NODDING
SYNDROME
ALLIANCE

End of Project Evaluation Report

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Contents

EXECUTIVE SUMMARY

The project “Nodding Syndrome Alliance” (NSA) is the title of a 3-year intervention led by Amref Health Africa (AMREF), in collaboration with the NGOs Doctors with Africa - CUAMM, OVCI - la Nostra Famiglia, Light for the World and Sudan Evangelical Mission (SEM). Operating under the name of the Nodding Syndrome Alliance, the consortium aimed to provide a pioneering and integrated response to address the needs of communities affected by epilepsy (especially Nodding Syndrome, NS) in Western Equatoria. The NSA project ran from 1st September 2019 to 31st August 2022.

Objective of the end-term evaluation

To assess the performance of the project against set objectives, indicators and targets, review programme strategy and methods, verify progress against recommendations provided by the mid-term evaluation carried out in 2021, and inform learning.

Methodology

The end term analysis used a mixed methodology, which involved qualitative and quantitative approaches. The survey took place throughout a period of 10 days of August 2022. The evaluation took place in the project locations, namely: Maridi, Mundri West, Mundri East and Juba counties and interviewed a broad range of stakeholders, together with key informants drawn from the government, implementing partners and beneficiaries.

MAJOR FINDINGS AND KEY RESULTS

Relevance

According to focus group discussions and key informant interviews, the project is pertinent to the various needs of the recipients, their local communities, and county authorities. Project beneficiaries, guardians, and volunteers all lamented the situation before the project started and attributed the (positive) shift to the initiative, adding that the project interventions are pertinent to their needs. For example, PWE-NS frequently experienced seizures prior to the start of the project, and the cost of the medication was unaffordable and/or unsustainable for the majority of them. This was duly addressed by the project.

Effectiveness

The investment made by this project in areas that meet the needs of the beneficiaries but are given low priority in government budgetary allocations, such as the provision of medications and financial support for the hiring of clinical officers for mental health care, is a standout feature of the initiative. Additionally, the project was able to effectively raise awareness of Nodding Syndrome and epilepsy, as well as to promote co-ownership of the project by the County Departments of Health. Fully utilizing the project's resources and the technical expertise held by consortium partners, the government, and other organizations was a strength that allowed the project to achieve its set goals.

Impact

Positive impacts were mostly seen in the areas of access health services leading to reduced seizures and availability of antiepileptic medicatication. There was increased awareness and visibility for the conditions. Beneficiaries also reported significant impact in their economic lives due to two livelihood components (savings and farming groups).

The project impact materialized across all levels – such as community level, the level of self-care, the level of primary health care, as well as in the areas of inclusive education, food security, livelihoods.

Sustainability

The evaluation looked at the project's sustainability strategies and how far they had been implemented, as well as the likelihood that the project's activities and results would be continued once the main funding comes to an end. From the start, NSA partners recognized that the Ministry of Health's full participation was critical to achieving long-term change, both technically and in terms of the work focusing on epilepsy at the county level. Despite the earlier indication during the midterm review that the Government would step up and plan for a takeover, this scenario has not materialized and no viable strategy of sustaining the initiative from the duty bearers emerged. As will be highlighted in this report the implementation partners have put up key strategies that will assist in the short tem, such as extended support on supply of medication and also engaging new funders.

Conclusion

Analysis of the qualitative and quantitative evaluation data demonstrates that the NSA project was on target and largely successful in achieving its objectives. The NSA project contributed to the overarching objective of meeting the specific needs of people with epilepsy and nodding syndrome, allowing these individuals and their communities to gradually become more resilient.

Chapter 1: Background

NSA (Nodding Syndrome Alliance) is the title of a 3-year intervention [AID 011898] whose aim is to provide a pioneering and integrated response to address the needs of communities affected by Nodding Syndrome (NS) and epilepsy in the former state of Western Equatoria. The project therefore aims to meet specific needs of people with epilepsy and Nodding Syndrome (PWE-NS), as well as of their communities, by adopting integrated, multisectoral interventions to enable these people and their communities to become more resilient. NS is a degenerative neurological condition and form of epilepsy. The former Western Equatoria State is the epidemiological epicentre of NS; cases have also been reported in the Democratic Republic of Congo and Uganda. The causes of NS are unknown; indeed, the global scientific community has been working to determine its aetiology for the last 15 years or so. The age of onset for NS ranges between 5 and 15 years old. The condition causes neurological and physical disabilities. The complications of the condition may result in early death. The experience of the Ugandan Ministry of Health and NSA partner OVCI in Juba has shown that the condition can be stabilized by administering standard antiepileptic drugs (AED). However, the public health system in South Sudan does not currently have adequate supplies of these drugs. If the condition is not treated, it leads to social exclusion and early death for a significant percentage of children. It is estimated that there at least 10,000 neglected cases of suspected epilepsy/NS in the former state of Western Equatoria. However, clinical treatment is just one of the four areas that this project addresses. Rural communities in South Sudan often associate epilepsy with inaccurate myths; this creates stigma and in turn means that PWE-NS become isolated from society. The project therefore promotes the key role that communities must play in transforming the negative paradigm of NS/epilepsy into pathways to inclusion. This should enable healthcare services to identify and take on cases more effectively. The project's community approach is built on pre-established networks: community-based rehabilitation (CBR) and South Sudan's national community health strategy (the Boma Health Initiative). By linking clinical treatment services with these community networks, the project tries to ensure patient adherence to antiepileptic drug therapy and gives children the opportunity to start or resume primary education, among other results. The project attempts at promoting future sustainability and inclusion by adopting measures to help improve food security for families of children with epilepsy/NS and enable them to be more self-sufficient. Other sustainable measures include generating epidemiological data in target areas and by providing support during technical meetings with national and global stakeholders within the national Task Force for Neglected Tropical Diseases. The NSA project is implemented by a consortium of different national and international organizations, which came together to provide a pioneering and integrated response to address the needs of communities affected by Nodding Syndrome (NS) and epilepsy in Western Equatoria and Central Equatoria States (South Sudan). The consortium comprises the following members: Amref Health Africa (lead agency), Light for The World, CUAMM, OVCI, Sudan Evangelical Mission.

The project received funding from the Italian Agency for Development Cooperation and from BAND Foundation (USA). Its duration spans from 1st September 2019 until 31st August 2022.

Overall Objective of the project
Support neglected communities in South Sudan's Equatoria region to achieve SDG 3 (SDG 3.3, 3.4).

Specific Objective of the project
To meet specific health and food security needs for people living with epilepsy and nodding syndrome (PLWE-NS) by adopting integrated, multi-sectoral measures so that these people and their communities can become more resilient.

Expected results of the project

1. The community will have a network to identify, treat and integrate people with nodding syndrome and epilepsy.
2. The health systems in the former states of Amadi and Maridi (in the present Western Equatoria State) will provide direct preventive and treatment services to people with nodding syndrome and epilepsy. This includes specific epilepsy treatment and treatment for health and nutritional complications.
3. Greater food security and improved self-sufficiency for families who have children with nodding syndrome and epilepsy.
4. National and state-level authorities will receive help with planning and implementing preventive and treatment solutions for people with nodding syndrome and epilepsy, as part of a wider network of social and health services.

Targeted Beneficiaries

- 300 children below 5 years old (50% Female; 50% Male)
- 15,000 children between 5 years and 18 years old (50% Female; 50% Male)
- 15,000 adults (50% Female; 50% Male)

Among the targeted children (<18 years), 900 children with epilepsy / Nodding Syndrome shall be assisted through dedicated clinical services and home-based follow ups.

Objectives of this Evaluation

The main objective of the evaluation was to "provide NSA with an assessment of the programmatic implementation of the NSA project based on the project's logical framework, the project's indicators, and some common practices in the evaluation of both community-based and facility-based epilepsy services." Moreover, the end-term evaluation was expected to look at progress made by the project against the recommendations provided by the mid-term evaluation in 2021.

Finally, the Terms of Reference (ToR) indicated that "the evaluation [would] review the overall goals of the project, its outputs and the activities for each output against questions related with the Relevance, Effectiveness, Efficiency, Impact and Lessons Learned." (see ToR in Annex 1).

Specific objectives

The main **objectives** of the end-term evaluation were:

i) To assess progress towards the achievement of selected project's results, outputs, and indicators.
ii) To identify and document factors and limitations affecting the above-mentioned progress.
iii) To assess beneficiaries and patients' satisfaction with the services offered by the project.
iv) To assess the progress of the consortium pertaining to the mid-term project evaluation recommendations.
v) More broadly, to evaluate the community-based services and facility-based services for people with epilepsy / Nodding Syndrome which the project established and supports.
vi) To document good practices, generate evidence-based lessons and provide recommendations for the continuation of the project services and an effective hand-over, if viable.

Evaluation methodology

Introduction

This section deals with the methodology employed in carrying out the end-term evaluation. More specifically, it describes in detail the various approaches used in conducting the midterm evaluation and the target scope for each approach used. The composition of the team which carried out the end term was:

a. Action Amos – Lead Consultant
b. Eddie Chengo – Epileptologist
c. Phillip Pitia – Data Analyst

Evaluation design

The end-term evaluation adopted a mixed descriptive quantitative and qualitative evaluation design, with additional triangulation of data sources to better corroborate and interpret findings. The approach allowed for complementarity of data sources, thus ensuring reliable and valid evaluation estimates.

Duration: The study duration was 10 days starting from 18th to 25th of August,2022.

a. Desk Research

Desk research as a secondary source of information entailed review of relevant documents with a view to inform on tool design. Key documents that were reviewed included the project start-up documents, including the project Logical Framework, narrative quarterly reports, and other readily available literature on Nodding Syndrome and epilepsy in South Sudan.

b. Quantitative Methods

The quantitative component included:

i. 3 epilepsy clinics' evaluation (Maridi, Mundri and Lui) through direct observation by an expert clinician and epileptologist. The evaluation recurred to a customized checklist, developed based on relevant items comprised in the World Health Organization Assessment Instrument for Mental Health Systems (WHO AIMS 2.2 – 2005). This evaluation was aimed at measuring achievement against Result Indicator no. 2A.11

ii. To measure progress against Specific Objective Indicator no. 2 as well as Result Indicator no. 2B, the data analyst extracted data from 2 types of registers at the 3 epilepsy clinics of Maridi, Mundri and Lui. The data extracted at each location pertained to a different, purposively sampled period of 6 months: February - July 2022.

iii. To measure progress against Result Indicator 1A, the data analyst obtained data on children followed up at home since project inception by directly interrogating project volunteers

(HHPs, BHWs, CBRWs) and verifying the reported data against the volunteers' data collection tools (whenever availed). Differently from the approach used in the Mid-Term Evaluation, all volunteers were targeted this time around. Depending on their area of operations, they were convened in Mundri (19th August 2022), in Lui (22nd August 2022) and in Maridi (24th August 2022).

c. Qualitative Methods

The qualitative component entailed use of predominantly semi-structured Key Informant Interviews (KIIs) and Focus Group Discussions (FGDs) to provide a more in-depth analysis of measurement areas which were difficult to assess through quantitative approaches alone. The KIIs mainly targeted key informants who were purposively selected based on their positions of influence regarding this project and related to Nodding Syndrome and Epilepsy.

The evaluation conducted is summarised in the following 4 steps:

Step 1: In July 2022, NSA Consortium made the essential project documentation available electronically to the evaluation team. Among them were the following key documents:

a) Grant Agreement and Annexes including the project plan and logical framework
b) Project Technical Team reports of the project
c) Partnership Governance Team reports
d) Field monthly coordination meetings minutes
e) Mid-term evaluation report and reccommendations (plus related action plan)

The evaluation team prepared an inception report for NSA project with an outline of the evaluation process as well as a list of key tools to be used.

Step 2: Identification of some of the key informants in Juba and all three project sites

Step 3: The evaluation team travelled to Juba first, then Mundri, Lui and Maridi to conduct face-to-face interviews with key informants and to visit clinical sites. The visits took place from 18th August to 25th August Based on recommendations from the Consortium Coordinator the team met with key national decision makers at the MoH (see Annex 4 for the list of people met).

