UNIVERSITY OF NAIROBI

COLLEGE OF HEALTH SCIENCES

DEPARTMENT OF CLINICAL MEDICINE AND THERAPEUTICS

DETERMINATION OF THE ACCURACY OF A COMPUTERISED ALGORITHM TO DIAGNOSE EPILEPSY IN A LOW-INCOME URBAN POPULATION IN KENYA

DR QUINCY OYARO MONG'ARE

H58/37653/2020

A DISSERTATION SUBMITTED IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTER OF MEDICINE IN INTERNAL MEDICINE.

2023

STUDENT'S DECLARATION

Principal Investigator
Dr Quincy Oyaro Mong'are
Registrar, Internal Medicine
Department of Clinical Medicine and Therapeutics
Faculty of Health Sciences
University of Nairobi
Registration Number: H58/37653/2020

I hereby confirm that this is my original work and to the best of my knowledge has not been submitted elsewhere for examination. All resources and materials used or quoted have been indicated and acknowledged using reference.

Signed.....Date.....23/11/23

SUPERVISORS' APPROVAL

This dissertation has been submitted with the approval of my supervisors and the chairman of the department.

DR. KWASA THOMAS O. O.

Consultant Physician and Neurologist

Department of Clinical Medicine & Therapeutics

University of Nairobi

Signed..... Date..24/11/2023.....

PROF. KAYIMA JOSHUA K.

Consultant Physician and Nephrologist

Department of Clinical Medicine & Therapeutics

University of Nairobi

Signed..... Date..22/11/023.....

PROF. E. O. AMAYO

Chairman of the Department of Clinical Medicine and Therapeutics

Consultant Physician and Neurologist

University of Nairobi

UNIVERSITY OF NAIROBI
COLLEGE OF HEALTH SCIENCES
DEPARTMENT OF CLINICAL MEDICINE & THERAPEUTICS
P.O. BOX 19676 - 00202 NAIROBI

Signed..... Date..27/11/2023.....

ACKNOWLEDGEMENT

I wish to thank my supervisors for their guidance as well as my friends and family who supported me during this process.

Table of Contents

LIST OF ABBREVIATIONS

AI	Artificial Intelligence
APHRC	African Population & Health Research Centre
EEG	Electroencephalogram
EPInA	Epilepsy Pathway Innovation in Africa
EQ	Epilepsy Questionnaire
FI	Field Interviewer
FN	False Negatives
FP	False Positives
ILAE	International league Against Epilepsy

KAWE	Kenya Association for the Welfare of People Living with Epilepsy
MRI	Magnetic Resonance Imaging
NIHR	National Institute of Health research
NPV	Negative Predictive value
NUHDSS	Nairobi Urban Health and Demographic Surveillance System
PHW	Primary Healthcare Workers
PPV	Positive predictive value
SDG	Sustainable Development goals
TN	True Negatives
TP	True Positives
APP	Application
ASM	Antiseizure Medication
LMIC	Low- and Middle-income countries
HIV	Human Immunodeficiency Virus
KNH-UoN ERC	Kenyatta National Hospital- University of Nairobi Ethics and Research Committee
KEMRI SERU	KEMRI SERU (Kenya Medical Research Institute Scientific and Ethics Review Unit)

ABSTRACT

Background: Epilepsy can be challenging to diagnose as epileptic seizures vary significantly in presentation and can be mimicked by other conditions. Neurologists are also quite few as compared to the rest of the population. Tools that can assist healthcare workers to better characterize epileptic seizures and subsequently, diagnose epilepsy would be invaluable in reducing the morbidity and mortality associated with the condition. The Epilepsy Pathway Innovation in Africa (EPInA) project developed such a tool in the form of a computerized algorithm that can run as an application on mobile devices and that could be used by primary healthcare workers to screen for epilepsy.

Objectives: To determine the accuracy of the EPInA diagnostic algorithm in diagnosing epilepsy in a low-income urban population in Kenya.

Methodology: A clinic-based cross-sectional study in which the diagnostic algorithm was administered by primary healthcare workers to 388 patients who had previously been screened for features consistent with Epilepsy and subsequently referred to 4 different primary healthcare clinics in the areas of Korogocho and Viwandani for review by a neurologist. Based on the participant's responses, the algorithm generated a score between 0 to 100 indicating the likelihood of an epilepsy diagnosis. The patients were then seen by a neurologist who came up with a clinical diagnosis. The algorithm's results were then compared to the neurologist, whose diagnosis, in this case, was the 'reference standard."

Results: After assessment by the Neurologist, 73.2% (284/388) of the participants were found to be epileptic, 11.1% (43/388) were suspected to be epileptic and 15.7% (61/388) were not epileptic. The agreement between the application score and the neurologists' diagnoses was fair (weighted kappa = 61.6%). Assuming an application score cut-off for epilepsy of 96 and no epilepsy of <30 the sensitivity and specificity at detecting epilepsy were 73.9% (95% CI=68.5-78.7%) and 60.6% (95% CI=60.0-69.4%) respectively with Positive and Negative predictive values of 83.7% (95% CI=78.6-87.7%) and. 50.0% (95% CI=37.9-54.3%) respectively.

On the other hand, the sensitivity and specificity at detecting no epilepsy were 27.9% (95% CI=18.2-40.2%) and 90.8% (87.2-93.5%) respectively with Positive and negative predictive values of 36.2% (30.0-50.5%) and 87.1% (95% CI = 83.1-90.3%) respectively.

Conclusion: Our algorithm was suboptimal in its ability to reliably distinguish epilepsy from non-epilepsy and as such requires refinement to improve and optimize its accuracy before a rollout can be considered.

1. CHAPTER ONE: INTRODUCTION

1.1Background

Epilepsy is a chronic noncommunicable disease that is characterized by recurrent seizures. It affects about 50 million people worldwide, most of whom live in low and middle-income countries(LMIC)(1).

Although Epilepsy can be a debilitating disease with serious physical, economic and social consequences, its morbidity, and mortality can be reduced by controlling the frequency of seizure episodes. Overall, up to 80% of patients can become seizure-free on Antiseizure medication(ASM) treatment(2).

A big factor undermining the management of Epilepsy is that it can be a significant challenge to diagnose even for experienced physicians as epileptic seizures may never be observed by the attending healthcare worker and even then, vary significantly in presentation and can be mimicked by other conditions e.g., fainting, migraines, and panic attacks. This is compounded by the fact that Healthcare human resources, especially in specific specialized areas such as Neurology, are sorely lacking in Sub-Saharan Africa. A report by the American Academy of Neurology estimates the number of neurologists in Africa at **0.03 per 100000 people**, while the WHO recommends at least 1 neurologist per 100,000(3).

Technology, and especially its mobile subset, is quickly advancing in Africa. Statistics on ownership of mobile phones on the continent from 2015 to 2018 showed that 86% of young males(ages 15 to 29 years) in Africa owned a mobile phone, compared to 77% of females(4). In Kenya, the penetration rate of mobile Internet users was estimated to be 83%(5). This high rate of mobile phone usage on the continent provides a platform to investigate and implement various health interventions that can reach a large number of people. Brenda Kharono et al conducted a cross-sectional observational survey to assess technology access and use among youth aged 14–24 receiving general outpatient or human immunodeficiency virus (HIV) care in three hospitals in Nairobi, Kenya. They recommended that Intervention developers and policymakers should consider smartphone and social media interventions as candidates for youth health programs(6)

The Epilepsy Pathway Innovation in Africa (EPInA) project is a multiyear (2019-2024) research project funded by the National Institute of Health Research (NIHR) through Oxford University and implemented by the African Population Health Research Centre (APHRC). It seeks to address the high epilepsy burden in Sub-Saharan Africa by testing interventions in the epilepsy treatment pathway, that is prevention, diagnosis, treatment, and awareness.

Under the diagnostic arm of the pathway, EPINA developed a mobile application that could be used by PHWs (Primary health care workers) to screen for epilepsy in the community.

This study nested under the bigger EPInA umbrella sought to determine the accuracy of this application as tested in a low-income urban population in Nairobi.

2. CHAPTER TWO: LITERATURE REVIEW

2.1. Epilepsy Definition and Classification:

The International League Against Epilepsy(ILAE) is a multinational organization dealing in Epilepsy research that came up with a practical definition of epilepsy used by most bodies as the standard of defining the condition(7).

According to the ILAE definition, a person is considered to have epilepsy if they meet any of the following conditions:

1. At least two unprovoked (or reflex) seizures occur greater than 24 hours apart.
2. One unprovoked (or reflex) seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next 10 years.
3. Diagnosis of an epilepsy syndrome (An epilepsy syndrome is a type of epilepsy that is identified by a specific type of seizure and by the findings on EEG. Examples include Lennox-Gastaut syndrome, Juvenile myoclonic epilepsy and Dravet syndrome.)

