1. 1TITLE OF THE PROJECT

Parkinson's Disease Diagnosis, Perceptions, Awareness, and Care in Kenya

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3. ABSTRACT

Parkinson's disease (PD) is one of the major neurodegenerative conditions in sub-Saharan Africa (SSA), particularly among aging adults. However, little is known about the epidemiology, service availability, and population-level awareness of PD due to the weak capacity of the primary health care system and PD-related poor knowledge in the SSA setting. There is an apparent lack of data on PD in SSA, including Kenya. This study aims to 1) validate tools for screening, estimate the prevalence of PD at the population level, and assess the knowledge and attitudes of influential community advisors; 2) assess the healthcare service availability and readiness to manage PD, and 3) estimate patient caseloads in neurology clinics and identify barriers and facilitators to diagnosis and referral along the care cascade. The Work package (WP) will employ a concurrent mixed-methods approach, including household surveys to be conducted within Nairobi Urban Health and Demographic Surveillance System (NUHDSS) and Siaya HDSS each recruiting 1500 older people 60+ years. We will conduct in-depth interviews (n=40) with community health advisors, including traditional healers, community health volunteers, and medicine sellers. WP2 will assess service availability and readiness in three tertiary hospitals, one each from Nairobi and Siaya, and a sample of primary care facilities in Kisumu (n=50) using a systems assessment tool customized for PD. WP3 will estimate patient caseloads in 3 neurology clinics of the selected tertiary hospitals in WP2 and conduct in-depth interviews with PD patient-caregiver dyads (n=45). Focus group discussions (n=3) with patient support groups and caregivers will be conducted. The findings are expected to inform and support community education programs, the development of care models, capacity-building programs for healthcare workers, and policy decisions for improving PD care in SSA.

4. LAY SUMMARY

Parkinson's disease (PD) is one of the serious chronic conditions affecting many other people across the world. Advanced countries have better health systems to support people with PD. Still, the knowledge of PD at both community and health system levels is very poor in sub-Saharan Africa (SSA), including Kenya. Although PD affects many older adults in Kenya and SSA, people with PD are seen as having witchcraft, isolated, and stigmatized due to limited understanding and poor diagnosis of the condition. People with PD, therefore, do not receive the needed care and medical treatment in the community and health system. In this study, we will first screen 1,500 older adults (60+ years) each from Nairobi and Siaya from selected households to estimate the prevalence of PD. In addition, we will interview 40 influential community actors such as traditional healers, religious leaders, community health volunteers, and medicine sellers to assess the knowledge and attitude of some community actors about PD. We will interview personnel in 3 tertiary health facilities in Nairobi and Siaya to understand how the healthcare services are available and ready to manage PD. Finally, we will estimate patient caseloads in 3 neurology clinics in the tertiary hospitals, interview 45 caregivers of people with PD, and conduct three (3) focus group discussions with patient support groups and caregivers in Kenya. We believe that this study will improve the understanding of PD and provide important answers for the community members, healthcare practitioners, community-based educational programs, and policy actions/decisions for PD care in Kenya and SSA.

5. INTRODUCTION AND BACKGROUND

Demographic transition is dramatically occurring and more people in sub-Saharan Africa (SSA) are currently surviving to an older age. Population aging is considered a global public health success but also brings about new health challenges in a form of chronic diseases, including cardiovascular diseases, dementia, cancers, neurodegenerative disorders, and premature mortality, particularly in SSA. Parkinson's disease (PD) has been identified as a serious neurodegenerative disorder but the PD-related knowledge in SSA and elsewhere remains limited

(Kowal et al., 2013; Mokaya et al., 2017). There is limited access to diagnosis, treatment, and multidisciplinary care, and a poor survival rate of people with PD in SSA; a likely reason for the lower prevalence. Although studies are limited, the cumulative population-based incidence of PD in SSA may be greater than those observed in Western countries. Research has shown that up to 50% of people with PD are not diagnosed and untreated (Blanckenberg et al., 2013) resulting in increased morbidity and impaired quality of life (Dotchin & Walker, 2012). Many healthcare workers and community members in SSA lack adequate knowledge and awareness of PD (Mshana et al., 2011). Even after the diagnosis of PD, there is a huge challenge regarding the availability, affordability, and sustainability of medication and care (Bhat et al., 2015; Lepule et al., 2019).

Studies suggest that advanced PD is not curable and the current treatment modalities alleviate symptomatic effects by slowing/delaying disease progression (Bhat et al., 2015). The symptomatic treatment primarily focuses on dopamine-replacement therapy which may offer symptomatic relief for patients (Lees et al., 2009; Kakkar & Dahiya, 2015; Yadav & Li, 2015). Pramipexole has been identified as an effective adjunctive antiparkinsonian therapy for PD in SSA (Parkinson's Study Group, 2007). Deep brain stimulation (DBS), a form of stereotactic surgery is an adjunct option for the treatment of PD and to overcome the limitations imposed on long-term levodopa therapy (Kakkar & Dahiya, 2015). However, DBS may increase the risk of infection and prohibitive costs of procedure and device maintenance (Picillo et al., 2016). Ethnomedicines such as *Boophone disticha* have been used to treat neurological disorders (Lepule et al., 2019), but these plants have not been assessed *in vitro* for cytoprotective activity (Amoateng et al., 2018; Lepule et al., 2019; Yadav & Li, 2015). Effective management and state-of-the-art treatment of PD can help ensure as high a quality of life as possible as the disease progresses (Mokaya et al., 2017). However, there are considerable gaps in PD care due to socioeconomic status and system bottlenecks (Naik & LaFaver, 2018). Importantly, many PD therapeutic modalities are either unavailable or expensive (Amoateng et al., 2018), and this unmet need for PD management is evident in SSA. A qualitative interview with 28 PD patients in Tanzania found that only two respondents had commenced western type treatment through outsourcing drugs from other parts of the country (Mshana et al., 2011).