Step 4: The last step consisted of preparing the report. This final draft included findings, recommendations and lessons learned for NSA project team to review. After NSA feedback on the draft, the report was finalized and submitted to AMREF for sharing with other partners and other interested parties

The evaluation was guided by the OECD evaluation criteria to determine **Effectiveness, Relevance, Efficiency, Impact, and Sustainability** of the project with reference to the four (4) result areas shown below (See table 1)

Table 1: Key Results for Evaluation

Key Results
1. The community will have a network to identify, treat and integrate people with nodding syndrome and epilepsy. 2. The health systems in the former states of Amadi and Maridi (in the present Western Equatoria State) will provide direct preventive and treatment services to people with nodding syndrome and epilepsy. This includes specific epilepsy treatment and treatment for health and nutritional complications. 3. Greater food security and improved self-sufficiency for families who have children with nodding syndrome and epilepsy. 4. National and state-level authorities will receive help with planning and implementing preventive and treatment solutions for people with nodding syndrome and epilepsy, as part of a wider network of social and health services. **Beneficiaries** • 300 children below 5 years old (50% Female; 50% Male) • 15,000 children between 5 years and 18 years old (50% Female; 50% Male) • 15,000 adults (50% Female; 50% Male) Among the targeted children (<18 years), 900 children with epilepsy / Nodding Syndrome shall be assisted through dedicated clinical services and home-based follow ups.

d. Data Analysis

Data collected through quantitative methods was analysed using Microsoft Excel software. On the other hand, data collected using qualitative methods were transcribed and then analysed using NVIVO 12 software, grouping all of collected information by themes to facilitate content analysis.

e. Ethical Considerations

The evaluation's purpose was presented to all target respondents prior to conducting interviews and focus groups. All responders provided verbal agreement, which was requested and secured. Furthermore, participants in the evaluation were free to refuse to answer any questions that made them uncomfortable, as well as to end the interview whenever they felt it was appropriate. Furthermore, when conducting the project end-term evaluation, the evaluators adhered to Amref Health Africa's safeguarding policy.

f. Risks and Limitations

Considering the security environment in South Sudan, the consultants needed to cleared by national and local authorties and were accompanied by Amref Health Africa staff (or its partners') throughout the evaluation exercise. However, during all KIIs and most FGDs, project staff did not participate or attend, to ensure the respondents could feel free to openly answer all questions posed.

Data Quality Assurance

To ensure the quality of the analysis, triangulation and validation of findings was based on information taken from all sources including the documents, interviews and site visits. No conclusions will be based on only one opinion.

Chapter 2: Findings

This section highlights the progress made towards the purpose, objectives of the project as well as assessment of progress towards the achievement of selected project’s results, outputs, and indicators.To ensure that there is a link to the midterm evaluation the evaluators highlighted actions against the recommendations that were made during that evaluation. (Table 2)

Table 2: Review of Midterm Recommendations

			Updates on progress	
	Mid-Term Project Evaluation – Recommendations	**Proposed solution / intervention**	**Status at the end of the project**	**Notes**
A.	**General - For the Consortium**			
A.1	Increase community awareness initiatives involving role families to educate the public about epilepsy's causes and misunderstandings	More frequent radio talk shows and jingles in Y3 (AHA). SEM to boost micro-awareness campaigns. All involving role families.	🟩	Completed
A.2	Create IEC materials in local tongues	AHA can take the lead and develop and print some IEC material, in consultation with partners. Partners will then help in dissemination.	🟥 -	This activity has been incorporated in a new proposal to be submitted to BAND Foundation, for future, adequate implementation
A.3	Because the project areas are large, volunteers will require transportation assistance to ensure that they can cover a greater area, and this will also serve as a motivator.	Provision of bycicles to AHA and SEM's volunteers.	🟩	Completed
A.4	Screen deserving families with a high number of epilepsy patients for home-based clinical services or transportation assistance to ensure consistency in clinical visits.	SEM to consider sponsoring transportation for some of these families.	🟩	Completed
A.5	Increase monitoring of CBRWs in Mundri East	SEM to appoint (and support) a supervisor of CBRWs in Mundri East	🟨	No explanation, and continued using the Government Supervisor
A.6	Closely monitor and boost VSLA/microcredit component in Year 3	SEM to conduct closer supervision and engage further with these groups + increase investments	🟨	Work in progress
A.7	Increase medical supervision of Epilepsy Clinic at Mundri PHCC	CUAMM proposes to use a MO from Mundri Team to checks out Mundri PHCC, once a month	🟩	Completed

A.8	Document Best Practices for replication in other counties (or countries) and encourage county-to-county exchange visits at all levels	SEM does so already, during CBRWs' refresher trainings. CUAMM could allow some of its project staff to visit other clinics. The consortium can document best practices in a specific document, in the next few months.	🟨	Partially completed
B	**County and State Level**			
B.1	In the second half of the project, the development of county epilepsy plans should be considered as an add-on	AHA could explore the feasibility of this activity. It may be included in future project proposal as an activity with dedicated funding.	🟥	Future proposal
C	**National Level**			
C.1	Under the existing mental health working group, the NSA consortium needs to influence formation of an epilepsy taskforce or working group.	AHA can avail the Consortium Coordinator to establish this TWG.	🟥	The MHPSS TWG (from which a sub-group on Epilepsy could be established) has been suspended - awaiting for decisions by MOH, IMC and UNICEF
C.2	The project needs to strengthen support for the formation of a group of persons with epilepsy to add to epilepsy advocacy in South Sudan, if resources allow.	The consortium could strengthen the collaboration with IFEA (local NGO) and advocate for the latter to include more People Living With Epilepsy	🟩	IFEA has been engaged in radio talk shows, strengtheing the collaboration with this local NGO.
D	**Epilepsy Clinics - For CUAMM and AHA**			
D.1	***Cross-cutting***			
D.1.1	Amend some items of the "Epilepsy new patient form/ intake" before re-printing	AHA and CUAMM could quickly revise the layout of this form, before printing the next stock	🟩	Completed
D.2	***Maridi***			
D.2.1	Need more sanitizer hand washing points for patients	CUAMM to provide	🟩	Completed
D.2.2	Waiting area needs improvement in safety	CUAMM to provide mattresses	🟩	Completed
D.2.3	Need chairs for patients	CUAMM to provide benches	🟩	Completed
D.2.4	Partitioning the room	CUAMM to provide screen	🟩	Completed
D.2.5	Need pen torch, patella hammer, and smaller tape measure for children.	CUAMM to provide	🟩	Completed

D.2.6	diagnosis and management of epilepsy wall chart and a bin card	AHA to provide reference material (e.g., manuals, guidelines, etc.). AHA and CUAMM could develop, print and distribute additional job aids.	🟩	Completed
D.2.7	Improve on documentation	CUAMM to invest time and technical assistance to improve this aspect	🟨	Work in progress
D.2.8	Need to have diazepam at the clinic	CUAMM to provide	🟩	Completed
D.2.9	Need to have an emergency kit	CUAMM to provide	🟩	Completed
D.3	***Mundri***			
D.3.1	Need more sanitizer hand washing points for patients	CUAMM to provide	🟩	Completed
D.3.2	Leaking roof needs to be fixed urgently.	AHA and CUAMM to mobilize resources to build a new, safer space	🟩	Completed
D.3.3	Need a pen torch, patella hammer,	CUAMM to provide	🟩	Completed
D.3.4	diagnosis and management of epilepsy wall chart and a bin card	AHA to provide reference material (e.g., manuals, guidelines, etc.). AHA and CUAMM could develop, print and distribute additional job aids.	🟩	Completed
D.3.5	Improve on documentation on change of treatment	CUAMM to invest time and techncial assistance to improve this aspect	🟨	work in progress
D.3.6	Need to have an emergency kit.	CUAMM to provide	🟩	Completed
D.3.7	Cotton wool was out of stock.	CUAMM to provide	🟩	Completed
D.4	***Lui***			
D.4.1	Need more sanitizer hand washing points for patients	CUAMM to provide	🟩	Completed
D.4.2	Shelves need to be fixed	CUAMM to ensure adequate space is available for filing	🟨	AHA obtained the permission from Health-Net TPO to allow CUAMM to use their cabinets, which are already in CUAMM's epilepsy clinic
D.4.3	Need chairs for patients + shelter for patients	CUAMM to provide	🟨	Work in progress
D.4.4	organize room to utilize examination coach and screen.	CUAMM to provide	🟨	Work in progress
D.4.5	Need a pen torch, patella hammer, screen	CUAMM to provide	🟩	Completed
D.4.6	diagnosis and management of epilepsy wall chart and a bin card	AHA to provide reference material (e.g., manuals, guidelines, etc.). AHA and CUAMM could develop, print and distribute additional job aids.	🟩	Completed
D.4.7	Improve on documentation	CUAMM to invest time and technical assistance to improve this aspect	🟨	Work in progress
D.4.8	Need to have diazepam at the clinic	CUAMM to provide	🟩 -	Completed
D.4.9	Need to have an emergency kit	CUAMM to provide	🟩 -	Completed

Based on the independent and holistic mid term assessment the evaluators provided a fresh, unbiased view of the project, identified potential for improvement and produced actionable, realistic, results-oriented and concrete recommendations. Most of these recommendations were found to be acted on by partners and the project team, bringing about major improvements in implementation.

2.1. Relevance

By implementing integrated, multi-sectoral interventions for PWE-NS, the NSA project sought to address the specific healthcare and food security needs of PWE-NS in order to help these individuals and their communities in the former Maridi and Amadi States become more resilient. The three levels on which the initiative was concentrated were community, primary (and secondary) health care, and policy and planning level. This was demonstrated by cross-sectoral initiatives such home-based care and follow-up, awareness raising, school reintegration, food security, and livelihood. For health care, the requirement for primary care was met by clinical care and referrals for specialized examinations. The availability of data and information exchange and coordination with the Ministry of Health proven to be essential input for interactions at the national policy level. Focus group participants and participants in key informant interviews confirmed that the initiative was relevant to the wide variety of needs of the beneficiaries, their local communities, and county authorities.

Discussions with the respondent revealed that the project's ability to enhance access to medication, increase knowledge about epilepsy and nodding syndrome, and mobilize individuals to seek treatment was its major benefit to society. This occurred in the project areas at the community level (among parents, teachers, and kids), as well as among a wide range of stakeholders. In fact, 85% of respondents said that this was one of the project's significant points of differentiation in addressing the major issue of ignorance around epilepsy and Nodding Syndrome in the project areas. This was largely ensured by the project's holistic strategy, which involved health authorities, community people, teachers, parents, and kids in the mobilization and house visits conducted at the county and national levels for the purpose of raising awareness. Table below summarises the evaluators assessment:

Table 3: Evaluators Summary Assessment on Relevance

Relevance				
	Satisfactory	**Unsatisfactory**	**Satisfactory**	**Highly satisfactory**
Alignment of delivered activities and outputs with the priorities of the targeted counties and country				X
Alignment of the given activities and outputs with the beneficiaries' priorities				X
Complementarities and areas of synergy with other work being conducted			X	

i) to what extent the services provided by the project are relevant to the needs of the targeted beneficiaries (patients, their families, their communities)?

Direct beneficiaries, their families and their communities

The evaluation found that the project interventions are relevant to the needs and challenges faced by the project beneficiaries, guardians, and project volunteers – as they directly reported. People with epilepsy and nodding syndrome said that the project had successfully managed to lower seizures among those who are affected in all three project sites. The programme also addressed and lessened stigma and discrimination against persons with epilepsy and nodding syndrome. The majority of respondents said their kids weren't in school previously but were now back. By putting in place a referral mechanism, the project also helped solve the problem of not attending to serious situations. Even families with modest resources were able to get both treatment and medicine because access to medication was free. Many people are now beginning to comprehend the causes of the two conditions, which were formerly attributed to witchcraft, war, and divine punishment. This has reduced the ignorance that existed around the two conditions.

"In my community I was regarded as a mad person but after starying to take medication my situation stabilised. I am now able to work at home and at our garden" (Mundri FGD)

"Before the project I dropped out of school due to epilepsy as I could not access medication. And I know some that died due to seizure or no medication" (Mundri FGD)

"Teachers were regarding us as dead people but now we are enjoying to be in class with others and also well dressed". (Mundri School Visit)

The initiative also filled a vacuum in psychosocial assistance by ensuring that home visits are conducted by project-trained teams. Since they are now supporting their families by taking care of themselves—which was previously the responsibility of their parents and relatives—by bathing, brushing their teeth, and using the restroom, they are essentially doing everything on their own with only sporadic assistance from their parents and relatives. As a result, they have regained their dignity and are once again accepted by their parents and relatives.

Since the medication was now accessible, public forums, including radios, accommodated NS/Epilepsy.

The programme was able to address both economic and food security issues since those who had the condition could work at home and contribute financially while they were seizure-free, allowing caretakers and guardians to focus on looking after their families. Beneficiaries and their families, who were typically left out of development projects that helped people with various conditions, had the opportunity to participate through a farming group or a community savings groups.

ii) To what extent is the project relevant to policies and strategies of the Ministry of Health of South Sudan?

County Health Authorities

As per result areas 2 and 4, the project intended to assist the county health systems in addressing the major obstacles to obtaining access to healthcare services , availability of medicines and supplying up to date data. In order to address this, the project prioritized investments in health infrastructure (such as opening clinics) and made sure that the necessary staff members and medicines were on hand. Data was made available at all levels, from county to national. According to the review, the NSA project matched the health priorities specified by the counties.

The project was aimed to support the local health system to address the main constraints that hampered achievement of access to health services by the targeted beneficiaries.

The local health authorities highlighted the relevance of the project in their areas, noting that the project invested in needy areas that had concerned the counties for years. They had reported the absence of available medication or any health-related support, despite the severity and the magnitude of the problem was well known.

According to the authorities the project also addressed the shortage of epilepsy-related data at county level. There was a direct investment in equipment and infrastructure, ranging from supply of furniture and IT sets to building a new clinic in Mundri.