Seizures can either be classified into generalized, focal, or unknown onset and epilepsy types as focal, generalized, combined generalized and unknown with various changes in terminologies done by the ILAE 2017 revision:

(1) "Partial" was changed to "focal".

(2) Awareness is used to classify focal seizures.

(3) The terms dyscognitive, simple partial, complex partial, psychic, and secondarily generalized were eliminated.

(4) New focal seizure types include automatisms, behavior arrest, hyperkinetic, autonomic, cognitive, and emotional.

(5) Atonic, clonic, epileptic spasms, myoclonic, and tonic seizures can be either focal or generalized in onset.

(6) The term Focal to bilateral tonic–clonic seizure replaces secondarily generalized seizure.

(7) New generalized seizure types are absence seizure with eyelid myoclonia, myoclonic absence, myoclonic–atonic, myoclonic–tonic-clonic; and

(8) Seizures of unknown onset may have features that can still be classified.

The following table is a comparison between previously used terminologies and their equivalents in the 2017 classification:

Table 1:

Comparison Between Old and New Terminologies

Old Terminology	New Terminology
Partial Seizure	Focal Seizure
Focal seizure with secondary generalization	Focal to bilateral tonic-clonic
Simple Partial	Focal Aware
Psychomotor and Dyscognitive	Focal impaired awareness
Grand mal	Generalized tonic-clonic
Infantile Spasm	Epileptic Spasm

2.2 Burden of Epilepsy

Worldwide, Epilepsy accounts for 0.5% of the global burden of disease (GBD) and affects people of all ages, sexes, races, income groups and geographical locations. Around 7.6 per 1000 persons have epilepsy during their lifetime. It has a range of causes, from genetic, metabolic, infectious, structural, immune, and unknown. Lower and middle-income countries (LMIC) (139 per 100 000 person-years) have a higher incidence of epilepsy compared with high-income countries (HIC) (48.9)(1).

According to a systematic analysis by Abigail Paul et al, active epilepsy was estimated to affect 4.4 million people in Sub–Saharan Africa, and lifetime epilepsy i.e., diagnosis of epilepsy

(recurrent unprovoked seizures) at some point before the prevalence period or date was 5.4 million. Active epilepsy prevalence peaked between the ages 20–29 at 11.5/1000 and also in the 40–49 age group at 8.2/1000. The lowest prevalence of 3.1/1000 was seen in the 60+ age group. The analysis showed a high prevalence of epilepsy, especially in young adults, and this has important consequences for both the workforce and community structures of those affected(8).

A 2021 study by Symon M Kariuki et al in Kilifi Kenya found a prevalence of lifetime and active epilepsy of 31.7/1,000 persons and 21.6/1,000 respectively(9).

These statistics show the incredible burden of epilepsy in Sub-Saharan Africa. This is exacerbated by the fact that most of those affected are young adults, most of whom are expected to provide for their families and communities. Finding tools that will increase the diagnostic rate of epilepsy and therefore enroll more affected individuals in treatment will ease this burden by enabling epileptics to resume their day-to-day activities once their seizures are controlled.

It is also important to note that epilepsy is associated with significant stigma(10), as in some communities epileptic seizures are thought to be the result of witchcraft or curses. Controlling seizures in epileptics eases the social pressure faced by these individuals and their families but more work needs to be done in educating the general population on epilepsy, its causes and treatment.

2.3 Diagnosing Epilepsy

Making an epilepsy diagnosis can be challenging. A study by K G Hampel et al found a number of factors contributing to this difficulty (11). One of the main challenges is the fact that epileptic seizures are transient, occur relatively infrequently and the physician who must carry out the diagnosis may never see them.

Additionally, there are also many clinical events, that present similarly to epileptic seizures and, consequently, can be mistaken for them. The following is a list of such possible conditions.

1. Syncope: Can be reflex(vasovagal), Orthostatic, Cardiac or Neurogenic
2. Psychogenic attacks: Panic disorder, Dissociative non-epileptic attack disorder, Rages
3. Migraines

4. Sleep disorders: Excessive somnolence, Parasomnia
5. Paroxysmal movement disorders and ataxias
6. Endocrine, metabolic, and toxic causes: hypoglycemia, hypocalcemia, phaeochromocytoma, carcinoid syndrome.

Finally, the fact that EEGs (electroencephalogram) and MRI (magnetic resonance imaging) of the brain, are subject to error increases the difficulty in making an epilepsy diagnosis.

In a 2010 study by F Boesebeck et al, researchers conducted a retrospective examination of the rate of and risk factors for misdiagnosing non-epileptic transient events as epilepsy and vice versa. This was done in a neurological intensive care unit. Among patients initially diagnosed with epilepsy, 13.9% were proven not to have epilepsy. Among those with a final diagnosis of epilepsy or seizure disorder, 15.6% had actually initially received misdiagnoses(12). There were many factors that contributed to the misdiagnoses, but the results illustrated that making a diagnosis of epilepsy is not straightforward.

It is also important to note that missing a diagnosis of epilepsy can be disastrous. Epileptics can suffer severe injuries if they get a seizure in a hazardous environment, or even get head trauma after falls. An undiagnosed epileptic operating dangerous machinery or driving a car can cause accidents that put others at risk.

A review article by Rita Nguyen and Jose' F Tellez Zenteno published in the Neurology international journal in 2009(13) looked at various epidemiological studies on the risk of injuries in epileptics and found the rates of injuries and accidents to be higher in epileptics than in non-epileptic controls. The risk of injuries was diminished when seizures were controlled or absent. This further illustrates that discovering and treating undiagnosed epilepsy will greatly reduce these individuals' morbidity.

2.4 Technology in Medicine and study tool

Technology is quickly moving forward in many fields, including that of medicine. This is a result of advancements in computer processing power, cheaper production costs and smarter Artificial intelligence (AI)

Artificial intelligence is a combines computer science and data to solve problems. It also incorporates other sub-fields such as machine learning and deep learning. AI algorithms create systems that make predictions and classifications based on data they are fed (15).

For an AI algorithm to be effective, the computer systems must first be fed data. Once the algorithm has been exposed to enough data, the performance can be analyzed to ensure accuracy, like examining a student. These algorithm "tests" usually involve inputting test data to which the programmers know the answers allowing them to assess the algorithm's effectiveness in determining the correct answer and based on these results, the algorithm can be modified to improve its accuracy(16).

In a place like Sub-Saharan Africa, where a lack of Human resources is a huge rate-limiting step in delivering healthcare to the masses, technologies that can assist and in some cases, even replace the function of healthcare workers in various situations could be a huge step toward countries achieving good health and well-being(SDG 3) for their populations

A 2020 article by Ayomide Owoyemi et al, published in the multidisciplinary journal, Frontiers in Digital Health, quoted various cases in which AI proved a useful tool for tackling health challenges, reducing costs and improving health access and quality but also recommended that African countries need to come up with laws and policies to guide the development of this technology and protect its users(14). The article illustrated the untapped potential that Artificial Intelligence has in improving healthcare in Africa but also that a lot needs to be done in terms of creating favorable infrastructure and in training professionals on technology use.

Various algorithms to help detect epilepsy and even predict epilepsy outcomes have been described in literature. Mark R Keezer et al described a screening questionnaire and algorithm for estimating epilepsy prevalence and incidence. The algorithm, named the Canadian Longitudinal Study on Aging Epilepsy Algorithm (CLSA-EA) was developed to identify persons with epilepsy from a sample of participants obtained from the aforementioned study alongside an epilepsy-enriched sample of clinic-based participants. Their tool was to be highly sensitive and specific for the identification of persons with a lifetime history of epilepsy as well as active epilepsy i.e. The sensitivity and specificity of the algorithm for a lifetime history of epilepsy were 97.1% and 98.1%, and for active epilepsy were 100% and 98.6%(17).

E Wayne Holden et al described an algorithm that was developed to detect epilepsy in managed care organizations. This algorithm was able to detect epilepsy cases after examining combinations of diagnosis, diagnostic procedures, and medication use(18).

Lara Jehi in her 2020 article in the Epilepsia journal, described promising algorithms that can convert facts and data into objective epilepsy outcome predictions but also conceded that more work is needed to improve upon these existing algorithms and study their implementation(19).

An epilepsy diagnostic algorithm was developed by EPinA in conjunction with Oxford University using ethnographic data from various research sites in Sub-Saharan Africa (Tanzania, Ghana and Kenya). Data from each site was used to create a culturally appropriate diagnostic questionnaire to better determine the characteristics of episodes of transient neurological dysfunction. The questionnaire was converted into an algorithm that was subsequently incorporated into a mobile application. The application ran the algorithm after a patient had answered a set of weighted questions and then came up with a score of between 0 to 100 based on the answers given by the patient. A score closer to 100 indicated a higher likelihood of the patient being epileptic and vice versa. Primary Health care Workers (PHWs) were trained on how to use the application in a standardized manner and subsequently administered it to the patients prior to them seeing a qualified neurologist.