The majority of PD patients and their families either associate PD with the normal aging process or ascribe spiritual connotations such as curses or witchcraft and in most cases turn to traditional medicine and faith healers for help (Thune-Boyle et al., 2006). Spirituality and religious faith remain an important resource for those for whom it has relevance, in coping with chronic illness, providing emotional comfort, helping to maintain self-esteem, and better tolerance of pain and other symptoms (Dezutter et al., 2011; Redfern & Coles, 2015). Studies on the role of traditional medicine and healers in shaping beliefs about PD are limited in SSA. Proper diagnosis toward improving treatment and care for people with PD may require an understanding of how PD is perceived and conceptualized within communities. Knowledge and perceptions (beliefs and attitudes) are crucial for the psychological outcomes in people with PD (Moore & Simon, 2006; Simpson et al., 2013).

6. JUSTIFICATION FOR THE PROJECT

Our studies among older people in Kenya have shown that they are grossly underrepresented in research, yet they bear a disproportionate burden of chronic diseases that affect their quality of life. A study led by the African Population and Health Research Center in Nairobi urban informal settlements revealed that 13% of adults aged 60 years and older had functional limitations impairing their ability to carry out activities of daily living such as feeding, toileting, bathing, dressing, walking, and transfer oneself (Gyasi et al., 2022). A bulk of these limitations may be attributed to chronic diseases, including PD, which is often undiagnosed and not timely managed. Little is known about the epidemiology and care available for people with PD in many SSA countries (Okubadejo, 2006). The lower prevalence of PD reported in SSA is partly attributed to a lack of awareness and underreporting of the disease symptoms, stigma, and high mortality rates (Kaddumukasa, 2015; Walker, 2014). Harries (1973) reported that PD made a significant contribution to chronic disabling neurological diseases in Kenya. Symptoms of PD are often

confused with general expectations of aging and, therefore, not reported. A systematic review on PD in SSA identified several methodological gaps with most prevalence studies using a WHO screening protocol that is not specific for PD diagnosis. There are, thus, large gaps in data on the prevalence of PD in low- and middle-income countries (LMICs). The prevalence of PD among older people in Africa is undercounted, giving a false impression that PD risk is lower. The gaps in knowledge on prevalence and burden are also mirrored in gaps in availability and use of services and low public awareness of the disease. There are likely to be many patients in SSA with undiagnosed and untreated PD.

The lack of quality and timely primary data significantly inhibits the global community's ability to appropriately target efforts, engage country governments, and increase global attention and funding for PD. There is limited data on the hospital caseload and characteristics of patients with PD attending outpatient clinics managed by neurology specialists in Kenya (Amod, 2019; Bower, 2005; Okubadejo, 2010). Differences in individuals' health-seeking behavior and perception of PD in Africa have contributed to the under-reporting of cases. Patients with neurological diseases such as PD are often stigmatized and may not present timely for services. Traditional healers tend to be the first point of contact before seeking professional medical help, thus leading to delays in accessing professional services. Most African countries do not have stand-alone policies for PD but rather hidden under many geriatric conditions with no specific actions defined. Health system strengthening interventions are thus required to enable improved care for PD. Understanding how service delivery for PD happens across different levels of care will help identify systems needs and priorities for interventions. The majority of patients with PD do not always access comprehensive care (van Halteren, 2020), largely due to underdeveloped and inappropriate care delivery approaches (Schuller, 2017). A recent systematic review and meta-analysis (Rajan et al., 2020) have shown that there is limited data on integrated care for PD.

We have ongoing studies funded by the Hewlett Foundation, investigating the long-term social care needs of older people in Kenya, within which we plan to nest population-based studies for PD and assess the health system barriers and facilitators for the care of people with PD. The findings of this study will provide knowledge of prevalence, diagnosis, practices, public health, and policy relevance in PD management to improve the quality of life of people with PD and their families in SSA.

7. GOALS AND OBJECTIVES

7.1. Aim

The study aims to determine the prevalence, diagnosis, and population-level perception/awareness about PD in SSA to improve the care and treatment gaps in Kenya.

7.2. Specific objectives

1. To determine the prevalence of PD at the population level in Kenya.
2. To explore the knowledge/attitudes of traditional healers, medicine sellers, religious leaders, and community health volunteers regarding PD management in Kenya.
3. To assess the healthcare service availability and readiness to manage PD in Kenya.
4. To estimate patient PD caseloads in neurology clinics and identify barriers and facilitators to diagnosis and referral along the care cascade.

8. DESIGN AND METHODOLOGY

8.1. Study site (geographical)

This study has three work packages (WPs), which will be implemented in different geographical areas: WP1 entails tool validation for screening people with PD and estimation of the prevalence of PD at the population level, assessing knowledge and attitudes of influential community advisors (covering objectives 1 and 2). This WP will be implemented in two sites: 1- Nairobi Urban Demographic Surveillance System (HDSS) in Korogocho and Viwandani to represent an

urban informal setting, a pioneer HDSS which was established by APHRC since 2002 (Wamukoya et al.,2020). 2- Siaya HDSS to represent a rural setting, established by KEMRI/CDC. Both sites will over a sampling framework to select 1500 older people aged 60+ years from each site. WP2 will be an assessment of the healthcare service availability and readiness to manage PD in Kenya will be conducted in three tertiary hospitals in Nairobi, Kisumu, and Mombasa and in 50 primary healthcare facilities in Kisumu. WP3 which entails estimation of patient caseloads in neurology clinics and barriers and facilitators to diagnosis and referral of PD will be implemented in the three neurology clinics in Nairobi, Kisumu. A separate protocol is under review and will be annexed to this protocol once approved.