It seemed that the project was initially not welcome due to the precedence of NGOs who come in and do projects and leave. KII (Maridi)

As a County we were relieved to have the project that was holistic as it covered all aspect of healthcare for the affected people. KII (Mundri)

National Authorities

The South Sudanese government's National Health Policy 2016–2026 aims to boost the country's healthcare system through health sector reforms and better coordinate health policies, institutional structures, capacities, and processes (National Health Policy, 2016). The South Sudan Development Plan (2011–2013), Vision 2040, and the Transitional Constitution of the Republic of South Sudan (2005) all serve as the foundation for the National Health Policy 2016–2026, which also considers global health initiatives like the Paris Declaration on Aid Effectiveness, the Millennium and Sustainable Development Goals, and the Agenda for Sustainable Development to further the primary healthcare ethos. Three crucial elements of the project were relevant under this setting. First, by providing Lui, Mundri, and Maridi with high-impact epilepsy healthcare services. Throughout the course of the initiative's implementation, the project also offered crucial assistance in maintaining nodding syndrome and epilepsy health services through a constant supply of anti-sizure drugs `during this time. Thirdly, it provided clinical officials and front-line volunteers with training on how to mobilize and handle cases of

"There is an established data capturing system that fed into our Health Information System. If I have any epilepsy up-to-date information it is from Western Equatoria, and I have been using this in many other forums" KII (Juba) nodding syndrome and epilepsy. The project also contributed to feeding the national Health Information System, with up-to-date epilespy health data from the three project sites. This was confirmed by the Ministry of Health officials.

2.2. Effectiveness

The project has, on the whole, been successful in producing the desired outputs and results. The project's key performance metrics across the continuum of care were achieved, which showed better access and utilization of services. Better care quality and an increase in the number of patients are the results of health workers' technical skill training and commitment. By establishing home-based support, the initiative strengthened the community's structures, which had a significant impact on people's adoption of healthy behaviors and practices. Last but not least, the initiative was successful in establishing clear collaboration responsibilities across NSA consortium partners, allowing them to carry out their various mandates considerably more successfully.

Table 4: Evaluators Assessment on Effectiveness

Effectiveness				
	Highly unsatisfactory	**Unsatisfactory**	**Satisfactory**	**Highly satisfactory**
Level of satisfaction of the project's main clients with the services they received				**X**
Changes created by the project regarding behaviour/ attitude				**X**
Effectiveness of the project activities in enabling capacities and influencing policymaking			**X**	
Participants' knowledge increased through media				**X**

i. The extent the project is achieving the intended outputs.

Table 5: Outputs Achievements

Output code	**Output description (over 3 years)**	**Assessed value (if available)**	**Overall assessment**
1.1.b	development of 1 strategic document	Developed	Minutes of Project Inception specified the contents of the initial strategic document which are covering: - consortium management mechanisms - and its governance, the strategies relating to accountability - potential synergies with ongoing research projects, - the tools for data collection - monitoring and evaluation mechanisms of the initiative,

			- the risks and countermeasures to be adopted and - the reporting rules established by the donor. The evaluators also were shared the post mid term action plan that guided implementation of recommendations.
1.2.a	30 HHPs/BHWs trained and engaged	47 trained volunteers were reported to be active. The lead consultant met with most of them.	Volunteer records show numbers achieved during the period under review, which shows that there is a functioning system in place. HHPs/BHWs are identifying cases of epilepsy/nodding syndrome and making referrals including home-based follow ups The project invested in their capacity through training and providing modes of transports (bicycles) for the project volunteers. Theyare engaged fully in the community, as reflected in their reports presented to the evaluators.
1.2.b	21 CBRWs trained and engaged	21 trained volunteers were reported to be active. The lead consultant met with most of them.	They were all retained and are still performing duties. The majority of them were introduced to the evaluators during the ETE, and the evaluators examined the submitted reports to determine how they had done.
1.2.c	2 CBRWs on a formative visit in Uganda	3 staff from SEM's CBR Program	A detailed report on this activity is available.
1.3.a	1 set of tools developed for volunteers to record and report data	In use	The evaluation team evaluated the available tools (Family Folder; Household Visit Form; Referral Form; BHT Reporting Form) developed and in use. and noted that they were being updated regularly. All volunteers were sufficiently familiar with the their tools, a reflection that were fully engaged.
1.4.a	900 children w/ epilepsy/NS assisted through home visits	1200 Children followed up at home	The evaluation team noted also that over 50 percent of those reached by volunteers were being followed up on a regular basis
1.4.b	33 Monthly coordination meetings with CHDs	38 meetings were done	The meeting minutes were evaluated by the evaluators, who noticed that these meetings occurred regularly.
1.6.a	18 awareness campaigns	115 small sessions in Year 3	The evaluators observed that the 18 large campaigns were divided into smaller ones as a strategy of reaching many people and engaging with small groups more effectively than with large gatherings.
1.6.b	93 Radio airplays	93 weeks of broadcasting (both jingles and talk shows)	The evaluators in discussion with beneficiaries noted that: - Communities had opportunities to interact with Government health officials and the project team on the radio; - Hearing someone sharing their everyday experiences and coming from your own community to share their story on the radio was validating.
2.1.a	4 epilepsy clinics established	3 clinics established in Mundri, Lui and Maridi	3 were confirmed and, also, there was a new built structure in Mundri supported by the project. The mobile clinic failed to materialize due to logistical arrangements within the project.

2.1.b	900 children with epilepsy / NS assisted through epilepsy clinics	1214 children had been enrolled at the epilepsy clinics up to August 31st, 2022	Records at the clinics were reviewed and confirmed this figure. There was also a high defaulting rate, which will be discussed in the conclusion section.
2.2.a	1 stock of AEDs available at each epilepsy clinic	Drugs were readily available in all clinics	The supply aspect of the project was successful, and the medications were of diverse types.
2.2.b	1 set of basic equipment available at each epilepsy clinic	Blood pressure machine, thermometer, weighing scale, tape measure height measure, are standardised and available across all sites – with minor exceptions	See assessment in Chapter 4 of this report
2.5.a	2 Clinical Officers underwent intensive training on epilepsy at Usratuna	Each clinic has a clinician who had recently attended a five-day training course on epilepsy and nodding syndrome at Usratuna	No other intensive training was offered since April 2021. However, continuous medical education sessions and supportive supervision by CUAMM doctors were provided throughout.
3.2.a & 3.4c reported under livelihoods			

ii. The extent the project is achieving the expected results and their indicators

SO Indicator no. 2: 85% of the target population, i.e., of people with clinically diagnosed nodding syndrome or other forms of epilepsy that have access to a set of standard drugs among the target population

Table 6 summarizes the data collected from the three health facilities of Maridi Hospital, Mundri PHCC and Lui Hospital on patients' access to AED upon registration at the epilepsy clinic, within the sampled period 1st February 2022 – 31st July 2022 (6 months).

Table 6: Data collected from three health facilities

Mundri

Month	Access M	Access F	Did not Access	Total Access	Total	%
feb-22	17	6	0	23	23	100.0%
mar-22	12	14	0	26	26	100.0%
apr-22	9	10	0	19	19	100.0%
May-22	9	5	0	14	14	100.0%
Jun-22	4	3	0	7	7	100.0%
Jul-22	6	4	0	10	10	100.0%
TOT	**57**	**42**	**0**	**99**	**99**	**100.0%**

Lui

Month	Access M	Access F	Did not Access	Total Access	Total	%
feb-22	0	3	0	3	3	100.0%
mar-22	6	4	0	10	10	100.0%
apr-22	5	6	0	11	11	100.0%
May-22	4	2	0	6	6	100.0%
Jun-22	2	1	0	3	3	100.0%
Jul-22	1	3	1	4	5	80.0%
TOT	**18**	**19**	**1**	**37**	**38**	**97.4%**

Maridi

Month	Access M	Access F	Did not Access	Total Access	Total	%
feb-22	7	6	0	13	13	100.0%
mar-22	9	6	0	15	15	100.0%
apr-22	6	12	0	18	18	100.0%
May-22	3	1	0	4	4	100.0%
Jun-22	7	6	0	13	13	100.0%
Jul-22	10	4	0	14	14	100.0%
TOT	**42**	**35**	**0**	**77**	**77**	**100.0%**

TOTAL

Month	Access M	Access F	Did not Access	Total Access	Total	%
feb-22	24	15	0	39	39	100.0%
mar-22	27	24	0	51	51	100.0%
apr-22	20	28	0	48	48	100.0%
May-22	16	8	0	24	24	100.0%
Jun-22	13	10	0	23	23	100.0%
Jul-22	17	11	1	28	29	96.6%
TOT	**117**	**96**	**1**	**213**	**214**	**99.5%**

According to the findings 99.5% (213/214) of the sampled new patients from the registers in the 3 clinics had access to AED upon registration within the months of Feb 2022 to July 2022. While 0.5% did not have access to AED due to diagnosis of other conditions different from epilepsy; other factors include unsatisfactory signs/symptoms presented by the patient to the clinician that prevent the patients from being initiated on treatment.

Result 1: The community has a network for the identification, treatment, and inclusion of people with nodding syndrome and epilepsy

Result Indicator 1A: 85% of children diagnosed with epilepsy/NS receive community follow-up services

Table 7 summarizes the data collected on children with epilepsy / NS receiving home-based follow-up care in the three locations of Maridi, Mundri and Lui through the BHWs/HHPs and CBRWs.

Table 7: % of children with epilepsy

Lui Hospital			
	# Children Registered by CBRWs/HHPs/BHWs	**# Followed up**	**% Followed up**
Male	71	35	49.3
Female	74	39	52.7
Total	**145**	**74**	**51.0**
Mundri PHCC			
	# Children Registered by CBRWs/HHPs/BHWs	**# Followed up**	**% Followed up**
Male	222	95	42.8
Female	176	68	38.6
Total	**398**	**163**	**41.0**
Maridi Hospital			
	# Children Registered by CBRWs/HHPs/BHWs	**# Followed up**	**% Followed up**
Male	354	168	47.5
Female	323	204	63.2
Total	**677**	**372**	**54.9**
Overall			
	# Children Registered by CBRWs/HHPs/BHWs	**# Followed up**	**% Followed up**
Male	647	298	46.1
Female	573	311	54.3
Total	**1,220**	**609**	**49.9**

A total of 1,220 child patient (18 yrs and below) were registered by CBRWs/HHPs/BHWs in the areas around the 3 epilepsy clinics within the project period. Among them, there are 609 patients that were regularly followedup by the CBRWs and the HHPs within the project period, that is 49.9%. The remaining 50.1 % could not easily be located, this can be due to the long distance of the villages from which the patients come from and the challenges in the movement of the volunteers. The area with the highest % of child patients not followed up is Mundri West County, with 59% of the child patients not followed up.

Result 2: The health system in the former states of Amadi and Maridi delivers preventive and curative services to people with nodding syndrome and epilepsy, both in the form of specific treatment for epilepsy and in the form of treatment of health and nutritional complications

Result Indicator 2A: 4 equipped health care personnel and facilities (equipped with diagnostic/curative skills and tools) delivering care to people living with nodding syndrome and epilepsy

There has been progress since the midterm evaluation. In each of the three project counties, there are three (3) epilepsy clinics with trained medical personnel and facilities that provide care for persons with nodding syndrome and epilepsy. The clinical practice standards are followed. Chapter 4 contains additional information on the status of the facilities and the clinical practice of the health care personnel employed there.

Result Indicator 2B: 85% of patients diagnosed with nodding syndrome/epilepsy who regularly access the medication treatment, in compliance with the minimum standards of visits per trimester (i.e., 1 visit every 3 months)

Table 8 summarizes the data collected on the % of patients diagnosed with nodding syndrome/epilepsy who regularly access the medication treatment, in compliance with the minimum standards of visits per quarter (i.e., 1 visit every 3 months) from the three Epilepsy Clinics of Maridi Hospital, Mundri PHCC and Lui Hospital. The period taken into consideration in the analysis is 6 months (February 2022 – July 2022).

Table 8: Numbers of patients accessing medical treatment

Mundri				
Month	**# Registered**	**# Defaulters**	**Regularly Attending = # Registered - # Defaulters**	**Regular Attendance %**
feb-22	1417	591	826	58.3%
mar-22	1443	591	852	59.0%
apr-22	1462	486	976	66.8%
May-22	1476	507	969	65.7%
Jun-22	1483	571	912	61.5%
Jul-22	1493	612	881	59.0%
			AVG	**61.7%**
Lui				
			Regularly Attending =	

Month	# Registered	# Defaulters	# Registered - # Defaulters	Regular Attendance %
feb-22	540	255	285	52.8%
mar-22	550	243	307	55.8%
apr-22	561	242	319	56.9%
May-22	566	246	320	56.5%
Jun-22	569	252	317	55.7%
Jul-22	573	277	296	51.7%
			AVG	**54.9%**

Maridi

Month	# Registered	# Defaulters	Regularly Attending = # Registered - # Defaulters	Regular Attendance %
feb-22	1302	308	994	76.3%
mar-22	1319	376	943	71.5%
apr-22	1334	412	922	69.1%
May-22	1339	428	911	68.0%
Jun-22	1353	428	925	68.4%
Jul-22	1370	484	886	64.7%
			AVG	**69.7%**

Total

Month	# Registered	# Defaulters	Regularly Attending = # Registered - # Defaulters	Regular Attendance %
feb-22	3259	1154	2105	64.6%
mar-22	3312	1210	2102	63.5%
apr-22	3357	1140	2217	66.0%
May-22	3381	1181	2200	65.1%
Jun-22	3405	1251	2154	63.3%
Jul-22	3436	1373	2063	60.0%
			AVG	**63.7%**

According to the results tabled above, a total of 3,436 patients had been enrolled at the three epilepsy clinics by the end of July 2022. The biggest proportion of patients who, on average, access medication regularly (i.e., at least once every quarter) was recorded in Maridi (69.7%), while the lowest proportion was recorded in Lui (54.9%). The latter may be due to the location of Lui as a rural area with the settlement pattern being far away from the hospital, and also priorities are given to farming other than treating epilepsy seizure, which are regarded as minor according to some of the CHVs interviewed. Overall, the percentage of patients diagnosed with nodding syndrome/epilepsy who regularly access the medication treatment, in compliance with the minimum standards of visits per quarter (i.e., 1 visit every3 months) stood at 63.7% over the six months period taken into account.