As per the Kenya data protection act of 2019(20), the application did not collect any personal data from study participants and as such, there was no risk of such information being transmitted to unwanted parties, whether in or outside the country.

A similar tool had previously been used and validated in India and Nepal(21). It was incorporated into an application to run on phones using the Android operating system and had eleven questions that mirrored a doctor's history-taking process when trying to make an epilepsy diagnosis. These questions had been previously defined after studying a Nepalese population of suspected epileptics and choosing the questions with the best predictive value for an epilepsy diagnosis. The tool was administered by various groups that included: non-medical volunteers, health workers, or inexperienced doctors to 132 patients in three different populations in India and Nepal and its results compared with the ''reference standard'' diagnosis of a neurologist. There was good agreement between the app's results and the neurologists' diagnoses (weighted kappa = 75.3%). An app score of 90 or greater had a sensitivity of 88% and a specificity of 100% for diagnosing epilepsy. This tool proved effective in diagnosing both epileptic and non-epileptic seizures in the study populations. Its sensitivity and specificity were high and compared well with clinical diagnosis.

2.5 Study Justification

The difficulty of diagnosing epilepsy(12), coupled with the very low number of qualified neurologists in Sub-Saharan Africa (3), leads to a great number of neurological diseases, including epilepsy, going undetected. Subsequently, many people who are living with the disease go undiagnosed and untreated greatly increasing their morbidity (13) and mortality(22) as well as leading to an increased social and economic burden on their families and communities(10)

In Africa, Primary healthcare workers vastly outnumber both general Physicians and Specialists(23) and it is likely that most epileptic patients will never encounter a specialist neurologist during the course of their illness. It would therefore be particularly useful if an easy-to-use algorithm to diagnose epilepsy was made available to primary healthcare workers. This would ease the impossible burden placed on the few neurologists we have on the continent.

Our study proposed to determine the accuracy of a computerized tool developed to assist primary healthcare workers with little neurological training to reliably detect and diagnose epilepsy.

2.6 Research Question

Can epilepsy be diagnosed effectively by primary healthcare workers using a computerized diagnostic algorithm?

2.7 Objectives

2.7.1 Broad Objective

1. To determine the accuracy of an app-based algorithm used by primary healthcare workers to diagnose epilepsy.

2.7.3 Specific Objectives

1. To determine the sensitivity and specificity of an Epilepsy diagnostic algorithm in a low-income urban Population.
2. To determine the Negative Predictive Value(NPV) and Positive Predictive Value(PPV) of an Epilepsy diagnostic algorithm in a low-income urban Population.

3. CHAPTER THREE: STUDY METHODOLOGY

3.1 Study Design

Clinic-based cross-sectional study with point-of-care data input done between February 2023 and April 2023.

3.2 Study Area

The study was conducted in various clinics located in the Nairobi Urban Health and Demographic Surveillance System (NUHDSS), a pioneer urban Health and Demographic Surveillance System in sub-Saharan Africa (SSA) that provides a platform to investigate the long-term consequences of urban slum residence on health and socioeconomic outcomes(24).

The clinics/Health centers that were used for the study were:

1. Kariobangi North Health Centre
2. Korogocho Health Centre
3. Lunga Lunga Health Centre
4. Kwa Ruben Health Centre

This was done with assistance from staff from APHRC and the Nairobi County Division of Health, as part of the overall EPInA study

3.3 Study Population

Trained APHRC field interviewers screened adult patients living in the informal settlements of Viwandani and Korogocho captured under NUHDSS for those with a history of transient events that may have been epileptic seizures. This process involved interviewing the head of household or an adult representative using a 10-item standardized epilepsy questionnaire(25). Out of these the following criteria were used to determine participants that would proceed to the next phase of the study:

Inclusion criteria

- Adult participants (above 18 years) with symptoms consistent with epilepsy
- Those willing to sign an informed written consent.

Exclusion criteria

- Patients unable to give history and who did not have a reliable eyewitness accompanying them.

3.4 Sample Size Calculation

Our minimum sample size was determined using Buderer's formulae for diagnostic accuracy studies based on sensitivity(26).

Buderer's formulae for diagnostic accuracy studies based on sensitivity:

$$Nse = \frac{Z^2 \, x \, S_N \, x \, (1 - S_N)}{d^2 \, x \, p}$$

Definitions:

Nse = sample size based on sensitivity

S_N = anticipated sensitivity (88%) based on the sensitivity of a similar tool that was used in Nepal and India(21)

Z = standard normal deviate for critical region (1.96 for 95% CI)

d = Maximum marginal error (93.6-80.6 = 13/2 = 6.5)

p = prevalence of epilepsy (approximated to be 50%) since there existed no literature on epilepsy prevalence in the study population

Computation of sample size:

$$Nse = \frac{1.96^2 \, x \, 0.88 \, x \, (1 - 0.88)}{0.065^2 \, x \, 0.5} = 193$$

Based on the sensitivity of the tool, the minimum sample size, n, was determined to be 193 participants. This was the minimum population size required for our study to give acceptable results. Our study managed to recruit 388 participants.

3.5 Study Procedure

Residents of the NUHDSS that had initially been screened by the APHRC field interviewers to identify participants with features of possible Epilepsy. were then referred to the clinics in Korogocho and Viwandani to see a Neurologist.

Our study's entry point was the clinic stage. At the clinics, consent was taken, relevant data collected, and The Epilepsy diagnostic algorithm was administered to participants by the Primary Healthcare workers (Clinical Officers and Nurses) working at the specific facility, each of whom had their own tablet computer. Multiple training sessions on the use of the tablet and the algorithm had been done prior to the commencement of the study.

The clinical phase of the study involved the Neurologist taking a focused history to elicit symptoms consistent with epilepsy. They subsequently came up with a diagnosis grouping the patients into Epileptic, non-epileptic or unknown categories. It is important to note that the Neurologist was blinded from the algorithm's result as he evaluated the patients.

The Neurologist we used in our study had more than 30 years of clinical experience in treating epilepsy and other Neurological disorders in addition to being a senior lecturer in the Department of Clinical Medicine and Therapeutics at the University of Nairobi.

The results of both the algorithm and the Neurologist were then compared to determine the former's diagnostic accuracy using the Neurologist's diagnosis as the "reference standard.". Our target Sensitivity plus Specificity for the algorithm was at least 1.5, as recommended in the literature for a useful test(27).

In this study, my role as the primary investigator encompassed the following activities:

- Training the primary Healthcare workers at each facility on the correct usage of the tool and supervising its administration during the study process, providing assistance where necessary.

- Assisting the Neurologist to evaluate patients after they had passed the algorithm stage and subsequently recording the Neurologist's diagnosis on a tablet computer.
- Analyzing and comparing the Algorithm's and Neurologist's results.

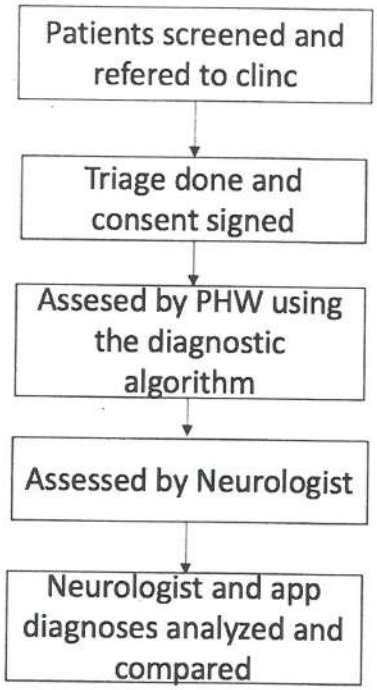

Figure 1: Process flow of the study

3.6 Data Storage and Analysis

Each Field interviewer was required to synchronize the data on their tablet daily into the main server storage located in a secure space within the field offices. The server in the field office was a staging database for quality control and data audit by the quality control team. Once data on the staging database was verified and validated, they were synchronized to the archival servers in the main office. These archival servers were stored in a secured and climate-controlled server room that had restricted access. The data manager extracted data from these archival servers and conducted another level of quality control and data audit. The

cleaned and labelled datasets were then stored on a dedicated project server in the main office where they were available for use by researchers and partners. Data was encrypted during storage and transmission. Further, different password encryption at different access levels ensured the data's security and the privacy of the primary subjects.

Data were keyed into Microsoft Excel, assessed for completeness, errors and accuracy and thereafter exported into SPSS for analysis. The sociodemographic and clinical characteristics of study participants were analyzed and presented as frequency and proportions for categorical variables or as means with standard deviations for continuous data.

The sensitivity, specificity, NPV, PPV and diagnostic accuracy of the Epilepsy diagnostic algorithm were reported after cut-offs to maximize the same had been calculated and set using Youden index(j) analysis(28).