8.2. Study design

This study will employ a concurrent mixed-methods approach in which our qualitative and quantitative strands of the study will be conducted concurrently. This approach will be employed in the interest of time, particularly when we are not interested in either an explanatory or exploratory sequential approach. Kenya was purposively selected for this study because APHRC is implementing national-level studies among older people from other funding sources. The current study will be nested into the APHRC's ongoing Hewlett project and will leverage the resources such as personnel of the existing survey.

8.3. Sampling (*Sample size determination and sampling procedures)*

Specific sampling designs and procedures are proposed under different strands of the study. We describe the detailed design, methods, sample size estimation, and sampling for each study aim structured under specific work packages (WPs) below.

8.4. Procedures

Preparation for the study

Fieldworkers who are already conducting regular demographic surveillance surveys among older adults in Kenya and those with medical and health-related backgrounds such as nurses will be trained to conduct the population-level screening for PD. The field teams will consist of one field supervisor, three team leaders, and field interviewers (FIs). Protocol training will be organized to ensure the quality control of the study. The focus will be on ensuring a good understanding of the study design, data collection procedure, and instruments. During these training exercises, all project staff will be provided with the latest version of the interviewer manual. The practical phase of training will involve role-playing in which field interviewers practice interview sessions with each other as expert respondents.

Main study

This study will have three work packages (WPs), including 1) tool validation for screening people with PD and estimation of the prevalence of PD at the population level, assess knowledge and attitudes of influential community advisors; 2) assessment of the healthcare service availability and readiness to manage PD in Kenya; and 3) Estimation of patient caseloads in neurology clinics and barriers and facilitators to diagnosis and referral of PD in Kenya.

Work Package (WP) 1: Prevalence of PD

WP 1 will be a population-level survey which is the first stage of a two-stage process to identify participants with PD in Kenya. A cross-sectional survey representative of ethnolinguistic regions in Kenya will be conducted among older people. WP 1 will consist of four key components outlined as follows:

WP1.1: Clinical validation of screening tool for PD:

Our starting point will be validating the PD screening questionnaire (PDSQ), which was recently validated in South Africa but for various dialects of Zulu (Nelson, 2020). The PDSQ is a 6-Item Screening Questionnaire for PD (Fereshtehnejad, 2014). This tool will be translated into Swahili. We will undertake a clinical calibration of PDSQ to provide essential information on the accuracy of this tool in diagnosing PD in Kenya. The purpose of this exercise is not to decide whether or not to use the PDSQ in the survey or to change and revise it prior to the main survey. Rather, the purpose is to contextualize it, help interpret the survey findings, and provide important information for future surveys. The screening of the participants will take place in their own households by the study team that will be deployed to the selected study communities using a screening tool/questionnaire of six items.

Sampling and data: A sample comprising 200 older people (with an approximately equal number of females and males) aged 60+ years, broken down into PD Cases (n = 100 people with PD) recruited from neurology clinics with known diagnosis of PD in hospitals and Healthy Controls (n = 100 older people recruited from adult clinics with no history of PD). In the validation process, first, all 200 participants (PD cases and Health Controls) will be interviewed by the lay interviewer who will administer the PDSQ. The interviewers will be blinded from the diagnosis.

WP1.2: Estimate the national prevalence of PD

Work under WP1.2 will be the main component of WP1. A cross-sectional and representative survey of older people in Kenya will be conducted. In this phase, we will estimate the prevalence of PD among older people in Kenya.

Pilot study: After the validation, prior to the main survey, a pilot study will be conducted among 50 older people to check the performance of the survey instruments, including the length of the interviews, and the understanding of the different questions by the respondents. Specifically, the pilot will aim to 1) test and familiarize the design of the instruments 2) evaluate the feasibility of the study in urban settings 3) affirm the validity and reliability of the instruments, and 4) familiarize the data collection staff with the questionnaires and procedures. Each fieldworker or research assistant will conduct pilot interviews in one purposively selected household in the study areas. Data generated from the pilot will be used to improve the instruments and processes for the main study.

Methods and sampling: Based on studies on the prevalence of PD among older people in sub-Saharan Africa, estimated at 285/100,000 over 2 years, which translates into a prevalence of ~1% (Okubadejo et al. 2006). For cross-sectional surveys to estimate anticipated population prevalence/proportion p with a specified absolute precision d, the sample size is computed using the Cochrane formula (Cochrane, 1977) Table 1 presents the minimum sample total sizes required at each site to estimate expected population proportion at a level of significance of 5%, for the different levels of absolute precision assuming a non-response rate of 10% and design effect of 1.5. A sample size of 1500 will enable us to determine this prevalence with a precision of ±1 %. Assuming equal groups of men and women, the sample size of 1500 allows us to detect a difference of 3% between groups with 90% power.

Table 1: Sample size scenarios for the survey of PD in Kenya

Precision (d)	Expected population proportion (p)				
	1%	1.5%	2.%	3%	4%
1%	634	945	1255	1864	2458
2%	159	237	314	466	615

Sampling In each of the selected HDSS site (HDSS sites) will be randomly selected 1500 older people. A list of all households with older people (age 60+ years) will be generated from the most recent census for the HDSS. Then 1500 households will be randomly selected and one older person (60+ years) will be randomly selected from the household and approached for an interview. Trained interviewers will administer the validated PDSQ to the older people identified in the selected households.