Result 3: Strengthen food security and the livelihood system of families with children suffering from nodding syndrome and epilepsy

Through the provision of agricultural training and kits, as well as the creation and/or the support of Village Loans & Savings Associations (VSLAs) in some project locations, the NSA project successfully addressed food security and economic empowerment of selected beneficiaries in the short term. Table 9 below illustrates progress towards the set outputs under Result area 3.

Table 9: Livelihood Effectiveness Assessment

Output code	Output description (over 3 years)	Assessed value (if available)	Overall assessment
3.2.a	1 FFS activated in Mundri (SEM)	1 FFS with a field for demonstration	Evaluators visited the site of farming demonstration and met persons with epilepsy and their produce for 2022
3.2.b	2 FFSs activated in Maridi (AHA)	1 demonstration plot in place	Its existence was confirmed during the MTE. During the MTE at least one of the two fields was visited, in Ngirinda. During the ETE the evaluators failed to meet the group due to change in flight time out of Maridi
3.3.a	400 families of PWE/NS receive HH agricultural kits	458 families	This was confirmed through the project records and during the Focus group discussions in Mundri and Maridi
3.3.b	3 groups of farmers receive seeds	2 Groups established in Maridi with a total of 100 people 1 Group of 30 created in Mundri	This was confirmed through the project records and during the Focus group discussions in Mundri and Maridi. In Maridi the beneficiaries were eventually 108.

3.4.a	100 families supported to establish or join saving groups	173 by the end of Year 2, an additional 125 families by the end of Year 3	This reflects 198% increase from the projection and many families indicated that they had started small businesses, as reflected in 2 Focus group discussions in Mundri and Maridi
3.4.c	150 Micro-credit loans disbursed and micro economic activities supported	153 loans across Maridi and Mundri, provided through 8 VSLA groups	The disbursement of loans was extensively reported in 2 Focus group discussions in Mundri and Maridi

The project's achievement as shown above were deemed "very good" for the output indicators corresponding to Result 3, suggesting that the project's performance was smooth. The non-existence of this work in Lui may be explained by the fact that the project partners's operations in Mundri East county were comparatively smaller than in Maridi and Mundri West Counties, thus limited structures were in place to build food security and livelihood activities upon.

The chart below highlight the year two and three livelihoods effort and inputs.

Livelihood Highlights for Year 2 & 3

MUNDRI

Tools provided - pangas, axes, rakes, hand hoes, measuring rope, and slashers.

Seeds distributed - 7 farmer's groups with 130 (88 females, 42 male). Seed type - groundnut (serenut variety), beans (yellow beans variety), cowpeas, amaranthus (E.A seed variety), and tomato (E.A seed variety).

Training - trained 80 (17 male and 63 female) farmers on agronomic practices.

VSLA kits and seed funding - Aroboya Mirimagya VSLA group 28 (2 male, 26 female) members; Olemaro VSLA group 20 (7 male, 13 female) members; and Wiri Adi Kyigo Aba VSLA group 30 (9 male, 21 female) members.

VSLA Regulations - Aroboya Mirimagya, Olemaro, Wiri Adi Kyigo Aba, and Wiri Omba Ku VSLA groups have written group regulations that guides borrowing and repayment.

MARIDI

Training - on agricultural practices offered in Year 2 (ended in August 2021). 100 families benefited from training and agricultural tools in Year 2.

Seeds distributed - received a new consignment of seeds in Year 3 (September 2021), amounting to a total of 425 kg of seeds. These included: groundnut, cabbage, eggplant, green capsicum, sesame, beans, sorghum and mais.

VSLA Membership - Eman VSLA group had 25 (6 male, 19 female) and the Wiri Omba Ku VSLA group had 22 (6 male, 16 female) members.

Beneficiaries Quote

" We are now able to fend for ourselves since we started taking loans from the project. I can pay for my child school fees after doing business of selling mandasi…" Focus Group Discussion's participant (Mundri).

Result 4: National and state authorities are supported in planning and implementation of preventive and curative responses aimed at people with nodding syndrome and epilepsy within the wider network of social and health services

During the project duration the NSA did support the national and local governments in planning and implementing responses for people with epilepsy and nodding syndrome to a large extent. The following sections discuss the various outcome indicators.

Result Indicator 4B: Increased availability of epidemiological information on epilepsy/NS in endemic areas

South Sudan struggles to allocate resources to match the burden of sickness because of, among other factors, weak health information systems. Primary level health information is frequently paper-based and of poor quality. Electronic central reporting to the MOH is common, but MOHs frequently lack the staff needed to collect, analyze, and act on this data. Assessments of illness burden are frequently incorrect and unreliable since there are ineffective data systems available.

Over the project period the project directly assisted the National and County authorities in raising the capacity of the medical staff at three project health facilities. The project closely collaborated with County Health Offices to solve health system issues that hindered the provision of quality data on epilepsy/NS care. Key informants confirmed that County Government and NSA project investments had increased the ability of health facilities to provide high-quality service. When it comes to anti-seizure drugs' availability, for instance, they were no stock outs throughout the implementation period. By keeping accurate records and periodically making data on supply levels and AED usage available, stock outs were prevented. In the third year, epilepsy clinics employed Microsoft Excel tools they had created and were utilizing to digitize the data collecting. The County Health Authorities eventually started obtaining more detailed and comprehensive data as a result of these instruments' facilitation of data sharing and analysis.

At the county level, the evaluation team found that there is a increased engagement on epilepsy and nodding syndrome to the extend that the Ministry of Health is prepared to have policy discussions of intergrating epilepsy into primary health care and establish an Epilepsy Unit. The key informants at the Mundri and Maridi County Health Departments knew how many people lived in each jurisdiction and what the project's target populations were. Through coordination meetings and quarterly reports, county officials have access to the information. There was also a highlight of how information was shared from technical implementing team to the county authority and the to the regional minister in charge of health and then to the national level.

Summarized Achievement Analysis, per result

Results	Key	Enabling Factor
Result R.1 - The community has a network for the identification, treatment, and inclusion of people with Nodding Syndrome and epilepsy.	🟩	There was **high participation** in all the three (3) counties of Maridi, Mundri East and Mundri West.
Result R.2 – The health system in the states of Amadi and Maridi provides preventive and curative services aimed at people suffering from Nodding Syndrome and epilepsy, both in the form of specific treatments for epilepsy and nodding syndrome in the form of treatment of health and nutritional complications.	🟩	Highly satisfactory, especially in terms of the **availability of the necessary medications** and the ability of the volunteers' and clinical support teams.
Result R.3 – Strengthen the food security and livelihood system of families with children with Nodding Syndrome and epilepsy.	🟩	**Food security** improved, however it is threatened by South Sudan's general economic stresses, insecurity and weather-related shocks.
Result R.4 – National and state authorities are supported in the planning and implementation of preventive and curative responses for people with Nodding Syndrome and epilepsy within the broader network of social and health services.	🟨	**Direct engagement with relevant duty bearers**: There is potential for further engagement despite the contributions already made by the project.

iv. What are the disabling factors hindering progress?

The following obstacles and gaps were recognized by the evaluators as potential threats to the project's ability to meet its aims, albeit they had little effect.

- ✓ A **rise in default rates** among patients traveling from remote areas as a result of the expensive transportation needed to get to epilepsy clinics.

- ✓ **Non adherence**: The desire of some patients to discontinue treatment on their own without a doctor's approval when their seizure frequency decreases.

- ✓ **Non uniformity of data tools:** Different members of the consortium have used their own data collection tools, and it proved difficult to “integrate” them. To date, cross-analysis of data is still difficult (e.g., cross-analyzing data on epilepsy clinic registers and data on community volunteers’ registers).

- ✓ **Target Areas:** Selection of areas to be targeted through Boma Health Workers: the project was too ambitious, over-stretching its reach to very remote areas where patients are very unlikely to be able to move and access treatment at the established epilepsy clinics.

- ✓ **Duplication:** Some instances of overlapping of partners’ structures. For instance: BHWs in Mundri West and East managed by CUAMM but supported by Amref; some areas being served by both CBRWs (SEM) and HHPs/BHWs (Amref).

- ✓ **Insecurity, lack of infrastructure, high costs of operations** have made it quite difficult to monitor and supervise activities as much as the coordination team wished.

- ✓ To a certain extent, **the lack of neurological / epileptological expertise** within the project team slowed the development and adoption of tools, guidelines and alike which are geared towards provide better quality / effective care to PWE. This expertise was availed by specialists who were not consistently engaged by the project throughout its duration.

- ✓ **The Covid19 pandemic** outbreak impacted the first set-up phase: some activities and processes were harder to re-direct and rectify at later stage.

Notable Quotes on Effectiveness

The evaluators asked individual key informants about the reasons why they thought the project was able to deliver and here is what they said.

"Because of its output, outcome and impact it made toward people living with epilepsy and nodding syndrome, 90% of people living with epilepsy and nodding syndrome have greatly improved, some went back to schools, businesses, domestic work, walking, working, eating and bathing alone as a result of this project activities". KII (Mundri)

"By and large, in several instances, beneficiaries and project teams have reported a high level of satisfaction". KII (Maridi)

"Drugs were always available, procured on time. Data collection and record keeping was good. Tools of work were available." KII (Mundri)

"Because AMREF is doing follow ups, training providers to volunteers, clinicians, good record keeping this is a testimony that all has been done orderly." KII(Mundri)

" Because part of the project is bringing external expertise such to train local clinicians and two neurologists, and two EEG technical experts to train local nurse ond officers." KII (Maridi)

"Collaboration was good. The referral system was great and AMREF did support the research and information was readily available." KII (Maridi)

2.3. Efficiency

The information in this section describes the conclusions regarding the efficiency of the methods utilized to carry out project activities. The efficiency of project management, the effective use of project resources, and the evaluation of coordination and cooperation with other stakeholders were the main areas of analysis.

Table 10:Evaluators assessment on Efficiency

Efficiency				
	Highly unsatisfactory	**Unsatisfactory**	**Satisfactory**	**Highly satisfactory**
Collaboration and coordination mechanisms between the implementing partners and county teams within NSA project that ensure efficiencies and coherence of response				**X**
Provision of services and support in a timely and reliable manner, according to the priorities established by NSA				**X**
Presence of protocols and practices to ascertain that good practices (including clinical) and lessons learned are recognized and integrated into work practices			**X**	

i. To which extents are outputs and results are being achieved at a reasonable cost, compared to equally effective alternative approaches?

Two preliminary remarks have to be made before moving to the efficiency evaluation:

- Being no audit, this evaluation accepted as such the results reported in the consecutive annual reports.
- The ToR of this evaluation did not include any comprehensive review of the financial component of the project. As a result, the report contains no section on the cost effectiveness of activities.

ii. How well has the project achieved outputs and results within the intended timeframe? How well in line is the project implementation with the overall work plan?

In second half of the project an additional implementation matrix was developed for the project, and most of the implementing partners staff were aware of its existence. Most of the major external risks were predicted but did not occur. The major factors that ended up impacting on the project's progress were internal and concerned the effect of clinic staff turnover in Maridi on the management of activities. However, as indicated by key informants this did not impact negatively on the project but it was a lost investment as the first team that departed were trained the previous year.

iii. How and how well did the coordination of project partners and stakeholders work?

Collaboration and coordination mechanisms between the implementing partners and technical teams on the ground ensured efficiency and coherence of response. Provision of services and support were provided in a timely and reliable manner, according to the priorities of the project. Clear evidence of the integration of clinical protocols and epilepsy protocols into work practices was found during the evaluation.

A range of management and decision-making structures were established at two levels, senior (Project Governance Team - PGT) and local (Project Technical Team) levels, to support successful implementation of the project. The PGT level served as an advisory body with oversight of the grant implementation. At local level, there were other structures, including: a Project Management Team and Implementation Committee at County level that brought together different county government officials and external stakeholders as well as AMREF, CUAMM and SEM. The PTT should have met monthly; while it did so initially, very few meetings were held in the final semester of the project, despite the fact that the PGT convened quarterly as shown by the minutes that were shared. There were also a series of meeting by the NSA Consortium Coordinator online following up on implementation of the 3 sites. Each implementing partner had a contact person in each of the sites.