A Receiver Operating Characteristics (ROC) Curve(29) was used to illustrate the diagnostic test's diagnostic ability. This is a plot of (1−specificity) of a test on the x-axis against its sensitivity on the y-axis for all possible cut-off points. The accuracy of the test was determined based on the closeness of the ROC curve to the top left-hand corner of the box, where sensitivity and specificity were maximized (better ability to differentiate between diseased and non-diseased). Also, an identical curve was produced by plotting the false positive rate on the x-axis against the true positive rate on the y-axis where the characteristics of the application were represented by the upper curve and characteristics of the reference standard represented on the middle curve. The area under this curve represented the overall accuracy of the test, with a value closer to 1.0 indicating high sensitivity and specificity. The dotted line on the graph represented the line of zero discrimination with an area under the curve of 0.5.

The weighted Kappa score was used to evaluate the agreement between the algorithm and neurologist scores (30).

3.7 Ethical Consideration

1. Ethical approval for the overall study was obtained from KEMRI SERU (Kenya Medical Research Institute Scientific and Ethics Review Unit). Ethical approval for this nested study was obtained from the KNH-UoN ERC (Kenyatta National Hospital-University of Nairobi Ethics and Research Committee).

2. Informed consent was obtained from the study participants and documented guardians prior to conducting the study.
3. After data collection, information obtained was used for research purposes and confidentiality was strictly maintained.

3.8 COVID-19 prevention measures

1. Masks were provided to all participants and researchers.
2. Sanitisers and handwashing stations were made available at strategic points in all the clinics.
3. Participants and researchers were questioned on whether they had flu-like symptoms and asked to stay home until these resolved.
4. Researchers and participants were adequately spaced to avoid overcrowding and the potential spread of COVID-19.

4. CHAPTER FOUR: RESULTS

4.1 Recruitment of study participants

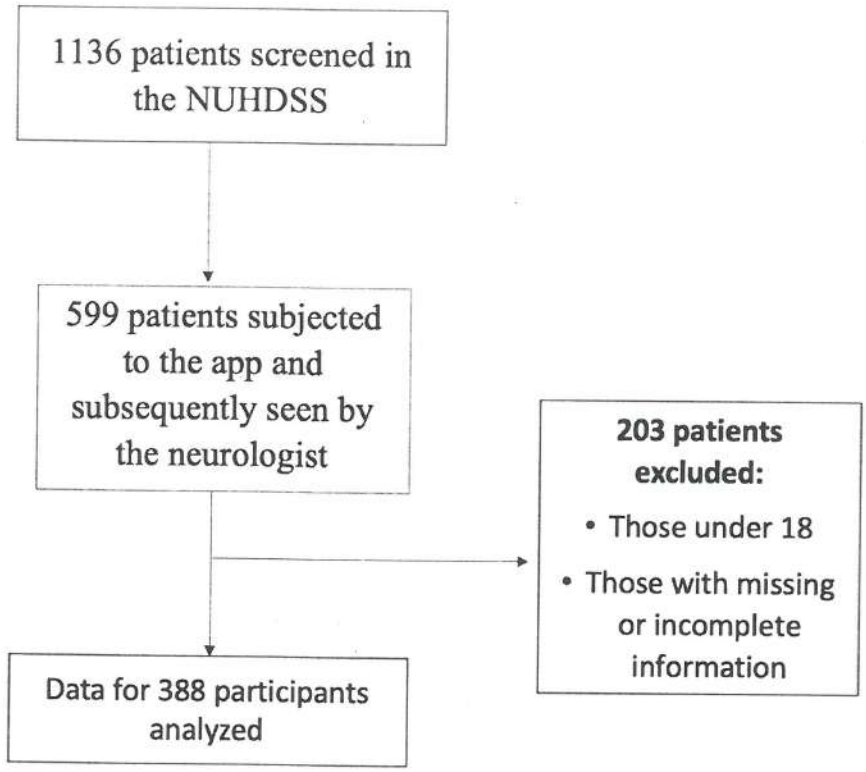

Fig 2: Recruitment of study participants

4.2 Socio-Demographic characteristics

Variable	Category	Number (n=388)	Percent (%)
Age (years)	Mean	34.1±10.7	
	Median	32	
	Range	18-71	
Gender	Male	183	47.3
	Female	205	52.8
Clinic site	Lunga Lunga	164	42.1
	Korogocho	95	24.5
	Kariobangi North	67	17.3
	Kwa Ruben	62	16.0

Table 2: Socio-demographics of study participants

A total of 388 adults, mean age of 34.1±10.7 years and a range of 18-71 years were evaluated. 56.2% (218/388) were young adults (18-34 years), 42.7% (166/388) were middle-aged (35-64 years)) and 1.0% (4/388) elderly (65+ years).