Data analysis: We will use Cohen's Kappa scores to estimate the level of agreement between clinician diagnosis and lay interviewers. Sensitivity, specificity, and positive and negative predictive values will also be used to compare diagnoses made by PDSQ administered by a trained lay interviewer and clinician-based diagnoses. We will estimate the prevalence of PD and associated 95% confidence intervals by gender. Given that the communities will be randomly selected through a multi-stage sampling our analysis will summarise the prevalence in each sampling unit. A weighted average of risk or prevalence will be used for each community based on a standard population and this is unbiased by the differential composition of each community with respect to confounding variables. We will also explore sociodemographic factors associated with PD by fitting multiple logistic regression models accounting for selection using weighted estimates.

WP1.3: Qualitative study with community health advisors

WP1.3 will employ a qualitative approach to assess the knowledge and practices of influential people, including traditional healers, medicine sellers, religious leaders, and community health volunteers regarding PD. Because people's health-seeking behaviors are strongly influenced by those in their communities, we take the hitherto unusual step of making an explicit exploration of this 'social cognitive' issue.

Sampling and data generation: We will identify influential people (n=40) such as traditional healers, religious leaders, medicine sellers, and community health volunteers from the same study communities from which older people will be recruited for the survey. The aim of this is to understand the knowledge and attitudes of these influential people on the care of PD and how they perceive referrals of PD patients to the healthcare system. The qualitative data will be coded and analyzed with a focus on key themes arising from the interviews i.e. We will, therefore, employ a thematic analytic approach.

WP2: Assessment of healthcare service availability and readiness to manage PD

This strand will explore the existing service delivery organizational structure, community linkages, referral pathways, clinical information systems, and integration with primary health care to determine service availability for PD and their level of implementation; identify service delivery aspects that hinder the early diagnosis of PD and long-term care 'journey' for patients through the primary, tertiary and national referral levels of health care in Kenya. This will be a survey of 50 primary health care facilities in Kisumu, 3 tertiary hospitals, one each from Kisumu, Mombasa, and Nairobi to assess the availability and status of services for people having PD and how cross-level services are integrated with community resources. The study will adopt and validate the *'Assessment of Chronic Illness Care'* (ACIC, v3.5) tool for evaluating care for chronic conditions (Oni et al., 2014; Baptista et al., 2016; Bonomi et al., 2002). It consists of 34 items covering seven aspects of the Chronic Care Model: Responses are broadly categorized into four descriptive levels ranging from "little or none" to "fully implemented" intervention. Within each of the four levels, respondents choose one of three ratings of the degree to which that description applies to their context.

Sample size and sampling: As there are many uncertainties regarding service availability for PD, any power calculation would be based on unverifiable or poorly grounded assumptions. We will randomly select 50 primary healthcare facilities in Kisumu and one tertiary hospital each from Kisumu, Mombasa, and Nairobi. One questionnaire will be administered per health facility.

Data analysis: The analysis will be descriptive. Mean scores for service availability will be calculated and compared across health facilities of the same level. The scores will range from 0 to 11, with 11 representing optimal care. The estimates for proportions and 95%CI of health care service availability and readiness will be determined for each of the high-level and regional referral hospitals. Simple weighted estimates and 95%CI will be obtained for similar proportions for PHC facilities given the selection probability. The analysis will consider adjustments/stratification by a facility-level factor if available.

WP3: Estimation of patient caseloads in neurology clinics and barriers and facilitators to diagnosis and referral of PD

In WP3, we will determine the caseloads of PD in three neurology outpatient clinics in Mombasa, Nairobi, and Kisumu and describe the challenges experienced by PD patients in accessing healthcare and describe the burden needs, and coping strategies of caregivers and the role of support groups in assisting patients with PD to cope with their disease. To determine the caseload attributable to PD, a retrospective record review of medical records in neurology outpatient clinics will be undertaken. A cross-sectional mixed-methods design will be used to determine treatment challenges, caregiver burden, and the role of support groups.

Sample size and sampling: Three neurology outpatient clinics in three tertiary hospitals in Kisumu, Mombasa, and Nairobi will be approached to participate in the study. A retrospective records review of PD patients attending these neurology clinics in the past five years will be assembled for information abstraction. In these circumstances, the sample size of the records cannot be determined in advance. However, a minimal sample size of 20 has been recommended as the minimum for a reliable neurology study (Hobart 2012). A data abstraction form will be designed to collect information on patient demographics (age, gender, educational status, marital status, occupation) and clinical profile (age at onset and diagnosis, clinical presentation, diagnosis, disease severity, comorbidity, and treatment). A sample of 45 PD patient-caregiver dyads will be enrolled to describe and determine the challenges that patients and their caregivers experience in accessing PD diagnosis, treatment, and referral for specialist assessment.

Statistical analysis: For each health facility we will estimate PD burden as a proportion of total neurology clinic attendance and explore any relationships with the prevalence reported from WP1. We will summarize the PD caseloads by patient characteristics to establish the characteristics of patients that attend care (e.g. age, education level, socioeconomic factors, disease severity). Wald test will be used to determine differences in the distribution of patient characteristics in a health facility. Findings from the PD patient-caregiver dyads will be summarized using descriptive statistics. The analysis will aim to document challenges, needs, and coping strategies in relation to the PD and work burden. Across health facilities, areas of consistency and priority will be identified.

Qualitative studies on barriers and facilitators of care: We will purposively recruit PD patient-caregiver dyads (n=45) receiving care from the participating neurology clinics for in-depth interviews to explore their perceptions of the disease, treatment-seeking behavior, challenges with the disease, and treatment. We will organize 3 focus group discussions for PD patients and caregivers, including patient support groups, to understand their perspectives and unmet healthcare needs. The caregiver burden will be assessed using the Zarit Burden Interview tool (Zhong, 2013). The qualitative data will be coded and analyzed with a focus on key themes arising from the interviews i.e. We will, therefore, employ a thematic content analysis.

