Indicate whether is once a day, twice a day, etc.
Any adverse effects of medication?	This means either mild or severe adverse effects of AED treatment.	Indicate adverse effects.
Any other treatment in addition to the antiepileptic drugs?	This includes supplements, treatment provided for other ailments.	Indicate as relevant.

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6. Physical examination		
All variables	Do not leave blank. If the information / answer / value is not available / applicable, please indicate: "N.A", or "NO", or "NONE", or "/", as appropriate.	
MUAC	An incorrect use of the MUAC measurement has been noticed. This measurement determines the diagnosis of MAM & SAM (section 7. Nutritional Assessment)	Comply with standard utilization of the MUAC tape.
7. Nutritional assessment		
Nutritional assessment	It appears that cases of MAM and SAM have been overestimated	Answer on the basis of the MUAC measurement taken, if applicable
8. Conclusion and management		
Treatment (same, modified, precise drug / dosage) + (medication given for 30 days, 60 days, or more)	In this section the clinician is expected to record any changes in treatment, e.g. change of AED, increment or decrement of dosage, etc.	<p>Fill as appropriate.</p> <p>Tick quantity of medication given to the patient</p> <ul style="list-style-type: none"> • 30 days • 60 days • > 60 days (not recommended!) <p>If drug regimen is changed, the column "TREATMENT" in the "EPILEPSY CLINIC REGISTER / NOTEBOOK" should also be updated.</p>
Loss to follow up/ defaulter client?	As "DEFAULTER" we define a patient who fails to come to the clinic for > 3 months in a row	Tick "YES" or "NO" by applying the definition of "DEFAULTER".
9. Referral pathway / Referred by		
Is the client followed-up by a CHW / CBR Worker?	This includes community volunteers such as CHWs, BHWs, HHPs, CBRWs...	Tick "YES" or "NO" as appropriate
If "YES", Name:	Sometimes this section is left blank.	Indicate name of the volunteer who follows up the patient at home and the organization that supports the volunteer (e.g. SEM, Amref, etc.)
Organization:	The name of the volunteer and his/her organization providing follow-up services to the patient can be: <ul style="list-style-type: none"> - provided by the patient him/herself - retrieved from SEM Client Card - retrieved from the patient's personal notebook 	
If "NO", refer to a CHW / CBR Worker and specify: - Name:	Each Epilepsy Clinic has its own list of contacts for BHW/HHP/CHWs and CBRWs and shall refer to it when referring patients for home-based follow-up.	Refer: iii. patients with complications (e.g. physical disabilities) to SEM CBRW: indicate the

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<p>- Organization:</p>		<p>CBRW's name & organization (SEM)</p> <p>iv. patients without complications to CHW/BHW/HHPs supported by Amref: indicate the volunteer's name & organization (Amref)</p> <p>The CO shall give the patient the name and contact number of the CHW/BHW/HHP or CBRW (available in the list of contacts provided by the project to the epilepsy clinic)</p>
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4. FILING

Each epilepsy clinic shall maintain a proper filing system, through which authorized personnel can easily and quickly retrieve a patient's personal file containing his/her registration records, referral forms, follow-up visit records, etc.

Here is what is necessary:

- Plastic envelopes with holes compatible with below ring binder file folder. Each envelop will contain the records of 1 patient only.
- Ring binder file folder (each file folder shall not contain more than 50 plastic envelopes / patients' personal files).
- Paper stickers.
- Shelves or cabinets.
- Computer

Each ring binder file folder shall be marked to show the range of patients' personal files contained. i.e.:

- i. The first ring binder file folder shall contain patients with File no. / Reg. no. from 1 to 50.
- ii. The second ring binder file folder shall contain patients with File no. / Reg. no. from 51 to 100.
- iii. The white "EPILEPSY NEW PATIENT FORM", once fully filled and signed, is teared off the register and inserted into a new plastic folder, with the front upper part facing the reader (to allow the latter to immediately see the File no. / Reg. no. of the patient).
- iv. The yellow carbon-copy of the "EPILEPSY NEW PATIENT FORM" remains in the hard-copy register.
- v. If the patient had come to the clinic with a referral note, the latter shall be inserted into his/her plastic folder.
- vi. When the patient comes back for follow-up visits, an "EPILEPSY MONTHLY FOLLOW UP FORM" is duly filled and signed by the clinician. The white "EPILEPSY MONTHLY FOLLOW UP FORM" is teared off the register and inserted into the plastic folder dedicated to this patient.