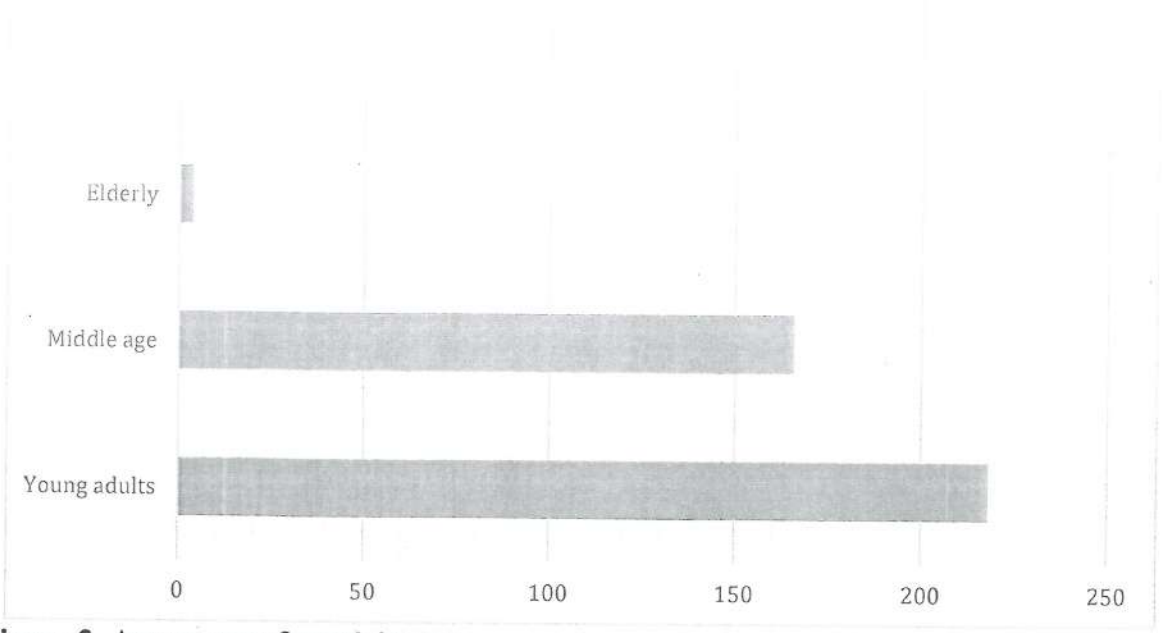

Figure 2. Age group of participants

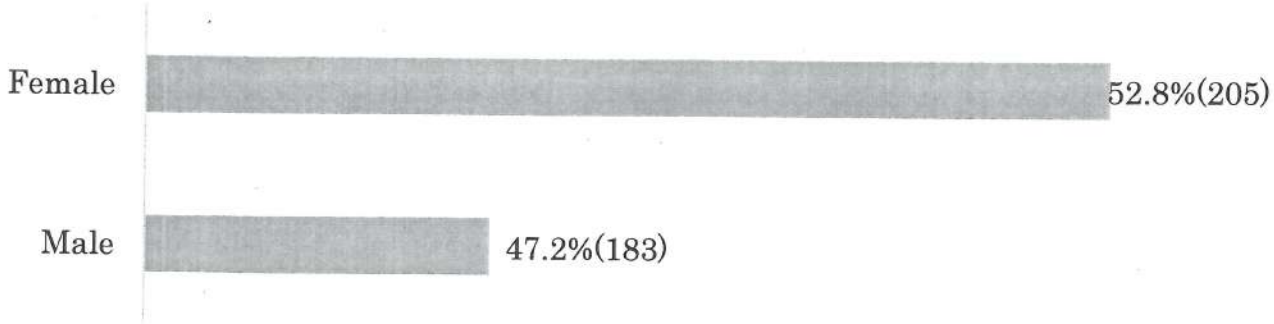

Figure 3. Sex of participants

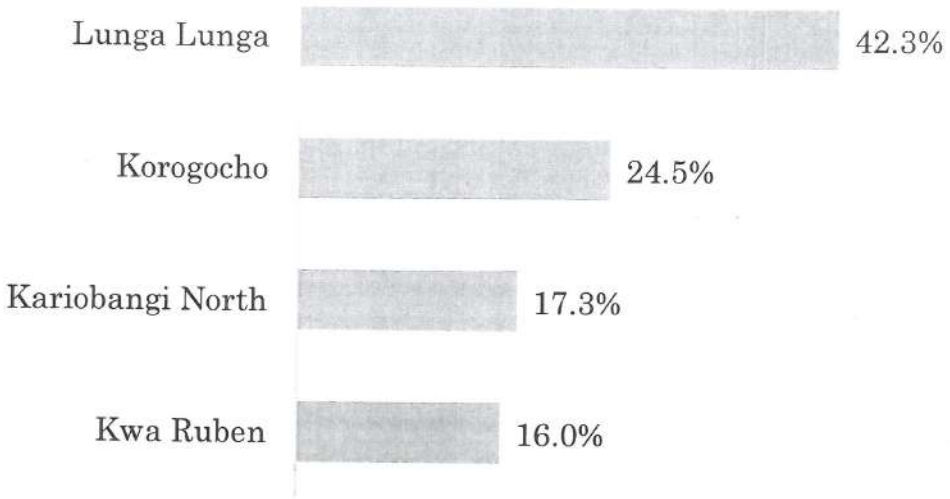

Figure 4. Clinical sites

4.3 Clinical characteristics

73.2% (284/388) of participants were epileptic. Of these, 59.5% (169/284) and 23.9% (68/284) were diagnosed with generalized and combined focal and generalized epilepsy, epilepsy type of 9.6% (27/284) was not known and 7% (20/284) had focal epilepsy. 11.1% (43/388) were suspected to be epileptic, of these, 76.7% (33/43) had an unknown or no documented epilepsy type, 14% (6/43) had generalized epilepsy and 4.7% (2/43) each had focal and combined focal and generalized epilepsy types. 15.7% (61/388) were not epileptic (Table 3).

Table 3. Diagnosis and Epilepsy type

			N (%)
Diagnosis	Confirmed		284 (73.2)
	Epilepsy type	Generalized	169 (59.5)
		Combined focal and generalized	68 (23.9)
		Unknown	27 (9.6)
		Focal	20 (7.0)
	Suspected		43 (11.1)
	Epilepsy type	Unknown	23 (53.5)
		None	10 (23.3)
		Generalized	6 (14.0)
		Combined focal and generalized	2 (4.7)
		Focal	2 (4.7)
	Not epileptic		61 (15.7)

4.4 Diagnostic accuracy

Mean probability score was 83.7±28.6%. Median score was 99.4 (77.9-100). Overall, 69.1% (268/388) scored between 91-100. 77.1% (219/284), 41.9% (18/43), and 50.8% (31/61) of participants with confirmed, suspected, and no epilepsy scored 91-100%.

Table 4. App probability scores of adults with confirmed, suspected or no epilepsy

Probability score	Total N=388	Confirmed N=284	Suspected N=43	Not epileptic N=61
0-10	18 (4.6)	7 (2.5)	6 (14.0)	5 (8.2)
11-20	20 (5.2)	7 (2.5)	4 (9.3)	9 (14.8)
21-30	9 (2.3)	2 (0.7)	4 (9.3)	3 (4.9)
31-40	3 (0.8)	1 (0.4)	2 (4.7)	0 (0.0)
41-50	1 (0.3)	1 (0.4)	0 (0.0)	0 (0.0)
51-60	17 (4.4)	11 (3.9)	2 (4.7)	4 (6.6)
61-70	13 (3.4)	11 (3.9)	1 (2.3)	1 (1.6)
71-80	20 (5.2)	16 (5.6)	1 (2.3)	3 (4.9)
81-90	19 (4.9)	9 (3.2)	5 (11.6)	5 (8.2)
91-100	268 (69.1)	219 (77.1)	18 (41.9)	31 (50.8)

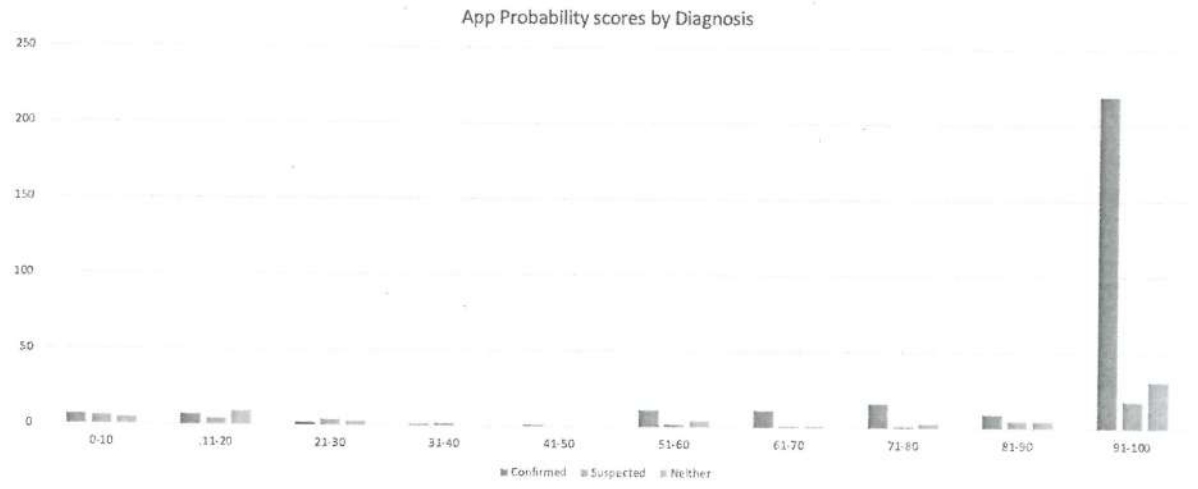

Figure 5: App probability scores by Diagnosis

Area under the curve, AUC was 0.71 (95% CI=0.65-0.77), p <0.001 (Figure 5)

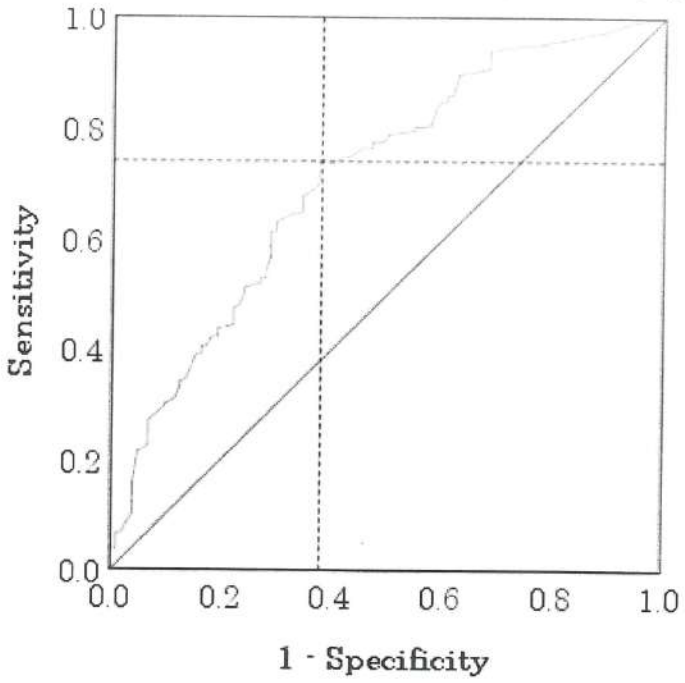

Figure 6. Diagnostic accuracy

Youden index (j) analysis was used to find the ideal cutoff for an epilepsy diagnosis. With a maximum j of 0.364, the ideal cutoff for epilepsy was 96%. Assuming a cutoff for epilepsy of 96% and no epilepsy of <30 (*Table 1*), the sensitivity and specificity at detecting epilepsy was 73.9% (95% CI=68.5-78.7%) and 60.6% (95% CI=60.0-69.4%). The positive and Negative predictive values were 83.7% (95% CI=78.6-87.7%) and. 50.0% (95% CI=37.9-54.3%) respectively.

On the other hand, the sensitivity and specificity at detecting no epilepsy was 27.9% (95% CI=18.2-40.2%) and 90.8% (87.2-93.5%). Positive and negative predictive values of 36.2% (30.0-50.5%) and 87.1% (95% CI = 83.1-90.3%) respectively.

Table 5 shows the agreement between the Neurologist and the app for the three diagnoses. The weighted kappa score indicates a "fair" level of agreement.