9. DATA MANAGEMENT

8.1 Data storage, access, sharing, and transfer

APHRC premises its data access and sharing practices on the principle that data is a public good and should be made available to all authorized users in a timely manner and in a user-friendly format. Any individual or organization using or seeking to access APHRC research data will be required to abide by the provisions of the Center's Data Sharing Procedures and Guidelines and Research Handbook. The database of this project will be managed on an MS-SQL server

platform. The system is developed and maintained on a net framework 3.5 and above and devExpress IDE framework for the front-end application that is used during data collection. After the field interviewers complete an interview using the tablet, they will save and store the data on the local database on the device. Each FI will be 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 will be a staging database for quality control and data audit by the quality control team. Once data on the staging database are verified and validated, they will be synchronized to the archival servers in the main office. These archival servers will be in a secured and climate-controlled server room that has restricted access. The data manager will extract data from these archival servers and conduct another level of quality control and data audit. The cleaned and labeled datasets will then be stored on a dedicated project server in the main office where they will be available for use by researchers and partners. Open SSL technology will be used to encrypt data during storage and transmission. Further, different password encryption at different access levels will ensure the security of the data and the privacy of the primary subjects.

10. TIMEFRAME

The study will run for 36 months beginning in January 2022 until December 2024, with the first six months utilized for preparatory work, including seeking ethical approvals, community engagement, and recruitment and training of the research team (Table 2). By the end of the second quarter of year 1 (2022), the ethical approvals, recruitment, and training for WP1.1, WP2, and WP3 will be completed. By the end of the fourth quarter of year 1 (2022), the field activities of WP1.1, WP2, and WP3, including piloting and reconnaissance activities, clinical validation of screening tools for PD, health system assessment, and patient assessments would be completed. A survey of 1500 older people and the estimation of the prevalence of PD in Kenya (WP1.2), 40 qualitative studies of community health advisors (WP1.3) will be completed by the end of the third quarter of year 3 (2024). In addition, data cleaning and analyses would be completed by the end of the first quarter of year 3 (2023). Reports and manuscript writing for all work packages as well as the dissemination of study findings would be completed by the end fourth quarter of the third year (2023).

Table 2: Study timelines

Activities/Project Year	**Year 1: 2023**				**Year 2: 2024**				**Year 3:2025**			
	1	2	3	4	1	2	3	4	1	2	3	4
Protocol development, IRB ethical approvals												
Recruitments and Training												
Piloting and reconnaissance activities												
WP1.1: Clinical validation of screening tool for PD												
WP2: Health system assessment												

WP3: Patient assessments												
WP1.2: Estimate the national prevalence of PD												
WP1.3: Qualitative study-community health advisors												
Data cleaning and analysis												
Feedback of results												
WP1-3: Reports and manuscript writing												
WP1-3: Dissemination of study findings												

11. ETHICAL CONSIDERATIONS

Risk to participating subjects

We anticipate minimal risks to the study participants; therefore, a data and safety monitoring plan is not required. Participants may experience distress or discomfort when answering questions. There is a possibility of the stigma associated with home visits of those being visited for the invitation to report at the clinics after screening positive for PD. To reduce the stigma associated with home visits, the participants will be given the choice of times and venues of visits. They do not have to answer any questions that make them feel uncomfortable, may ask to take a break at any time, or may stop the study at any time without any repercussions. It may take the participant at least 30 minutes in total, including the informed consent process and answering the screening questionnaire.

The benefit to study subjects or community

Knowing the prevalence, diagnostic gaps, and knowledge/awareness of PD is important in that it leads to the planning of management interventions by health stakeholders. Training of clinicians and nurses attending to participants who screen positive for PD may result in the improvement of clinical management. Also, individuals who screen positive for PD will be referred to the participating hospitals for further clinical assessment and will be assisted with transport for this visit. Our research staff will be trained on how to handle or refer participants with unmet needs or psychosocial challenges. They will offer this support by telephone or by visiting the participants at home. By participating in the study, individuals will be contributing to the body of knowledge on the management and care for PD.

Informed consent

Consent forms will be translated to Kiswahili illustrating the purpose of the study, risks, and benefits. The fieldworkers will take the study participants through the informed consenting process before and screening begins. Adults will give individual consent unless the participant is unable to, in which case a close caretaker will be approached.

Confidentiality

Participants will be assured about the confidentiality of the personal details obtained from them since PD is associated with some level of stigma in most parts of SSA. Community members will be informed and educated about the study through community sensitization meetings with the CAC and chief's barazas. Interviews will be carried out in private rooms. The study participants will be provided with the contact details of investigators for any inquiries and clarifications.

12. EXPECTED APPLICATION OF THE RESULTS

At the end of the study, we will have validated tools for PD screening, obtained PD prevalence estimates for Kenya, had a clear understanding of the health system and patient-level barriers to care, and identified opportunities for action. We will prepare a report and policy brief for decision-makers in Kenya to guide them in determining interventions. We will organize gerontology and Parkinson's disease-related workshops, including the Gerontological Society of America, Parkinson's Foundation, etc., to present these findings in Kenya and also present in