2.4. Impact

This sections below seek to as highlight the impact made against each of the project's key result area. It also highlights the 5 impacted groups in the project as indicated in the table below.

Table 11:Evaluators Impact Assessment

Category	**Impact**			
	Minor	***Moderate***	***Signficant***	***High***
Persons with NS/Epilepsy				**X**
Local community at large			**X**	
Government Ministry of Health		**X**		
County Health Departments			**X**	
Partners			**X**	

Result R.1 - The community has a network for the identification, treatment and inclusion of people with nodding syndrome and epilepsy.

Result 1 is about community structures being able to identify, refer and monitor cases, as well as fighting stigma and providing social support (e.g., school reintegration)

Increased School Enrollment

Over the course of the three years since the project began, most parents and teachers said that the kids' academic lives had much improved. As sezures were lessened, children began to enroll back in school. The ability of parents and teachers to manage epilepsy children has improved both at at home and at school. Teachers at some schools, particularly Mundri, reported that the childrens' academic performance had even improved. Students' physical appearance improved as a result of receiving uniforms.

"Concerning the pupils who were assisted to enroll back to school, I don't have data disaggregated by target area (county), but only comprehensive lists for Year 2 (tot: 63) and Year 3 (tot: 37)". KII (Mundri).

Involvement In Domestic Work

People with epilepsy started participating in family activities and helping out with household chores like cooking, cleaning, and gardening. Because some of them had previously been kept in homes or required guardianship, this was a significant change.

"For years I was kept under surviallence but now as you can see I have come to the clinic alone to collect medication and I also assist at home". FGD (Maridi)

Enhanced Awareness And Visibility

The effort has largely been successful in raising public awareness of people with nodding syndrome and epilepsy. According to an analysis of project narrative reports, this result saw a significant percentage of targets met and 100% of the planned activities were carried out. There has been an increase in knowledge about epilepsy, its causes, and treatments, as the respondents confirmed. The stigma associated with it has diminished among families of those who have the condition, even though it still exists in the general public. Radio shows had a significant role in spreading awareness of the condition.

Furthermore, a strong county-level engagement with Health Authorities contributed to awareness, buy-in and action and, potentially, onward sustainability.

"Increase the knowedge of epilepsy and Nodding Syndrome, elders of the community were involved and it increased. Also we have included epilepsy and nodding syndrome within Community Based Inclusive Development". KII (Juba)

"*We also heard about epilepsy on the radio when SEM was presenting about epilepsy on the radio*." FGD (Maridi)

However, despite these successes, some respondents stated that there are far more people in Western Equatorial that are yet to be reached and that false, harmful myths are still prevalent among general public.

Result R.2 – The health system in the states of Amadi and Maridi provides preventive and curative services aimed at people suffering from nodding syndrome and epilepsy, both in the form of specific treatments for epilepsy and in the form of treatment of health and nutritional complications.

Increased access to medication

Among people with epilepsy and nodding syndrome, there was widespread access to medicine, which decreased their seizure frequency. In all three project counties, this was emphasized by the majority of beneficiaries. When they all started taking medicine, all informants confirmed that their seizures had decreased. The other impact was noted in the establishment of a referral system for severe cases. This helped patients to access specialised services at no cost that would have been a dream to many.

"….My child has now been sizure free for 2 years and this has assisted all of us as a family. Our family never thought that we would never see this change." FGD (Mundri)

"I had two children who had epilepsy and the other one died in 2021 and I am left with one. However both had a reduction of seizures. Though the other died it could be other causes but I happy with the project that it has assited us……." FGD (Lui).

"My life has changed since I started taking medication. If this initiative ends I am going to die" FGD (Lui)

"As a clinician, I can report that 35% of my patients have been seizure-free for six months to two years or longer" . KII (Mundri)

By prioritizing work with health clinicians and specialists, the NSA project has been able to change the health personnels' knowledge, awareness and practices within the clinics to ensure good service delivery. The project was also successful in collecting specific, measurable data against many of the set indicators, along with anecdotal evidence collected during its implementation, which was shared with national officials.

Result R.3 – Strengthen the food security and livelihood system of families with children with nodding syndrome and epilepsy.

The NSA project aimed to improve the socioeconomic status of poor households by increasing agricultural production and improving nutritional practices. The project delivered interventions primarily through farmer groups. The data shows evidence of higher participation in the farmer groups in communities. Dropouts from farmer groups were also not significant. This evaluation suggests that the project brought about improvements in productivity and income for farmers across a number of key indicators. There was training that was provided for framers in year two and three to equip them with modern methods of farming, which proved as a good investment.

The VSLA groups had an impact on economic activities that VSLAs are meant to enable, i.e. beyond the increase in total savings, we find significant increases in the use of credit, including credit used for investment purposes. Likewise, respondents reported that they use their savings upon share-out for investments, primarily in small local small business. We also found there they could be a significant increase in the total income from enterprises, though no group was free to disclose amounts generated.

Despite increases in income through enhanced farming and participation in VSLAs, conventional wisdom suggests that food security and nutrition cannot be improved until the worst effects of poverty are eliminated and that income growth is a necessary prior condition for nutrition to improve. The results of this evaluation hint that this conjecture can be challenged.

Result R.4 – National and state authorities are supported in the planning and implementation of preventive and curative responses for people with nodding syndrome and epilepsy within the broader network of social and health services.

The evaluation team observed a significant amount of interest in the county and national policy discussions on epilepsy and nodding syndrome. According to key informants at the county and national levels, the project has created an atmosphere that is conducive to ongoing and sustained engagement.

The NSA project did a remarkable work of strengthening in-country capacities in the governmental sector along three outputs, 1) strengthening all elements of the epilepsy and nodding syndrome medication supply chain, 2) optimizing epilepsy and nodding syndrome case management , and 3) building up the clinical and pharmaceutical data collection and reporting system. The project sought to achieve all this by assisting in updating guidelines and standard operating procedures, by training professionals of various categories (clinicians, community health workers, …), by standardising patient records, dispensation records, and lots of other data collection tools, etc.

2.5 Sustainability

There is some evidence that the comprehensive strategy used by the NSA project was potentially conduicive for longer-term sustainability because of the high levels of buy-in and engagement by stakeholders which it encouraged from the very beginning, particularly in terms of its capacity to mobilize a diversified team of implementing partners, civil society, and other important county and national health stakeholders in the project. The evaluation examined the project's sustainability strategies as they emerged from project implementation and the prospects that the project's efforts had beyond its life cycle. Table 12 below shows the sustainability analysis based on key sustainability elements.

Table 12: Sustainability Elements Analysis

Elements				
Institutional	**Social**	**Technical**	**Financial**	**Policy**
NSA Consortium is sustainable as an alliance, but project sustainability depends on its ability to reach an agreement with the MOH to support / own / takeover project activities	Good quality, and acceptability is high on clinical services.	There is need of: 1) enhancing the clinical officers' capabilities 2) MOH supervision and monitoring key in ensuring continuity.	Conditions: 1) That MOH accepts implementation of cost recovery and other financial strategies. 2) To define how personnel costs currently paid by the project will be assumed	Condition: Continued county support

Despite significant sustainability weaknesses brought on by a lack of funding or a government takeover strategy, the initiative achieved the following short-term successes:

Sustainability of the strengthened leadership and governance

As it was reported in the Mid Term Evaluation the NSA project partners had recognised that the Ministry of Health’s full involvement was fundamental to the achievement of sustainable change, both technically and in the arrangement of the work focusing on epilepsy and nodding syndrome at county level. During the mid term evaluation, there were indications that the

Ministry of Health would ultimately be responsible for continuing the activities after the project phases out despite the limited support in budgets from National level that exists. At that time the strategies that the project had applied was to put the MOH on “the steering wheel” involving them in the planning, implementation and monitoring of project activities.

*<u>Observation</u>***:** There is a huge gap between the assupmtion above and the reality. The Ministry of Health is not prepared in principle or in practice to maintain the project's gains due to limited resources. There is no clear roadmap of how the project activities will be sustained by the Ministru of Health. The major gain over the last year was the capacity-related investment made to ensure that clinical officers are trained and able to provide quality care with minimal support and supervision.

> *As Government we need to ensure we integrate projects like these into Primary Health Care at inception. They should not run as standalone units because when the project ends like now we go back to zero. All the efforts will be gone.* KII (JUBA)

Nevertheless, the project implementing partners have demonstrated the will to sustain some of the work by taking the following measures:

- ✓ Submission of proposals for continuity of project activities;
- ✓ Mobilising resources for extension of services to December, 2022;
- ✓ Incorporating both epilepsy / nodding syndrome clinical work and community work into other programs (CUAMM, SEM and OVCI).

However these are just but short term measures, thus the Ministry of Health once more indicated that it would work on integrating the project activities into its existing package of health services.

The community and beneficiaries now have partners on the ground in the three counties whon they can turn to to advocate for support in form of the implementing partners who are still present in their localities. Additionally, for the community still has government whom they can approach to take over the project through advocacy though currently thereis no structure to unify their voice in the three counties. A good baseline has been established by the project showing evidence of change and any other future initiative can build on this.

Sustainability of the improved capacity at health facilities and at community level

As it was reported in the mid term evaluation technical and soft skills among health care professionals were and have continued to be enhanced at the health facilities to provide quality epilepsy / nodding syndrome services. The potential of this transformation being long-lasting appears optimistic for a variety of reasons, including the fact that healthcare professionals are mostly included into the human resources structure of their respective government facilities. Furthermore, volunteers pledged to continue to use their training and provide follow ups to persons with epilepsy / nodding syndrome within their proximity; this is also an indication that they will continue providing community-based support in terms of follow-ups, referrals and awareness raising.

Observation: The MOH will need to adopt the project's enhanced technical skills, by supporting and maintaining the trained staff beyond December 2022, otherwise it will be a lost investment.

Self-Sustenance

The NSA project fostered some sustainability by supporting food security and livelihood activities through farmers groups and VSLA groups, with the goal of improving families' economic situation and allowing them to be more self-sufficient and resilient. The VSLA groups have already begun to show signs of contributing to this sustenance, as evidenced by the small enterprises that these associations' members have established. Additionally, the 3 farming groups started selling their produce and indicated that they will keep some seed for the next planting season which shows the prospect of sustainability beyond the project.

Chapter 3: Conclusions, lessons learned and recommendations

3.1 Conclusions

1) NSA project design and implementation was found to be very relevant to the needs of Counties and the target population in general. The project addressed the needs of persons with epilepsy and nodding syndrome such as access to medication and services, economic empowerment and access to education for the affected persons.

2) The implementation of NSA accomplished all of the main objectives in that all the intended outcomes were achieved, outputs were produced and indicators' targets were reached to a good extent. Performance was slightly lower under Result area 4. Significant delays occurred in setting up some VSLA groups because of late mobilisation of communities but this did not jeopardise implementation.

3) The project was efficiently implemented through well-coordinated partnerships in the consortium, as well as with County governments and the National government. The partnerships created synergy through complementary capacities within the consortium and with the engaged communities. This evaluation also found compelling evidence that the NSA partnership, in collaboration with the government and communities, has worked well in the 3 project counties to deliver sustained health interventions over the three-year project period. There was buy-in and leadership at county and community levels, which ensured institutional support for project implementation.

4) The project has yielded considerable impact, such as improvements in the beneficiaries' access to medication, which had a push effect of fewer seizures among them. The majority of parents and educators said that the children's academic lives had significantly improved over the course of the project's three-year lifespan. The endeavor to increase public awareness of people with nodding syndrome and epilepsy has largely been acknowledged. People with epilepsy began taking part in family events and helping out with household responsibilities. There was enhanced capacity of the human resources both of the implementers and duty bearers, especially with regard to clinical personnel.

5) The government's support shows a clear intention to have further interactions around epilepsy and nodding syndrome, despite substantial weakness on establishing an adoption strategy. The Ministry of Health's complete participation, both technically and in the planning of the program focusing on epilepsy and nodding syndrome at the county level, was essential to the reported successes. The project's implementing partners also showed a desire to continue it by enlisting other partners and mobilizing additional resources.

3.2 Lessons Learnt

The section below aims to provide more detail on some of the key lessons learned during the course of the project:

1. **Awareness of Epilepsy and Nodding Syndrome**: a holistic approach is needed in creating awareness from the community to national level. Awareness should be supported by information material to ensure that those that are carrying the the awareness convey the right message.

2. **Engagement of Key Stakeholder**s: it is essential to work with teachers and parents to ensure adults are better equipped to assist children both at home and at school to reduce stigma.

3. **Multi-Stakeholder engagement**: as demonstrated by this project in particular, the establishment of multi-stakeholder advisory groups (County-level coordination meetings, PGT meetings), comprised of local implementers and duty bearers, provided guidance and expertise during the project implementation. The choice of participants proved strategic in ensuring key support during specific activities (e.g. monitoring and reporting).