Table 5. Kappa agreement scores between the app and neurologists

	Diagnosis by neurologist					
Diagnosis by app	Suspected	Confirmed	No epilepsy	Agreement (%)	Kappa	p-value
Suspected	**12**	58	20	71.4	0.03	0.246
Epilepsy	17	**210**	24	70.9	**0.33**	<0.001
No epilepsy	14	16	**17**	80.9	0.21	<0.001
Overall Kappa score	-	-	-	61.6	0.21	<0.001

5 CHAPTER FIVE: DISCUSSION, CONCLUSION AND RECOMMENDATIONS

5.1 Discussion

1136 patients were screened by field workers and referred to see a Neurologist. Of these 599 arrived at the clinic and were evaluated by the diagnostic application and subsequently seen by the neurologist. Out of the 599 who arrived at the clinic, 388 of these fit our inclusion criteria of age above 18 and had complete data at the time of the analysis. It was noted that some information put into the tablets was lost, probably due to network failures and user input errors, and as such participants with missing data could not be included in the data analysis stage, this also negatively impacted the study results by significantly reducing the data that was available for analysis.

After review by the neurologist, 284 participants were found to be epileptic, 43 suspected and 61 not epileptic. Generalized and combined focal and generalized epilepsy were the most common types of epilepsy among participants. This was comparable to the study by Abigail Paul et al(8) analyzing the prevalence of epilepsy in Africa. Their study found a predominance of generalized over partial seizures with a large proportion of the partial seizures developing into generalized seizures.

In addition to the neurological assessments, epilepsy was diagnosed using an app-based system and the findings were compared with the findings of the neurologist. Scores ranged from 0-100, with most participants with confirmed and suspected epilepsy found to range between 91% and 100%, that is 219 and 18 participants respectively. Of note, a significant number of participants found to be non-epileptic by the neurologist still fell within this range: a total of 31 out of 61 participants. This is concerning as it calls into question the ability of the app to distinguish non-epileptic patients from those who are truly epileptic.

After analyzing these results, the accuracy of the application in discriminating epilepsy from suspected and non-epilepsy cases was found to be suboptimal. Sensitivity and specificity were estimated to be 73.9% and 60.6% at a cutoff score of 96, this was nowhere near what was reported in our reference study from India and Nepal(21) that had sensitivities and specificities for epilepsy of 88% and 100% respectively using a cutoff score of 90 and also below the recommended sensitivity plus specificity recommended for a useful diagnostic test(19)

The application's ability to discriminate non-epilepsy from epilepsy and suspected epilepsy cases was also similarly poor with a sensitivity of just 27.9% but a specificity of 90.8% compared to 100% and 72% for the India and Nepal study.

The weighted *kappa* score of 0.21 indicated a "fair" level of agreement between the clinician and the app(30). This is also suboptimal and indicates that there was still many diagnoses in which the two diagnostic tests (Neurologist and Algorithm) did not agree.

Presenting the algorithm in electronic form as an application on a mobile device had various advantages, for example, easier and faster data input which reduced the time that would potentially be spent on each participant, reduced need for stationary i.e., paper, pens etc., which are all single-use as opposed to the tablets that can be used for any follow-up studies. Also, the digitization of the data made it easier to upload to other platforms for analysis and to share the same between data scientists and co-investigators. All these factors led to an overall easier process of data collection and analysis.

Inversely, the fact that quite a significant amount of data was incomplete or lost highlights some of the challenges that technology can bring about in terms of record keeping. This begs the question of whether important information such as medical records should always have a hard copy backup even as we embrace new innovative ways of storing our information.

The high attrition rate observed from screening to the clinic stage could be attributable to the mobile nature of the residents in the informal settlements in which the study was carried out, though this was not expected to negatively impact our results as we still managed to attain our minimal sample size.

Our tool had suboptimal sensitivity and specificity for detecting epilepsy. Its specificity in detecting non-epilepsy cases was exceptional but sensitivity was poor although it had a fair level of agreement with clinical diagnosis when measured by the Kappa statistic.
This poor performance and discrepancy in results between our study and the reference study in India and Nepal could be attributable to the fact that this is the first study of its kind with this particular tool and that the tool used in the latter study had previously been tested in a smaller population group and refined to exclude and include questions that would increase both its sensitivity and specificity. The same needs to be done for our tool. An audit may also need to be done to assess whether the primary health workers and neurologist had any challenges in the data input phase as this was not captured in real-time during the study.

5.2 Conclusion

The need for diagnostic tools that will ease the current burden of diagnosing epilepsy on the few neurologists in Sub-Saharan Africa is clear. Even though our algorithm could revolutionize how testing for epilepsy can be fast-tracked in underserved informal settlements in countries such as Kenya, there is a need for follow-up studies to refine and improve it for safe and effective screening for epilepsy in the community.

5.2 Strengths

- This study has several strengths, including being the first of its kind in Kenya and can thus be used as a reference for any such follow-up studies.
- The study was conducted in multiple informal settlements around Nairobi and thus was able to draw in a wide variety of participants.
- The questions in the diagnostic algorithm were created after work done with local communities and thus tailored to the study population as opposed to other studies which import study tools that were created for use in very different populations from those being studied.
- The fact that the Neurologist seeing the patient was blinded from the algorithm score reduced any bias that would have occurred while making their own clinical diagnosis.

5.3 Limitations

- Being a Nested study, only a small amount of data relevant to the study topic was made available to the principal investigator by the data administrators and as such analysis of participants' characteristics for example level of education, occupation and other factors that may have given a clue to the poor performance of the application was not possible.
- The fact that very few such studies have been done provides little information in the way of comparison.

5.4 Recommendations

- Further work needs to be done to optimize the algorithm's diagnostic accuracy before it can be rolled out, this may include forming a team to assess the poor performance of the application compared to the India and Nepal studies and eventually eliminating or adding questions to increase sensitivity.
- Any follow-up study should encompass population groups with different social and clinical characteristics i.e., higher-income urban populations as well as rural populations.
- In a follow-up study, it may be beneficial if the same patient was seen by 2 or 3 neurologists at once to increase the strength of the "reference standard" diagnosis.
- Follow-up studies should also include feedback forms for primary healthcare workers to assess the ease of use of the application and for study participants to give their thoughts on the same, this feedback could be used to further improve the application.
- In a follow-up study, a real-time assessment of the results could be done to see whether the algorithm could be improved for the next batch of participants.

References

1. Ren Minghui, Devora Kestel, Samuel Wiebe Epilepsy: a public health imperative. WHO; 2019: 6

2. Bonnett LJ, Tudur Smith C, Donegan S. Treatment outcome after failure of a first antiepileptic drug. Neurology. Aug 5; 83(6)552-60.

3. NajibKissani et al. Why does Africa have the lowest number of Neurologists and how to cover the Gap? J Neurol Sci. 2022 Mar;434(120119).

4. Mariam Saleh. Share of youth owning a mobile phone in Africa between 2015 and 2018. Share of youth owning a mobile phone in Africa between 2015 and 2018. 2023.

5. Shannon Mccrocklin. Smartphone and Mobile Internet Penetration In Africa And Globally. Available from: https://www.geopoll.com/blog/smartphone-mobile-internet-penetration-africa/. Sep 30 2019

6. Brenda Kharono, Anne Kaggiah, Cyrus Mugo. Mobile technology access and use among youth in Nairobi, Kenya: implications for mobile health intervention design. Mhealth. 2022 Jan ;8:7

7. The 2014 Definition of Epilepsy: A perspective for patients and caregivers. Available from: https://www.ilae.org/guidelines/definition-and-classification/the-2014-definition-of-epilepsy-a-perspective-for-patients-and-caregivers

8. Abigail Paul, Davies Adeloye, Rhiannon George-Carey. An estimate of the prevalence of epilepsy in Sub–Saharan Africa: A systematic analysis. J Glob Health. 2012 Dec;2(2): 020405

9. Symon M Kariuki, Anthony K Ngugi, Martha Z Kombe. Prevalence and mortality of epilepsies with convulsive and non-convulsive seizures in Kilifi, Kenya. Seizure. 2021 Jul 1;89: 51-55.

10. Barbara Hansen, Magdalena Szaflarski, E Martina Bebin. Affiliate stigma and caregiver burden in intractable epilepsy. Epilepsy Behav. 2018 Aug;85:1-6.

11. K G Hampel, M Garces-Sanchez, A Gomez-Ibanez. Diagnostic challenges in epilepsy. Rev Neurol. 2019 Mar 16;68(6):255-263.

12. F Boesebeck, S Freermann, C Kellinghaus. Misdiagnosis of epileptic and non-epileptic seizures in a neurological intensive care unit. Acta Neurol Scand. 2010 Sep; 122(3): 189-95

13. Rita Nguyen1 and José F. Téllez Zenteno. Injuries in epilepsy: a review of its prevalence, risk factors, type of injuries and prevention. Neurol Int. 2009 Nov 16;1(1):e20.

14. Ayomide Owoyemi. Joshua Owoyemi. Adenekan Osiyemi. Artificial Intelligence for Healthcare in Africa. Front Digit Health. 2020 Jul;2(6):1–5.