regional international conferences. Key findings will also be published in scholarly journals such as The Gerontologist, Journal of Affective Disorders, and Journal of Parkinson's Disease.
Findings from this study will demonstrate priority areas for action towards improving multidisciplinary care, elicit patient-level information to enable the development of person-centered and culturally relevant PD educational and health promotion interventions, and enable the development of early detection tools and guidelines for appropriate referral of persons with PD. Addressing the epidemiological and systems-related gaps will stimulate discussion on PD and enable the national and sub-national levels in Kenya to initiate appropriate improvement interventions and generate lessons for other LMICs.
Potential challenges: The challenges that may affect the implementation of the study include: first, disruptions of data collection by the COVID-19 pandemic, which could slow down the recruitment of participants. We will mitigate this risk by training field teams to collect data while observing precautions using institutional and country-specific guidelines. Study teams will be vaccinated before starting fieldwork and will be advised to wear face coverings at all times during data collection. Secondly, the identification of households with older people will be labor-intensive. However, given that this study is nested in another study that will identify older people, we will harmonize our recruitment period with that of the existing studies. This is possible because two investigators (Drs Razak Gyasi and Gershim Asiki) on this proposal are also Co-PIs on the ongoing older people's studies. Lastly, low staffing coupled with poor motivation at the primary healthcare clinics may delay the administering of the questionnaire as the facility staff may perceive this as a waste of their time. This challenge will be addressed by engaging the health managers at the county level. The ministry of health is a co-applicant (Muthoni G) on this proposal and will play a critical role in the sensitization of health facilities on the importance of the study.

Dissemination of research findings knowledge transfer: This study will estimate the prevalence of PD in Kenya and identify the extant gaps in knowledge, diagnosis, awareness, and care for people with PD in Kenya, and SSA as a whole. The scientific evidence obtained will be gleaned to inform the development and implementation of new policies regarding the gaps in healthcare for PD in SSA. The results of the study will be disseminated to various stakeholders and decision-makers, and the scientific community through local seminars and international conferences such as the Gerontological Society of America and Parkinson's Foundation annual meetings/ conferences. Our findings will also be published in peer-reviewed journals - *The Gerontologist, Journal of Affective Disorders, and Journal of Parkinson's Disease*. We will also publish the findings in high-impact, open-access international journals to inform the design of future prospective studies to better understand PD in LMICs. In addition, we will ensure knowledge sharing of our work and ensure full accessibility to the general public through social media, including Facebook and Twitter channels as well as newspaper articles in the local dailies in Kenya.

13. REFERENCES

Alonso Cánovas, A., Luquin Piudo, R., García Ruiz-Espiga, P., Burguera, J.A., Campos Arillo, V., Castro, A., Linazasoro, G., López Del Val, J., Vela, L., Martínez Castrillo, J.C., 2014. Dopaminergic agonists in Parkinson's disease. Neurologia 29, 230–241.

Amoateng, P., Quansah, E., Karikari, T. K., Asase, A., Osei-Safo, D., Kukuia, K. K. E., … Nyarko, A. K. (2018). Medicinal Plants Used in the Treatment of Mental and Neurological Disorders in Ghana. *Evidence-Based Compl Altter Med*, 2018, 1–14. doi:10.1155/2018/8590381

Amod FH, Bhigjee AI. Clinical series of Parkinson's disease in KwaZulu-Natal, South Africa: Retrospective chart review. *J Neurol Sci. 2019 Jun 15;401:62-65.*

Baptista DR, Wiens A, Pontarolo R, Regis L, Reis WC, Correr CJ. The chronic care model for type 2 diabetes: a systematic review. *Diabetol Metab Syndr. 2016 Jan 22;8:7.*

Bhat, A.H., Dar, K.B., Anees, S., Zargar, M.A., Masood, A., Sofi, M.A., Ganie, S.A. (2015). Oxidative stress, mitochondrial dysfunction and neurodegenerative diseases; a mechanistic insight. Biomedicine & Pharmacotherapy 74, 101–110.

Blanckenberg, J., Glanzmann, B., Okubadejo, N. U., Carr, J. A., & Bardien, S. (2013). The prevalence and genetics of Parkinson's disease in sub-Saharan Africans. *J. Neurol. Sci*. 335: 1e2.

Bonomi AE, Wagner EH, Glasgow RE, VonKorff M. Assessment of chronic illness care (ACIC): a practical tool to measure quality improvement. *Health Serv Res. 2002 Jun;37(3):791-820.*

Bower JH, Zenebe G. Neurologic services in the nations of Africa. *Neurology. 2005 Feb 8;64(3):412-5.*

Cochran, W. G. (1977). Sampling techniques (3rd ed.). New York: John Wiley & Sons.

Dezutter, J., Wachholtz, A., & Corveleyn, J. (2011). Prayer and pain: the mediating role of positive re-appraisal. *J Behav Med*, 34:542–549.

Fereshtehnejad SM, Shafieesabet M, Rahmani A, Farhadi F, Hadizadeh H, Shahidi GA, et al. A novel 6-item screening questionnaire for Parkinsonism: validation and comparison between different instruments. *Neuroepidemiology. 2014;43(3-4):178-93*

Gyasi, R. M., Aboderin, I., & Asiki, G. (2022). Prevalence and social risk factors of functional limitations among slum-dwelling older adults: Findings from the Nairobi Urban Health and Demographic Surveillance System. *Gerontology & Geriatric Medicine*, Doi.10.1177/23337214221088700

Harries JR. Neurological disorders in Kenya. In: Spillane JD, editor. Tropical Neurology, London: Oxford University Press; 1973, p 207-222.

Hobart JC, Cano SJ, Warner TT, Thompson AJ. What sample sizes for reliability and validity studies in neurology? *J Neurol. 2012 Dec;259(12):2681-94.*

Kaddumukasa M, Kakooza A, Kaddumukasa MN, Ddumba E, Mugenyi L, Sajatovic M, Katabira E. Knowledge and Attitudes of Parkinson's Disease in Rural and Urban Mukono District, Uganda: A Cross-Sectional, Community-Based Study. *Parkinsons Dis. 2015;2015:196150.*

Kakkar, A.K., Dahiya, N. (2015). Management of Parkinson′s disease: Current and future pharmacotherapy. European Journal of Pharmacology 750, 74–81.