4. **Partnerships**: some of the main lessons learned about successful partnerships during this project include:

   - The need for greater collaboration, particularly with other organisations focusing on similar areas of work.
   - Increased emphasis on lobbying and the establishment of strong links between local, county and national-level lobby work.
   - The importance of working with partners who have a mandate to work on health and a strong level of expertise, knowledge and understanding of the issues and context.
   - The value of strong, multi-sectoral project management and oversight.
   - The appointment of a dedicated staff member with a strong grounding in Global Health focus to support the project and ensure the Health Rights perspective is maintained throughout.

5. **Empowerment**: the project did not promote a charity approach, by allowing beneficiaries to start farming clubs and village savings groups. This allowed the benefiaciaries to be responsible by generating income for their families. This holistic approach helps to ensure that the project is not only seen through the medical model lense, but through the social model lense, too. Working with communities

as drivers of change rather than recipients of change enhances sustainability and yields better results, as they will embrace the advocacy efforts. Well trained Community Health Volunteers can bridge the gaps in community health and development programmes.

6. **Stakeholder analysis:** on issues such as health, education, rights and policy, internal and external stakeholder analysis should be done to ensure that the project is taking maximum advantage of connections with others already working on these issues for learning and impact. There was a good diversified range of organisations working on these issues in all three counties including Light for the World, CUAMM, AMREF and SEM. It was also be interesting to note interest by Universities. Involvement of relevant government departments in the project development, planning and implementation provides better chances to reaching positive effects. Engagement of high level duty bearers' leadership in programmes facilitates policy dialogue.

7. **Capacity Building**: having health professionals trained so as to better organize and deliver quality care is critical.

8. Future projects should have their **exit strategy** fully spelled out in their operational plan, just like other activities. NSA Consortium did have a written exit strategy, published in its project document, but it proved hard to realize.

3.3 Recommendations

a) Deepen the focus on issues already identified during the implementation of this project rather than widening the scope.
b) Ensure consultations with rights-holders (including children) to inform the focus of project objectives and activities.
c) Strengthen working relations with the Rights Organisations and ensure Human Rights elements are better embedded into the delivery of the project.
d) Undertake a strong stakeholder analysis, establish partnership agreements with national level advocacy partners and ensure active links between national and local advocacy work.
e) Empower beneficiaries to engage meaningfully in advocacy work at all levels and use effective participation methodologies to support this.
f) Encourage greater dialogue between beneficiaries and duty bearers to ensure sustainable advocacy beyond the existence of the project.
g) Promote internal links with other programme/project work and campaigns (e.g. food, governance and health/social rights) and ensure coherence of intervention already in the counties.
h) Ensure user-friendly training and materials on the intervention (i.e. farming and savings groups) are made available for the leaders of the groups.
i) Ensure user-friendly versions of the IEC material are posted in each health centre and community volunteers have them handy when in the communities, and make them available in good numbers.
j) Ensure beneficiaries participation in project management and decision-making and this can be done gradually supported by capacity building of the beneficiaries
k) Explore opportunities to work in partnership with other organisations working on health issues beyond the traditional partners in the just ended project.
l) Continue to explore opportunities for infrastructure improvement at health facilities.
m) Establish a unit cost for the project and use this to compare value offered by different approaches/different counties/overall.
n) Maintain the simple yet effective M&E system for the project that will allow teams to collect key data and assess progress towards outcomes on an annual basis.

Chapter 4: Clinical Observations

4.1 Objective

The Objective of this clinical end term evaluation was:

- To assess progress towards the achievement of selected clinical work results, outputs, and indicators.
- To identify and document factors and limitations affecting the above-mentioned progress.
- To assess beneficiaries and patients' satisfaction with the services offered by the project.
- To document good practices, generate evidence-based lessons and provide recommendations for the continuation of the project services and an effective hand-over, if viable.

4.2 Methods

a) Direct observation of the clinics' operations, service provision and infrastructure by an expert (the epileptologist). Observations followed a checklist tailor-made for this exercise, partially based on WHO AIMS 2.2.

b) Assessment of data collection tools and records: Epilepsy new patient form/ intake; Epilepsy Monthly follow up form; patient hospital files.

c) Semi-structured interviews with: medical officers, clinical officers, nurses, patients and their caregivers.

4.3 Results

1) Infrastructure Space and other accessories

a) Space

Each clinic has its own infrastructural challenge, however patients were able to get the services they require when they came to the clinic, below is summary of each clinic challenge and good practice.

Maridi

The space of the epilepsy clinic where patients are seen (consultation room) is not adequate. The consultation room has no privacy since there are no partitioning and/or screens. The three clinicians all see patients at once. However, it is well ventilated, protected from rain and wind. Clinicians reported that there is unpredictable power supply at the clinic. There is water supply stored in tanks with running taps. The clinicians were well protected with face mask and lab coats. There is need for land scaping from the patients shade to the consultation room.

Mundri

The space of the clinic is adequate and well ventilated, and has a shelter which serves as a waiting place for the patients. At the time of review there was power supply and there were sanitizers and masks and clinicians had lab coats. There is privacy during clinical reviews and patient examination

Lui

The consultation is small and not well ventilated, there is only one window. There is limited area protected from rain and sun.

b) Furniture

Maridi

There were enough chairs and sits at the time of the evaluation, both in the waiting area and the clinic. Cabinets and shelves for storing equipment, drugs and general use items were available. There were lockable cabinets for drugs and shelves for patients files.

Mundri

There were enough chairs and benches for patients and caregivers at the time of the visit. There were enough shelves and cabinets for file storage and other use.

Lui

There were enough chairs and benches for patients and cabinets for storing patient's files and items of general use. However, some files were kept in some boxes.

c) Medical equipment-

Maridi Most of the basic medical equipment (e.g., Blood pressure Machine, thermometer, weighing scale, tape measure, height scale) needed at the clinic were available and functional. However, for examination coach, pen torch, auriscope, and pen torch wree not available.

Mundri

Most of the basic medical equipment (e.g., thermometer, weighing scale, tape measure height measure,) needed at the clinic were available and functional. However, Blood pressure Machine, auriscope, and pen torch were not available.

Lui

Most of the basic medical equipment (e.g., Blood pressure Machine, thermometer, weighing scale, tape measure height measure,) needed at the clinic were available and functional. However, auriscope and pen torch were not available.

d) Job aids/on site reference materials

Job aids and summary charts for diagnosis and management of epilepsy and nodding syndrome were present, placed on the wall and easily seen during review. A file of Standard Operating Procedures, along with epilepsy guidelines, were available in the three clinics.

2. Patient care

a) Effectiveness of care

Maridi

Clinicians estimated that the majority of the patients have experienced good seizure control, about 70-75% had not experienced seizures for more than six months. Only about 20-25% have difficult to control seizures which occur about 1-3 times in a week but the severity of the seizures have gone down. Clinicians took an average of 7 minutes to see one patient who came for review.

Mundri

Clinicians estimated that the majority of the patients (60-70%) have experienced good seizure control meaning no seizure for more than six months. About 30% have difficult to control seizures which occur about 1-3 times in a week. Clinicians take an average of 10 minutes to see patients who came for review, and were keen in doing physical examination.

Lui

Clinicians estimated that the majority of the patients (50-60%) have experienced good seizure control of more than six months. About 10% have difficult to control seizures which occur more than 3 times in a week. About 40% still have about 1-2 seizures in 2-3 months. Clinicians take an average of 7 minutes to see patients who came for review.

b) Safe care for patients

Maridi

There is adequate infection prevention at the clinic, ranging from water points to sanitizers and face masks.

AED adverse effects are reported. Most of the effects are excessive drowsiness. However, these are not well documented in patients' notes. In this final evaluation I still observed treatment changes from one drug to another and clinician said it's due to side effects, but without documentation. No anaphylaxis reactions have been reported by the clinicians.

Mudri

There is adequate infection prevention at the clinics, ranging from water points to sanitizers and face masks. AED adverse effects are reported in patients' files. Most of the effects are excessive drowsiness.

Lui

There is adequate infection prevention at the clinics, ranging from water points to sanitizers and face masks. AED adverse effects are reported. Most of the effects are excessive drowsiness.

3. Organization of the clinic

A) Human resources

Maridi

The epilepsy clinic was run by three qualified clinical officers, four nurses and one aide closely supervised by a medical officer. Staff is contracted in line with other personnel at the hosting facility and appears within the establishment of the hosting facility.

There is good coordination between the clinical officer and the nurse to ensure that the treatment given is right for the individual patient. There are adequate staff and clear and well elaboratde hierarchy management structure. There is delegation of health activities and responsibilities among staff.

Mundri

The epilepsy clinic is run by two qualified clinical officers and one nurse.

There is good coordination between the clinical officer and the nurse to ensure that the treatment given is right for the individual patient. There are adequate staff and clear and well elaborated hierarchy management structure. There is delegation of health activities and responsibilities among staff.

Lui

The epilepsy clinic is run by one qualified clinical officer and one nurse.

There is good coordination between the clinical officer and the nurse to ensure that the treatment given is right for the individual patient. There are adequate staff and clear and well elaborated hierarchy management structure. There is delegation of health activities and responsibilities among staff.

b) Capacity building

Concerning Lui and Mundri at least one clinician at each facility underwent a 5-day training on mental health GAP, which has a topic on epilepsy. This training took place in the previous six months. However, in Maridi clinicians did not benefit from this training. None of the clinics have held a CME on epilepsy in the previous year.

4. Capacity of the staff provided by the project

Maridi

When the clinicians were asked their opinion on capacity building that the project has provided, they said it was very useful in that they learnt a lot about diagnosis and management of epilepsy.

Mundri

When the clinicians were asked their opinion on capacity building that the project has provided, they said it was very useful in that they learnt a lot about diagnosis and management of epilepsy. The nurse and the clinician who didn’t attend the training have benefited from their colleague who attended the training.

Lui

When the clinician was asked his opinion on capacity building that the project has provided, he said it was very useful in that he learnt a lot about diagnosis and management of epilepsy.

5. Need to enhance project clinical practice

Maridi

When the clinicians were asked their opinion on whether there was need to enhance the project’s clinical practice of N/S and epilepsy they said there was need. They said they needed more training since some of them are new.

Mundri

When the clinicians were asked their opinion on whether there was need to enhance the projects clinical practice of N/S and epilepsy they said there was need. They said they needed more training and requested for continuity of the project.

Lui

When the clinicians were asked their opinion on whether there was need to enhance the projects clinical practice of N/S and epilepsy they said there was need..

6. Health information system

a) Data collection tools and patient documentation

In all the three clinics there is the Epilepsy Clinic Register. There is a master register where all patients' details are recorded and given a unique number. It also has information on referrals. This registry is available in all three clinics.

There are two registries: for the new patients (Epilepsy new patient form/ intake) and follow up registry (Epilepsy Monthly follow up form). These forms have patients' bio data, vital signs, epilepsy/ seizure history, and physical and neurological examination information, past medical and birth history and family social history. They also contain questions on Nodding Syndrome assessment. The questions are relevant to obtain a diagnosis of epilepsy and Nodding Syndrome. However, to capture more information on seizure history for the purpose of classification a bigger text box is required. Changes on terminologies and classification need to be replaced with new terminologies. See recommendations.

b) Reporting

The clinicians in all the three clinics send data to their in-charge, who later sends it to the County Health Department. The latter then uploads the data onto the DHIS2.

5. Access to essential AEDs

a) AEDs

The essential four AEDs (phenobarbital, phenytoin, carbamazepine and sodium valproate) were all available in the three clinics. However, diazepam is not available in Mundri.

b) Consumables

All consumables needed at the clinic were available in all clinics including Drug sachets, cotton wool, gloves, disinfectant. However there is need to have an emergency kit in Mundri.

6. Administration

a) Roles

In all the three clinics I found a clear and well elaborated hierarchy management structure. There is delegation of activities (i.e., consultations/ patient review, drug dispensation, patient flow at the clinic, filling) and responsibilities among staff. Clinicians are satisfied with their line managers and have clear job descriptions. Clinicians know who to report to.

7. Patient satisfaction

Feedback

Maridi

I interviewed four patients (19-23 years) and two caregivers of patients with epilepsy. All had better seizure control, with someone having finished one and half years without a seizure. They were satisfied with the services offered and the interaction with clinicians. Some of the patients however requested for food and soap.

Mundri

I interviewed four patients (aged 18-30 years) and two caregivers of patients with epilepsy. All had better seizure contro,l with someone having finished one and half years without a seizure. They were satisfied with the services offered and the interaction with clinicians. Some of the patients however requested for food and soap.

Lui

I interviewed two patients (25 years) and two caregivers of patients with epilepsy. All had better seizure control, with someone having finished one and half years without a seizure. They were satisfied with the services offered and the interaction with clinicians. Some of the patients however requested for food and soap.

4.4 Conclusion and recommendations

Conclusion

There has been tremendous improvement in all the areas assessed, from the time of the midterm evaluation. Despite the difficulties (poor infrastructure, and other environmental and political issues) in South Sudan, we observed improves health outcomes among people with epilepsy and nodding syndrome, based on the the interviews and the home visits that we carried out during this end-term evaluation. Majority (70-80%) of the patients attending these clinics had excellent seizure control. This model of care is worth emulating.