15. Stuart R, Norvig P, Davis E. Artificial Intelligence: A Modern Approach. 3rd ed. 2010. 1(1);1-5

16. Daniel Greenfield, Sean Wilson. Artificial Intelligence in Medicine: Applications, implications, and limitations. Science in the news. June 2019.

17. Mark R. Keezer, Amelie Pelletier, Barbara Stechysin. The diagnostic test accuracy of a screening questionnaire and algorithm in the identification of adults with epilepsy. Epilepsia. 2014 Nov;55(11):1763–71.

18. E Wayne Holden, Elizabeth Grossman, Hoang Thanh Nguyen. Developing a Computer Algorithm to Identify Epilepsy Cases in Managed Care Organizations. 2005 Feb;8(1):1–14.

19. Lara Jehi. Algorithms in clinical epilepsy practice: Can they really help us predict epilepsy outcomes? Epilepsia. 2021 Mar;62(Suppl 2):71–7.

20. The data protection act. Sect. VI Nov 25, 2019 p. 48–50.

21. Victor Patterson, Mamta Singh, Hemav Rajbhandari. Validation of a phone app for epilepsy diagnosis in India and Nepal. Seizure. 2015 Aug;30:46–9.

22. Neligan A, Gail S Bell, Anthony L Johnson. The long-term risk of premature mortality in people with epilepsy. Brain. 2011 Feb;134(2):388–95.

23. Adam Ahmat, Sunny C Okoroafor, Isabel Kazanga. The health workforce status in the WHO African Region: findings of a cross- sectional study. BMJ Glob Health. 2022; 7(1)

24. Donatien Beguy, Patricia E, Blessing Mberu. Health & Demographic Surveillance System Profile: The Nairobi Urban Health and Demographic Surveillance System (NUHDSS). Int J Epidemiol. 2015 Apr;44(2):462-71

25. M Placencia, S M Cascante, J W Sander . Validation of a screening questionnaire for the detection of epileptic seizures in epidemiological studies. Brain 1992 Jun;115(Pt 3) :783-94.

26. N MBuderer. Statistical Methodology: I. Incorporating the Prevalence of Disease into the Sample Size Calculation for Sensitivity and Specificity. Am Emerg Med. 1996;3(9):895–900.

27. Michael power, Greg Fell, Michael right. Principles for high-quality, high -value testing. Evid Based Med. 2013 Feb;18(1)5-10.

28. Ronen Fluss, David Faraggi, Benjamin Reiser. . Estimation of the Youden Index and its associated cutoff point. Biom J.2005 Aug;47(4):458–72.

29. Francis Sahngun Nahm. Receiver operating characteristic curve: overview and practical use for clinicians. Korean J Anaesrhesiol. 2022 Feb;75(1):25–36.

30. Mary L McHugh. Interrater reliability: the kappa statistic. Biochem Med. 22(3):276–82.

Appendices

Appendix A: The role of each participating investigator

Appendix B: Participants Information sheet

Appendix C: Karatasi Ya Habari Ya Washiriki

Appendix D: Consent to participate in a research study

Appendix E: Fomu Ya Idhini

Appendix F: Questionnaire for the diagnostic app

Appendix A: The role of each participating investigator.

Principal Investigator: **DR QUINCY MONG'ARE;**

Department of Clinical Medicine and Therapeutics
University of Nairobi
Mobile; 0720630735

Supervisors:

DR KWASA THOMAS O O
MBChB, M. Med, C. T. M.
thomas.kwasa@uonbi.ac.ke
Consultant Physician and Neurologist
Department of Clinical Medicine & Therapeutics
University of Nairobi

PROF KAYIMA JOSHUA K.
MBChB (Makerere), M.Med (UoN), Neph Fellow (Edin), FRCP
joshua.kayima@uonbi.ac.ke
Consultant Physician and nephrologist
Department of Clinical Medicine & Therapeutics
University of Nairobi

Appendix B: Participants' Information and Consent Form

Title of Study: DETERMINATION OF THE ACCURACY OF A COMPUTERISED ALGORITHM TO DIAGNOSE EPILEPSY IN A LOW-INCOME URBAN POPULATION IN KENYA

Researcher's statement:

I would like to tell you about a study being conducted by researchers from the African Population and Health Research Centre (APHRC), University of Nairobi and University of Oxford in the United Kingdom

.

Research studies include only people who choose to take part. The purpose of this consent form is to give you the information you will need to help you decide whether to be in the study or not. You may ask any questions you have about the purpose of the research, including what happens if you participate in the research, the possible risks and benefits, your rights as a volunteer, and anything else about the research or this form that is not clear. When we have answered all your questions, you can decide if you want to be in the study or not. This process is called 'informed consent.' We will give you a copy of this form to keep.

You are being asked to take part in this study because you are:

- An adult aged 18 years and above
- A resident of the Nairobi Urban Demographic Surveillance System (NUHDSS) site
- The head of the household **OR** the household head spouse **OR** an adult household member

What is this study about?

The researchers listed at the top of this form are conducting the study. They would like to determine the prevalence and diagnostic gap for epilepsy and explore how sociocultural beliefs and stigma can be addressed to improve lives of the people living with epilepsy in this community. To do this, the head of this household or an adult representative will be interviewed using a standardized epilepsy questionnaire.

The purpose of this study is to determine the proportion of people living with epilepsy in this community. We will also assess the diagnostic gap and the feasibility of health workers using an app-based technology for improving the rate of accurate diagnosis of epilepsy and further explore the sociocultural beliefs, stigma and how these influence diagnosis and treatment of people living with epilepsy

How many people will take part in this study?

All residents of the NUHDSS will be asked to take part in this study.

What will happen if you decide to take part in this study?

.

Being part of this study involves participating in a survey that will take approximately 30 minutes. This survey has two stages. First, we will ask you some questions about yourself and members of your household regarding any previous history of a convulsion and in case you or any member of your household has any previous history of a convulsion, you will be requested to proceed to fill an epilepsy screening questionnaire. If you or any member of your household screen positive for epilepsy, you will be requested to proceed to the second stage where you or the household member will be referred for further screening and diagnosis by neurologist and a physician in the primary care facility participating in this study.

This survey will be an informal interaction, and we will request that you freely talk about anything you think is important for us to know related to this study. The surveys will be anonymous, meaning that the study staff member will not record your name or any personal information that can identify you.

How long will I be in the study?

The time duration for data collection in this community is approximately 4 months. However, the entire study will last up to one year.

Can I stop being in the study?

Yes. You can decide to stop at any time. Tell a study staff member if you wish to stop being in the study. Also, the study staff members may stop you from taking part in this study at any time if he or she believes it is in your best interest, if you do not follow the study rules, or if the study is stopped.

Will any parts of this study hurt or have other risks?

- Potential loss of privacy or confidentiality: One potential risk of being in the study is loss of privacy. We will do our best to make sure that the personal information gathered for this study is kept private. Since this consent form has your name on it, we will store it in a locked cabinet. Your name will not be connected to the other information you give us in the surveys or workshops. When this study is over, your identifying information will not be in any data, reports, or publications that result from the study.
- Risk of discomfort: Some of the questions in the surveys may make you uncomfortable or upset. You are free to refuse to answer any questions you do not wish to answer, or stop the survey at any time without affecting your participation in the study.
- For more information about risks and side effects, please ask one of the researchers.

Are there benefits to taking part in this study?

There will be no direct benefit to you, but your participation is likely to help us identify gaps in the diagnosis and management of epilepsy. If you or any member of your household screen positive for epilepsy, we will refer you or the household member to one of the facilities participating in this study for further clinical assessment and you or your household member will be assisted with transport reimbursement of Ksh 500 for this visit. Our research staff has been trained on how to handle or refer participants with unmet needs or psychosocial challenges. They will offer this support on the telephone or by visiting the participants at home.

What are the costs of taking part in this study?

You will not need to pay anything for any of the study activities.

Will I be paid for taking part in this study?

There will be no payment for study participation. Participants who screen positive will be assisted with transport to visit the referral facilities.

What are my choices?

Taking part in this study is your choice. If you choose to be in this study, you can leave the study at any time. If you decide not to take part in this study, there will be no penalties.

Who can answer my questions about the study?

You can talk to the study staff members about any questions, concerns, or complaints you have about this study. You can contact the study staff at Tel. 0728 086 584. You may also contact the Secretary of the Scientific and Ethics Review Unit at the Kenya Medical Research Institute at 020-2722541, 0722205901, 0717719477; Email address. This committee is concerned with the protection of volunteers in research projects.

Appendix C: Karatasi ya Habari ya Washiriki

Kauli ya mtafiti:

Ningependa kukuambia kuhusu utafiti unaofanywa na watafiti kutoka Kituo cha Utafiti wa Idadi ya Watu na Afya cha Afrika (APHRC), Chuo Kikuu cha Nairobi na Chuo Kikuu cha Oxford nchini Uingereza

.