Kowal, S. L., Dall, T. M., Chakrabarti, R., Storm, M. V., & Jain, A. (2013). The current and projected economic burden of Parkinson’s disease in the United States. *Movement Disorders*, 28(3), 311–318. doi:10.1002/mds.25292

Lees, A.J., Hardy, J., Revesz, T. (2009). Parkinson's disease. Lancet 373, 2055–2066.

Lepule, K. H., Cordier, W., Steenkamp, P., Nell, M., & Steenkamp, V. (2019). *The ability of three African herbal remedies to offer protection against an in vitro model of Parkinson's disease. South African Journal of Botany.* doi:10.1016/j.sajb.2019.01.033

Mokaya, J., Gray, W. K., & Carr, J. (2017). Beliefs, knowledge and attitudes towards Parkinson's disease among a Xhosa speaking black population in South Africa: A cross-sectional study. *Parkinsonism & Related Disorders,* 41, 51–57. doi:10.1016/j.parkreldis.2017.05.009

Moore, K. & Simon, S. (2006). Beliefs and knowledge about Parkinson's disease, E-JAP EJ. *Appl. Psychol.* 2: 15e21.

Mshana, G., Dotchin, C. L., & Walker, R. W. (2011). 'We call it the shaking illness': perceptions and experiences of Parkinson's disease in rural northern Tanzania. *BMC Public Health,* 11:219 http://www.biomedcentral.com/1471-2458/11/219

Naik, S. & LaFaver, K. (2018). Healthcare Disparities in African-American Patients with Parkinson's Disease: A Comprehensive Literature Review and Call to Action (P2.073). Neurology, 90 (15 Supplement). https://n.neurology.org/content/90/15_Supplement/P2.073.

Okubadejo NU, Bower JH, Rocca WA, Maraganore DM. Parkinson's disease in Africa: A systematic review of epidemiologic and genetic studies. *Mov Disord. 2006 Dec;21(12):2150-6.*

Okubadejo NU, Ojo OO, Oshinaike OO. Clinical profile of parkinsonism and Parkinson's disease in Lagos, Southwestern Nigeria. *BMC Neurol. 2010 Jan 5;10:1.*

Oni T, McGrath N, BeLue R, Roderick P, Colagiuri S, May CR, Levitt NS. Chronic diseases and multi-morbidity--a conceptual modification to the WHO ICCC model for countries in health transition. *BMC Public Health. 2014 Jun 9;14:575.*

Parkinson's Study Group (2007). Pramipexole in Levodopa-treated Parkinson Disease Patients of African, Asian, and Hispanic Heritage. *Clinical Neuropharmacology, 30(2), 72–85.* doi:10.1097/01.wnf.0000240943.59617.4c

Picillo M, Lozano AM, Kou N, Puppi Munhoz R, Fasano A. Programming Deep Brain Stimulation for Parkinson's Disease: The Toronto Western Hospital Algorithms. Brain Stimul. 2016 May-Jun;9(3):425-437. doi: 10.1016/j.brs.2016.02.004.

Rajan R, Brennan L, Bloem BR, Dahodwala N, Gardner J, Goldman JG, et al. Integrated Care in Parkinson's Disease: A Systematic Review and Meta-Analysis. *Mov Disord. 2020 Sep;35(9):1509-1531.*

Redfern, C., & Coles, A. (2015). Parkinson's Disease, Religion, and Spirituality. *Movement Disorders Clinical Practice,* 2(4), 341–346. doi:10.1002/mdc3.12206

Schuller KA, Vaughan B, Wright I. Models of Care Delivery for Patients With Parkinson Disease Living in Rural Areas. *Fam Community Health. 2017 Oct/Dec;40(4):324-330.*

Simpson, J., Crawford, T., & Lekwuwa, G. (2013). Illness beliefs and psychological outcome in people with Parkinson's disease. *Chronic Illn*. 9: 165e176.

Thune-Boyle, I. C., Stygall, J. A., Keshtgar, M. R., et al. (2006). Do religious/spiritual coping strategies affect illness adjustment in patients with cancer? A systematic review of the literature. *Soc Sci Med,* 63:151–164.

van Halteren AD, Munneke M, Smit E, Thomas S, Bloem BR, Darweesh SKL. Personalized Care Management for Persons with Parkinson's Disease. *J Parkinsons Dis. 2020;10(s1):S11-S20.*

Walker RW, Churm D, Dewhurst F, Samuel M, Ramsell A, Lawrie C, et al. Palliative care in people with idiopathic Parkinson's disease who die in hospital. *BMJ Support Palliat Care. 2014 Mar;4(1):64-7.*

Wamukoya, M., Kadengye, D. T., Iddi, S., & Chikozho, C. (2020). The Nairobi urban health and demographic surveillance of slum dwellers, 2002–2019: value, processes, and challenges. Global Epidemiology, 2, 100024.

WHO. World Report on Ageing and Health, 2015. http://www.who.int/ageing/events/world-report-2015-launch/en

Winkler, A.S., Mayer, M., Ombay, M., Mathias, B., Schmutzhard, E., & Jilek-Aall, L. (2009). Attitudes toward African traditional medicine and Christian spiritual healing regarding treatment of epilepsy in a rural community of northern Tanzania, *Afr. J. Tradit. Complement. Altern. Med*. 7: 162e170.
Wiech, K., Farias, M., Kahane, G., et al. (2008). An fMRI study measuring analgesia enhanced by religion as a belief system. *Pain,* 139:467–476.

Yadav, H.P., Li, Y., 2015. The development of treatment for Parkinson’s disease. Advances in Parkinson's Disease 4, 59–78.