Standardized epilepsy and Nodding Syndrome registry across the three sites were in use and data collection was good. This was an example of good practice developed by the project.

We recommend a Training of trainers who will routinely update clinicians on current issues pertaining to epilepsy management and classification. Routinely create awareness on preventive measures of epilepsy and nodding syndrome. Equip clinics with at least one consultant/medical officer who will review the difficult cases to treat. Equip clinics with investigative equipment (such as EEG) in the future. This will improve diagnosis and sound management.

Recommendations, per site

Site	Area assessed	Proposed recommendation
Maridi	1)Space	Need to improve on privacy. Provide screens and /or partitions.
	2) Medical equipment	Examination should be provide, patellar hammer, pen torch and auriscope should be provided as well.
	3) Safe care for patients	Severe adverse effects should be well recorded on the forms provided.
	4) Capacity building	Online or onsite N/S and epilepsy CMEs should be prioritized (at least 3 times a year)
Mundri	1) Medical equipment	Blood pressure machine should be on site. Height scale, patella hammer, pen torch should be provided.
	2) Capacity building	Online or onsite N/S and epilepsy CMEs should be prioritized (at least 3 times a year)
	3) Access to essential AEDs	Diazepam and First AID / Emergency KIT should be provided at the clinic.
Lui	1)Medical Equipment	Pen torch and Patella hammer should be provided
	2) Capacity building	Online or onsite N/S and epilepsy CMEs should be prioritized (at least 3 times a year)
	3) Data collection tools and patient documentation	Patients should be provided with documentation indicating their diagnosis and treatment. There is need for more cabinets for files.
	4) Other	There is need of a support staff, epilepsy Aide.

The epilepsy registry (new patients)	Part 2 Seizure/ Epilepsy related history	Type of epilepsy to be replaced with: 1) focal 2) generalized 3) combined generalized and focal 4) unknown
	Type of seizures	change wording from partial to focal
	Generalized seizures	add myoclonic, clonic and tonic seizures
	Focal seizures	add emotional

Appendices

APPENDIX ONE - TERMS OF REFERENCE

End-term evaluation of the "Nodding Syndrome Alliance" Project [AID 011898]

Terms of Reference

THE PROJECT

Project title: Nodding Syndrome Alliance

Lead Agency: Amref Health Africa

Country: South Sudan

Target areas: Jubek County; Maridi County; Mundri East County; Mundri West County.

Project period: 1st September 2019 – 31st August 2022 (3 years)

Background and overview of the project

NSA (Nodding Syndrome Alliance) is the title of a 3-year intervention proposed by Amref Health Africa, in collaboration with the NGOs Doctors with Africa CUAMM, OVCI la Nostra Famiglia, Light for the World and Sudan Evangelical Mission (SEM). Operating under the name of the Nodding Syndrome Alliance, the consortium aims to provide a pioneering and integrated response to address the needs of communities affected by Nodding Syndrome (NS) and epilepsy in the former state of Western Equatoria. The project therefore aims to meet specific healthcare and food security needs for people with epilepsy and Nodding Syndrome by adopting integrated, multisectoral measures for PLWE-NS (People Living with Epilepsy and Nodding Syndrome), to enable these people and their communities to become more resilient. NS is a degenerative neurological condition and form of epilepsy. The former Western Equatoria State is the epidemiological epicenter of NS; cases have also been reported in the Democratic Republic of Congo and Uganda. The causes of NS are unknown; indeed, the global scientific community has been working to determine its etiology for the last 15 years or so. The age of onset for NS ranges between 5 and 15 years old. The condition causes neurological and physical disabilities. The complications of the condition may result in early death. The experience of the Ugandan Ministry of Health and NSA partner OVCI in Juba has shown that the condition can be stabilized by administering standard antiepileptic drugs (AED). However, the public health system in South Sudan does not currently have supplies of these drugs. If the condition is not treated, it leads to early death and social exclusion for a significant percentage of children. It is estimated that there at least 10,000 neglected cases of suspected epilepsy/NS in the former state of Western Equatoria. However, clinical treatment is just one of the four areas that this project will address. Rural communities in South Sudan often associate epilepsy with inaccurate myths; this creates stigma and in turn means that children become isolated from society. The project will therefore promote the key role that communities have to play in transforming the negative paradigm of NS/epilepsy into pathways to inclusion. This will enable healthcare services to identify and take on cases more effectively. The project's community approach is built on pre-established networks: community-based rehabilitation (CBR) and South Sudan's national community health strategy (the Boma Health Initiative). By linking clinical treatment services with these community networks, the project will ensure patient adherence to antiepileptic drug therapy and will give children the opportunity to start or resume primary education. The project will promote future sustainability and inclusion by adopting measures to help improve food security for families of children with epilepsy/NS and enable them to be more self-sufficient. Other sustainable measures will include adopting integrated approaches to the epidemiological epilepsy/NS situation in the former Western Equatoria State by generating epidemiological data in target areas and by providing support during technical meetings with national and global stakeholders within the national Task Force for Neglected Tropical Diseases.

Overall Objective of the project

To help achieve SDG 3 (SDG 3.3, 3.4) by supporting neglected communities in the Equatoria region of South Sudan.

Specific Objective of the project

To meet specific health and food security needs for people living with epilepsy and nodding syndrome (PLWE- NS) by adopting integrated, multisectoral measures so that these people and their communities can become more resilient.

Expected results of the project

1. The community will have a network to identify, treat and integrate people with nodding syndrome and epilepsy.

2. The health systems in the states of Amadi and Maridi (the former Western Equatoria State) will providedirect preventive and treatment services to people with nodding syndrome and epilepsy. This will include specific epilepsy treatment and treatment for health and nutritional complications.
3. Greater food security and improved self-sufficiency for families who have children with nodding syndrome and epilepsy.
4. National and state-level authorities will receive help with planning and implementing preventive and treatment solutions for people with nodding syndrome and epilepsy, as part of a wider network of social and health services.

Beneficiaries:

- 300 children below 5 years old (50% Female; 50% Male)
- 15,000 children between 5 years and 18 years old (50% Female; 50% Male)
- 15,000 adults (50% Female; 50% Male)

Among the targeted children (<18 years), 900 children with epilepsy / Nodding Syndrome shall be assisted throughdedicated clinical services and home-based follow ups.

THE PROJECT END-TERM EVALUATION

The end-term evaluation is to be designed based on the project's logical framework, the project's indicators, andsome common practices in the evaluation of both community-based and facility-based epilepsy services.

Only a selected set of indicators will fall within the scope of this proposed end-term evaluation, whereas,geographically, the evaluation will encompass all the targeted areas.

Objectives

The main **objectives** of the end-term evaluation are:

i. To assess progress towards the achievement of selected project's results, outputs, and indicators.
ii. To identify and document factors and limitations affecting the above-mentioned progress.
iii. To assess beneficiaries and patients' satisfaction with the services offered by the project.
iv. To assess the progress of the consortium pertaining to the mid-term project evaluation recommendations.
v. More broadly, to evaluate the community-based services and facility-based services for people with epilepsy / Nodding Syndrome which the project established and supports.
vi. To document good practices, generate evidence-based lessons and provide recommendations for the continuation of the project services and an effective hand-over, if viable.

The evaluation should adopt the main OECD **evaluation criteria**:[1]

Relevance:

i. to what extent the services provided by the project are relevant to the needs of the targetedbeneficiaries (patients, their families, their communities)?
ii. To what extent is the project relevant to policies and strategies of the Ministry of Health of SouthSudan?

Effectiveness:

iii. To what extent the project is achieving the intended outputs?
iv. To what extent the project is achieving the expected results and their indicators?
v. What are the enabling factors facilitating progress? Which are the ones within the project'scontrol? Which are the ones outside the project's control?
vi. What are the disabling factors hindering progress? Which are the ones within the project'scontrol? Which are the ones outside the project's control?
vii. How appropriate and how realistic are the outputs and outcomes set forth by the project? Howadequate is the project design vis-à-vis the needs it intends to address?
viii. How appropriate and measurable are the project indicators?

Efficiency:

ix. To which extents are outputs and results are being achieved at a reasonable cost, compared toequally effective alternative approaches?
x. How well has the project achieved outputs and results within the intended timeframe? How wellin line is the project implementation with the overall work plan?
xi. How and how well does the coordination of project partners and stakeholders work?

Sustainability:

xii. Given the current set-up of the project, to which extent are services expected to be sustainable in the mid- and long-term? In regard to finances, operations, competencies.
xiii. To which extent is the intervention is owned by the local authorities? By the beneficiarycommunities?

Impact:

xiv. Which primary and secondary impacts is the intervention having?
xv. Identify and document positive and negative, intended, and unintended impacts of theintervention in middle run and in the long run.

Methodology

The evaluation will recur to mixed methods, thus both quantitative and qualitative. It will rely on both primarydata collected by the evaluators, direct observations performed by the same, and secondary data (project records) as well as some limited literature review.

Some proposed activities are listed below, and can assist in assessing the project performance under multipleOECD evaluation criteria:

- Key Informant Interviews with local health authorities and other stakeholders (Ministry ofHealth, County Health Departments, etc.)
- Household visits (direct beneficiaries)
- Consultations with project partners
- Consultations with clinical teams involved in the project implementation
- Consultations with community health volunteers involved in the project implementation
- Inspection of epilepsy clinics established by the project
- Review of project records
- Analysis of sampled project documentations (clinic registers, patient files, CHVs' family folders,

etc.)

Selected indicators to assess EFFECTIVENESS

As earlier indicated, only a selected set of indicators will fall within the scope of this end-term evaluation,namely:

- Specific Objective Indicator & Target no. 2: 85% of the target population, i.e., of people withclinically diagnosed nodding syndrome or other forms of epilepsy that have access to a set of standard drugs among the target population.
- Result 1, Indicator & Target no. 1.A: 85% of children diagnosed with epilepsy/NS receiving community follow-up services.
- Result 2, Indicator & Target no. 2.A: 4 equipped health care personnel and facilities (equipped with diagnostic/curative skills and tools) delivering care to people living with nodding syndrome and epilepsy.
- Result 2, Indicator & Target no. 2.B: 85% of patients diagnosed with nodding syndrome/epilepsy who regularly access the medication treatment, in compliance with the minimum standards of visits per trimester (i.e., 1 visit every 3 months).
- Result 4, Indicator & Target no. 4.B: Increased availability of epidemiological information onepilepsy/NS in endemic areas.

Proposed methodology to assess progress towards each indicator:

- Specific Objective Indicator & Target no. 2: 85% of the target population, i.e., of people withclinically diagnosed nodding syndrome or other forms of epilepsy that have access to a set of standard drugs among the target population.
  - The evaluators could check whether a statistically significant sample of patients received AED treatment upon registration. Epilepsy clinic registers can be used to derive the needed sample; registration forms, retrieved from patients' files, can be the source of information. It is

recommended that the method used within the framework of the mid-term evaluation is also adopted for this end-term evaluation, to make the outcomes of the two evaluations comparable

- Result 1, Indicator & Target no. 1.A: 85% of children diagnosed with epilepsy/NS receiving community follow-up services.
  - The evaluators could check whether a statistically significant sample of child patients are being followed-up at home by either AMREF or SEM volunteers. Epilepsy clinic registers and Excel databases can be used to derive the needed sample.
    - The source of verification could be both of the following:
      - Epilepsy clinic registers, including registration forms and follow-up forms, as they indicate whether a patient is being followed up at home.
      - Meeting with AMREF and SEM CHVs and verify with them, based on their recording tools, the % of the sample of children who are being followed up by the CHVs at that given time.
    - It is recommended that the method used within the framework of the mid-term evaluation is also adopted for this end-term evaluation, to make the outcomes of the two evaluations comparable

- Result 2, Indicator & Target no. 2.A: 4 equipped health care personnel and facilities (equipped with diagnostic/curative skills and tools) delivering care to people living with nodding syndrome and epilepsy.
  - The evaluators could just recur to direct observation and interaction with the healthcare personnel involved in the project. It is recommended to adopt the same checklist used within the framework of the mid-term project evaluation.

- Result 2, Indicator & Target no. 2.B: 85% of patients diagnosed with nodding syndrome/epilepsy who regularly access the medication treatment, in compliance with the minimum standards of visits per trimester (i.e., 1 visit every 3 months).
  - The evaluators could check the extent of defaulters (i.e., those who missed more than 3 monthly appointments) within a statistically significant sample of patients. Epilepsy clinic registers and Excel databases can be used to derive the needed sample; the same registers and Excel databases, as well as the patients' files, can be the source of information. It is recommended that the method used within the framework of the mid-term evaluation is also adopted for this end-term evaluation, to make the outcomes of the two evaluations comparable.

- Result 4, Indicator & Target no. 4.B: Increased availability of epidemiological information on epilepsy/NS in endemic areas.

- The evaluators could:
  - Conduct KIIs with officials at MOH and at County Health Departments.
  - Review records of Monthly Coordination Meetings.
  - Other documentation periodically shared by the project with local health authorities.