Masomo ya utafiti yanajumuisha watu tu wanaochagua kushiriki. Lengo la fomu hii ya ridhaa ni kukupa maelezo ambayo utahitaji kukusaidia kuamua ikiwa uwe katika utafiti au la. Unaweza kuuliza maswali yoyote uliyo nayo kuhusu madhumuni ya utafiti, ikiwa ni pamoja na kile kinachotokea ikiwa unashiriki katika utafiti, hatari na faida zinazowezekana, haki zako kama kujitolea, na kitu kingine chochote kuhusu utafiti au fomu hii ambayo haiko wazi. Tunapokuwa tumejibu maswali yako yote, unaweza kuamua ikiwa unataka kuwa katika utafiti au la. Utaratibu huu unaitwa 'informed consent.' Tutakupa nakala ya fomu hii ili uendelee.

Unaombwa kushiriki katika utafiti huu kwa sababu wewe ni:
Mtu mzima mwenye umri wa miaka 18 na zaidi
Mkazi wa eneo la Nairobi Urban Demographic Surveillance System (NUHDSS)
Mkuu wa kaya AU mke mkuu wa kaya AU mwanakaya mtu mzima

Utafiti huu unahusu nini?

Watafiti walioorodheshwa juu ya fomu hii wanafanya utafiti. Wangependa kubaini pengo la maambukizi na uchunguzi wa kifafa na kuchunguza jinsi imani za kijamii na unyanyapaa zinavyoweza kushughulikiwa ili kuboresha maisha ya watu wanaoishi na kifafa katika jamii hii. Ili kufanya hivyo, mkuu wa kaya hii au mwakilishi wa watu wazima atahojiwa kwa kutumia dodoso la kifafa sanifu.

Lengo la utafiti huu ni kubaini uwiano wa watu wanaoishi na kifafa katika jamii hii. Tutatathmini pia pengo la uchunguzi na uwezekano wa wahudumu wa afya kutumia teknolojia ya msingi ya programu kwa ajili ya kuboresha kiwango cha utambuzi sahihi wa kifafa na kuchunguza zaidi imani za kijamii, unyanyapaa na jinsi hizi zinavyoathiri utambuzi na matibabu ya watu wanaoishi na kifafa

Ni watu wangapi watashiriki katika utafiti huu?

Wakazi wote wa NUHDSS watatakiwa kushiriki katika utafiti huu.

Nini kitatokea ikiwa utashiriki katika utafiti huu?

.

Kuwa sehemu ya utafiti huu inahusisha kushiriki katika utafiti ambao utachukua takriban dakika 30. Utafiti huu una hatua mbili. Kwanza, tutakuuliza maswali kadhaa kuhusu wewe mwenyewe na wajumbe wa kaya yako kuhusu historia yoyote ya awali ya mvutano na ikiwa wewe au mtu yeyote wa kaya yako ana historia yoyote ya awali ya kuchanganyikiwa, utaombwa kuendelea kujaza dodoso la uchunguzi wa kifafa. Ikiwa wewe au mwanachama yeyote wa skrini yako ya kaya chanya kwa kifafa, utaombwa kuendelea hadi hatua ya pili ambapo wewe au mwanachama wa kaya atapewa rufaa ya uchunguzi zaidi na utambuzi na daktari wa neva na daktari katika kituo cha huduma ya msingi kinachoshiriki katika utafiti huu. Utafiti huu utakuwa mwingiliano usio rasmi, na tutakuomba uzungumze kwa uhuru juu ya chochote unachofikiria ni muhimu

Appendix D: Consent to Participate in the Study

I have read and understood the information in the consent form, and it has been explained to me. My questions and concerns have been addressed. I am also aware that participation is voluntary, and I can withdraw from the study at any time without consequences. I have agreed to participate in the study.

Name of participant/guardian _____ Date_____

Signature of Participant/Guardian_____

I confirm that I have explained the details of the research to the participant.

Researcher's Name _____

Date _____

Signature of Researcher_____

Appendix E: Fomu Ya Idhini

Nimeelezwa asili ya utafiti huu na kuakikishiwa kwamba kushiriki kwangu ni kwa hiari na kwamba hakutakua na athari mbaya kwa afya yangu.

Sahihi/alama ya kidole: .....

Tarehe: .....

Kauli ya Mtafiti

Nimeeleza madhumuni na maana ya utafiti kwa mshiriki.

Sahihi: .....

Tarehe: .....

Appendix F: Questionnaire for the diagnostic app

Questions	Possible Answers	
1. Do you have seizures or has anyone ever told you that you have fits? (Je, una kufitika au kuna mtu yeyote amewahi kukuambia kuma una kifafa?)	Yes (Ndio)	No (Hapana)
2. Do you experience episodes in which your legs or arms have jerking movements, or do you fall to the ground and lose consciousness? (je unapata matukio ambayo miguu au mikono yako inatetemeka au unaanguka na kupoteza fahamu?)		

3. During the episodes mentioned in question 2, have you ever bitten your tongue? (Katika haya matukio ya swali la pili, ushawahi kujiuma ulimi?)		
4. Have you ever wet yourself during the episodes mentioned in question 2? (Ushawahi kujikojolea katika haya matukio ya swali la pili?)		
5. During the episodes mentioned in question 2, do you lose contact with your surroundings? (Je! wakati wa matukio haya ya swali la pili unapoteza fahamu na mazingira yako?)		

6. Has anyone told you that you appear dazed during the episodes mentioned in question 2? (La mtu yeyote aliyekuambia kuwa unaonekana umeduwaa wakati wa matukio haya ya swali la pili?)		
7. During the episodes mentioned inquestion 2, does your body stiffen? (Je, mwill wako unakauka wakati wa matukio haya ya swali la pili?)		
8. Do you frequently not remember the episodes mentioned		

in question 2 or do you ever find yourself in a place or position and you do not know how you got there? (Je, hukumbuki matukio haya ya swali la pili mara kwa mara au umewahi kujikuta katika mahali au nafasi na hujui umefikaje hapo?)		
9. Have you been told that your arms, legs or body twitch or jerk during the episodes mentioned in question 2? 10. (Je ushawahi ambiwa kwamba mikono, miguu au mwili wako hutetemeka wakati wa matukio haya ya swali la pili?)		
11. Do you experience stomachache before		

or after the episodes mentioned in question 2? (Je, unapata maumivu ya tumbo kabla au badala ya matukio haya ya swali la pili?)		
12. Do you see odd things ii.e. flashes or bright lights before the episodes mentioned in question 2 occur? (Je unaona mambo yasiyo ya kawaida kabla ya vipindi hivi vya swali la pili kutokea?)		
13. Do you experience odd smells before the episodes mentioned in question 2 ? (Je, unapata harufu isiyo ya kawaida kabla ya matukio ya swali ya pili)		
14. Do you think anything brings on		

the episodes mentioned in question 2 ? (Je, unadhani kuna lolote linalochangia matukio haya ya swali la pili?) 15. Has anyone ever told you that you say things that don't make sense before, during or after the episodes mentioned in question 2 ? (je, kuna mtu yeyote amewahi kukuambia unasema mambo ambayo hayana maana kabla, wakati au baada ya matukio haya?)		
16. Do your arms, legs or face shake or tremble during the episodes mentioned in question 2?		

(Je, mikono, miguu au uso wako unatetemeka wakati wa matukio haya ya swali la pili?)		
17. Are you currently taking any non-traditional) medications? (Je, kwa sasa unatumia dawa zozote (zisizo za kitamaduni)?		

Determination of The Accuracy of A Computerized Algorithm To Diagnose Epilepsy In A Low-Income Urban Population In Kenya

ORIGINALITY REPORT

6%	6%	3%	3%
SIMILARITY INDEX	INTERNET SOURCES	PUBLICATIONS	STUDENT PAPERS

PRIMARY SOURCES

1	core.ac.uk Internet Source	1%
2	www.science.gov Internet Source	1%
3	www.researchgate.net Internet Source	1%
4	careersdocbox.com Internet Source	<1%
5	www.afro.who.int Internet Source	<1%
6	www.medrxiv.org Internet Source	<1%
7	Submitted to North Idaho College Student Paper	<1%
8	static.cigna.com Internet Source	<1%

Lead Supervisor and Chairman of the department approval:

Lead Supervisor:

DR. KWASA THOMAS O. O.

Consultant Physician and Neurologist

Department of Clinical Medicine & Therapeutics

University of Nairobi

Signed..... Date 24/11/2023

Chairman of the Department:

PROF. E. O. AMAYO

Chairman of the Department of Clinical Medicine and Therapeutics

Consultant Physician and Neurologist

University of Nairobi

UNIVERSITY OF NAIROBI
COLLEGE OF HEALTH SCIENCES
P.O. Box

Signed..... Date 27/11/23