Key deliverables

a) Inception Report (max 5 pages), outlining the detailed plan of the end-term evaluation and a detailed description of the intended methodology.

b) Final Report (max 25 pages), structured according to the OECD's evaluation criteria and clearly presenting the extent of target / output / indicator achievements and impact attained by the project. The Final Report shall include, as annexes:

   i. File containing raw data set and clean data set, concerning quantitative data collected and used for the end-term evaluation.
   ii. Copy of brief notes produced in the collection of qualitative data used for the end-term evaluation.
   iii. Pictorial evidence of the end-term evaluation activity.

Team composition

Ideally, the end-term evaluation should be performed by a mixed team, comprising of:

- 1 expert of community-based epilepsy interventions.
- 1 clinical expert on epilepsy (Clinical Officer, Medical Officer or above)

1 data analyst shall be recruited locally and separately, by the contracting agency, and should join the evaluators' team in the project intervention locations.

Timeframe

The end-term evaluation would take approximately 10 days in country, in the first half of the month of July 2022, plus some additional days for data analysis and reporting.

Requirements

The evaluator can be either an individual, a team, or an organization. In all cases, the Consultant shall be able to demonstrate:

a. Public Health / Mental Health qualification (university level), with substantive expertise in Epilepsy Care at community level.

b. Clinical qualification (diploma level), with substantive expertise in Epilepsy Care in resource-constrainedfacility settings.
c. Significant experience in monitoring and evaluation, research, of mental health interventions in Sub-Saharan African settings.
d. Strong interpersonal skills and capacity to work with people at all levels and with different culturalbackgrounds.
e. Committed to work and meet the deadline as agreed with the Consortium Coordinator.
f. Excellent English communication and writing skills.

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[1] European Union, “EVALUATION MATTERS – The evaluation policy for the European Union Development
Cooperation”, available at: https://ec.europa.eu/international-partnerships/system/files/evaluation-matters_en.pdf

APPENDIX TWO FOCUS GROUP DISCUSSION GUIDE

Focus Group Discussion Guide

Proposed participants: 6-8 beneficiaries and 3-5 Volunteers
Sampling strategy: Purposeful and non-probability
Language: English and Jubarabic
Project: Nodding Syndrome Alliance

All information should be recorded

NSA (Nodding Syndrome Alliance) is the title of a 3-year intervention proposed by Amref Health Africa, in collaboration with the NGOs Doctors with Africa CUAMM, OVCI la Nostra Famiglia, Light for the World and Sudan Evangelical Mission (SEM). Operating under the name of the Nodding Syndrome Alliance, the consortium aims to provide a pioneering and integrated response to address the needs of communities affected by Nodding Syndrome (NS) and epilepsy in the former state of Western Equatoria. The project therefore aims to meet specific healthcare and food security needs for people with epilepsy and Nodding Syndrome by adopting integrated, multi-sectoral measures for PLWE-NS (People Living with Epilepsy and Nodding Syndrome), to enable these people and their communities to become more resilient.

Informed consent – To be read to participants

Hello, my name is _______ and I am conducting this discussion on behalf of AMREF. We are conducting this group discussion among people like you to find out what you think about the project being implemented by the Nodding Syndrome Alliance. There is no right or wrong answers to the questions. I am just interested in your opinion. We will not ask for your name and the answers you will provide will be in strict confidence. Your responses are strictly voluntary. If we come to a question you do not wish to answer, please tell me and we will move on. However, your answers can be beneficial by providing information which may help to improve the project. We are also interested in the impact of the project conducted so please your answers will help to achieve the aim of this evaluation. Please note that we are not promising any development assistance – we are more interested in your thoughts on the ongoing project. Information on participants

1. Do you accept to be interviewed? Yes/No
2. County of discussion:
3. Title of participants: Beneficiaries/Volunteers
4. Age of participants Years:

1-5		**6-17**		**18-55**		**55+**	

5. Gender of participants:

Females		**Males**	

QUESTIONS

NB: **The questions will be answered by either the Beneficiaries or Volunteers or Both**

		Respondent	
Section	**Question**	**Beneficiaries**	**Volunteers**
Background	What was the NS/Epilepsy situation like before the project started?	**X**	**X**
	How were you selected or how did you become a beneficiary of this project?	**X**	
	How were you recruited as a volunteer?		**X**
	Please briefly describe your roles and responsibilities / involvement in this project.		**X**
Implementation/ Relevance	What kinds of activities are done in this project?	**X**	**X**
	6a. Are they useful / beneficial to you and your needs? If yes, to which extent? If not what can else can be done?	**X**	

	6a. Are they useful / beneficial to people with epilepsy, in your opinion? If yes, to which extent?		**X**
	6b. What kind of information was provided to you before or during these activities?	**X**	**X**
	6c. Was this useful?	**X**	**X**
	6d. Why or why not?	**X**	**X**
	Are there any campaign or promotional materials that are used?	**X**	**X**
	How is your work monitored?		**X**
	What kind of tools do you have as volunteers to support your work?		
Beneficiary Participation	Please describe the role of beneficiaries during , implementation, and monitoring of the project. To what extent are they involved?		**X**
	Maridi: Mundri:		

	Lui		
	Do any feedback mechanisms exist for beneficiaries to provide feedback regarding the project and its related services?		**X**
	Maridi: Mundri: Lui		
	Do you have any feedback or complaint mechanisms?	**X**	
	Maridi: Mundri: Lui		
Impact	Since the project started what changes have you noted? What kind of support do you receive from the project? (check medical + social visit)	**X**	**X**
	Maridi: Mundri: Lui		
Suggestions	What are some ways this project be improved?	**X**	**X**
	How can the project have a bigger positive impact on people with epilepsy, in your opinion?	**X**	**X**

Sustainability	What do you think will happen when the project will come to an end?	**X**	**X**
	What would you suggest authorities and organizations do to ensure continuity of services?	**X**	**X**
	i		

Thank you for your participation

APPENDIX THREE KEY INFORMANT INTERVIEWS GUIDE

TOOL 1: Key Informant Guide

TARGET GROUP

- Key Informant Interviews with local health authorities and other stakeholders (Ministry of Health, County Health Departments, etc.)
- Household visits (direct beneficiaries) – selected questions only
- Consultations with project partners
- Consultations with clinical teams involved in the project implementation
-

Name of Interviewer (s):___________________________________
Name of Interviewee_______________________________________
Position/Title____
Name of organisation______________________________________
Location/County____
Date of interview____

1. Relevance:

1.1 In your opinion, what is your perspective of this project under assessment?

☐ 1. It is of Interest to clinical practice
☐ 2. It is of Interest in helping people with NS/Epilepsy
☐ 3. It has opportunities for professional development
☐ 4. It is aligned to policies of government
☐ 5. It is assisting Government
☐ 6. It is assisting Families
☐ 7. Other (SPECIFY): ☐

1.2 In relation to your previous response, what is the single most important factor that attracts you to the project under assessment?

☐

1.3 In your opinion, are persons with NS/Epilepsy benefiting in this program under assessment?

☐ 1. Yes
☐ 2. No
☐ 3. I don't know

2.3.1 Explain your answer.

☐

2. Effectiveness:

2.1 In your opinion, how do you rate the project activities?

- ☐ 1. Poor
- ☐ 2. Good
- ☐ 3. Excellent
- ☐ 4. I don't know
- ☐ Why do say so: ☐

2.2 How well did you interact with the project implementing team?

- ☐ 1. So Often
- ☐ 2. Rarely
- ☐ 3. I don't know
- ☐

Why do say so: ☐

2.3 In your opinion, is there anything that you have noted that is making the project do well/not do well?

☐ Explain ☐

3. Efficiency: to be asked to implementing partners

3.1 How has the coordination and partnership worked?

- ☐ 1. Very well
- ☐ 2. Average
- ☐ 3. Good
- ☐ Why do you say so: ☐

3.2 In your opinion, what should be done as the project is ending?

☐

3.3 In your opinion, are there problems related to the project that you would want to highlight?

- ☐ 1. Yes
- ☐ 2. No

☐ 3. I don't know

3.3.1 If yes, please describe them, and suggest what could be done to overcome them.

☐

4. Impact

4.1 Where do you think the project has impacted most?

Category		Impact			
	I don't know 0	Too little 1	Sufficient 2	Greatly 3	Too much 4
1. Persons with N/S/Epilepsy	☐	☐	☐	☐	☐
2. Local community at large	☐	☐	☐	☐	☐
3. Government Ministry of Health	☐	☐	☐	☐	☐
4. County Health Department	☐	☐	☐	☐	☐
5. Partners	☐	☐	☐	☐	☐

4.2 What is the specific positive or nevative impact that the project has brought about

☐ Explain ☐

4.3 Do you believe that NS or epilepsy is contagious? (selected respondents only)

Explain ☐

5. Sustainability:

5.1 In your opinion, what steps should be taken to ensure the project is sustainable as it ends?

☐ Explain ☐

5.2 What opportunities are available for the community and persons with NS/Epilepsy to fully own the project?

☐
☐ 1. I don't know
☐ 2. Other (SPECIFY): ☐

6. Clinical Practice to selected key informants only

1.1 What is your opinion on the capacity building that the project has provided?

☐ 1. Very Good
☐ 2. Good
☐ 3. I don't know

Why do you say so?

☐

1.2 In your opinion, was there a need to enhance the project's clinical practice of NS/Epilepsy in any way?

☐ 1. Yes
☐ 2. No
☐ 3. I don't know

8.5.1 If yes, what key steps are needed to improve?

☐

7. Partnerships and Exchange

7.1 Is there any added value in the collaboration you had in this project?

☐ 1. Yes

☐ 2. No
☐ 3. I don't know

2.1.1 If yes, what is it?

☐ 1. Sharing of space
☐ 2. Learning
☐ 3. Sharing of resources and materials
☐ 4. Research
☐ 5. Support for project management
☐ 6. Clinical practice
☐ 7. Social care for PWE/NS
☐ 8. I don't know
☐ 9. Other (SPECIFY): ☐

7.2 In your opinion, was there a need to improve partnership?

☐ 1. Yes
☐ 2. No
☐ 3. I don't know

9.4.1 If yes, what steps could be taken to improve future partnerships?

☐

We have reached the end of our interview. Do you have any additional suggestions for the project?

THANK YOU FOR YOUR TIME!

Eddie Chengo (epileptologist) during his assessment of the epilepsy clinic at Mundri PHCC

Action Amos (Lead Consultantt) during an FGD with patients at Mundri PHCC

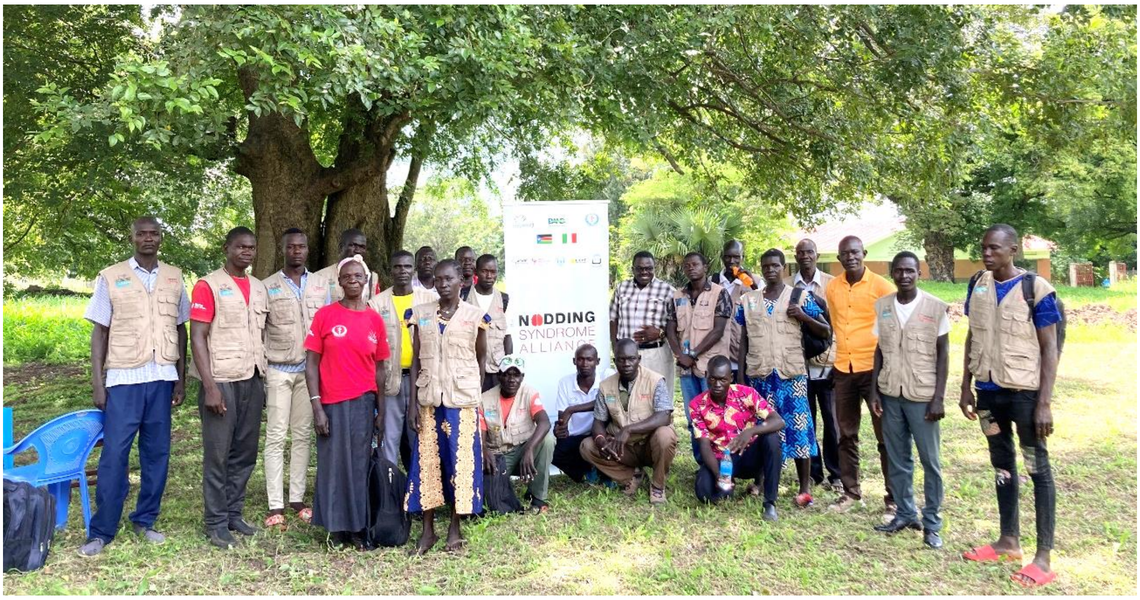
The new epilepsy clinic, built by the NSAlliance in May 2022

Philip Pitia (Data Analyst), extractin data from the epilepsy clinic's paper-based registers in Mundri

BHWs, HHPs and CBRWs who took part in FGDs and data analysis exercises in Mundri

BHWs, HHPs and CBRWs who took part in FGDs and data analysis exercises in Maridi

Philip Pitia (Data Analyst) during the verification of volunteers' registers in Mundri



BHWs and CBRWs who took part in FGDs and data analysis exercises in Lui

An FGD with patients at Lui Hospital

Action Amos (Lead Consultant) inspects a Farmers' Field School plot in Mundri