Zhong M, Evans A, Peppard R, Velakoulis D. Validity and reliability of the PDCB: a tool for the assessment of caregiver burden in Parkinson's disease. *Int Psychogeriatr. 2013 Sep;25(9):1437-41.*

14. BUDGET

Item	Total (KES)	Total (USD)
Ethical approvals	30,000	231
Mobilisation and dissemination of community leaders and participants	203,000	1562
Data Collection (Validation)	406,860	3130
Data Collection (Survey; Siaya and Nairobi HDSS sites)	3,083,600	23720
Overheads	770,655	5928
Total	**4,494,115**	**34570**

15. BUDGET JUSTIFICATION

The revised budget is 4,494,115 Kshs for the new amendments of the sample sizes in WP1. Ethical approvals in Nairobi County will come to 30,000 Kshs.Mobilisation and dissemination for both community leaders and participants will be at 203,000. Data collection activities such as clinical validation will take 406,860 Kshs whereas the survey in Nairobi and Siaya HDSS sites will take 3,083,600 Kshs in total.The overheads will total up to 770,655 Kshs.

16. APPENDICES

Appendix A: The role of each participating investigator.

Gershim Asiki, MD, MPH, PhD: A medical doctor with a Ph.D. in epidemiology; he is a Research Scientist at APHRC (Kenya) and will assist the PI in directing the grant through regular consultations, contractual accounting, and reporting. He will be the team lead for WP 1 and will ensure its implementation as per protocol. He will be the contact person and liaison with APHRC in the consortium. He will lead in publications related to WP 1. He will support all epidemiological aspects of the project for all work packages and will collaborate with PI and Prof. Obonyo in drafting study SOPs, consent forms, and other tools and ensuring adherence to local regulatory approvals, timelines, communications, study coordination, hosting investigator meetings are undertaken, supervise local study teams, and ensure that the highest ethical and quality standards are adhered to. He will also assist the team in disseminating the findings to policymakers in Kenya and ensure the publication of findings in high-impact journals.

Razak M. Gyasi, MPhil, PhD, PD, Associate Research Scientist at APHRC (Kenya), holds a Ph.D. in Social Policy with specialization in Social Gerontology from Lingnan University, Hong Kong, and an MPhil from Geographies of Health and Healthcare from Kwame Nkrumah University of Science and Technology, Ghana. As a social Gerontologist who has worked on

aging-related studies in SSA, Dr. Gyasi will be the project manager leading the data collection for WP1, ensuring study protocols and data collection tools are developed, ethical approvals are obtained, and will contribute to the overall project implementation.

Sylvia Kiwuwa-Muyingo, MSc, Ph.D. An Associate Research Scientist at APHRC with a Ph.D. in Biometry. She will work closely with the data manager on-site to ensure that clean data are collected and conduct analysis for all the quantitative aspects of the project.

Sharon Mugo RN, MPH. A research officer at APHRC with an MPH in public health and epidemiology. She will work closely with the team on-site to lead field activities and conduct day-to-day management of the project activities.

Dickens Samuel Aduda, MPH, Ph.D. The PI and primary applicant. He will be responsible for the overall technical, financial, and contractual performance of the project. He will lead in implementing WP 2. He will oversee administrative functions of the project in liaison with the grants manager; recruiting, interviewing, and hiring of study staff for WP 2; collaboration with the Co-PIs to guide the study implementation throughout its life course; drafting and submission of the study proposal for due ethics review and approval as well as due implementation. He will be the main point of contact with MJFF, ensuring accountability, submitting due reports, and monitoring the timely delivery of contractual deliverables, including the preparation of consolidated reports and publications. He will commit 20% FTE throughout the project period.

Ben Muok, MSc, Ph.D. is the director of the Directorate of Research. Innovation and Partnerships (DRIP) at JOOUST and a specialist in climate change and related impact on the health sector and will assist with implementation and oversight of aspects of the study governance, especially liaison with the University management board and senate, for feedback where needed. He will commit 15% FTE in Y1 and 10% for years 2 and 3.

Prof Charles Obonyo, MPH, Ph.D. is a Chief Research Officer specializing in Clinical Epidemiology. He is a Co-Principal Investigator and will oversee the work package assessing the patient caseload in neurology clinics and evaluation of patient barriers/facilitators to care and caregiver experiences and burden (WP 3). He will ensure the study is conducted to the highest ethical and scientific standards.

Dr. Muthoni Gichu, MB.Ch. B., MSc., MSc. Is a clinician and head of the Division of Geriatric Medicine, Department of Non-Communicable Diseases at the Ministry of Health, Kenya. She holds MSc in Gerontology and MSc in Exercise and Sports Science. She will play a critical role in the sensitization of health facilities on the importance of the study. Given her expertise and practical experiences, Muthoni will strategically offer the needed support to all work packages in this project.

Dr. Juzar Hooker, MD, and **Dr. Thomas Kwasa, MD:** are seasoned neurologists and senior faculty at Aga Khan University and the University of Nairobi respectively. They will directly support the project in terms of objective diagnosis of PD patients and review of the tools for screening/diagnosis. They will work with Dr. Gershim (WP 1) and Prof. Obonyo (WP 3) as well as participate in drafting and review of manuscripts; policy briefs and uptake of key study outputs for curriculum development and implementation at the university level. They will commit 13% FTE in Y1 and 10% in Y2 & Y3.

Appendix C: Consent forms for the main survey and qualitative study

CONSENT TO PARTICIPATE IN A RESEARCH STUDY

1. **Quantitative survey**

I**nformed Consent Form: Clinical validation of screening tool for PD**

Parkinson's Disease Diagnosis, Perceptions, Awareness, and Care in Kenya

Jaramogi Oginga Odinga University of Science and Technology (JOOUST)
Kisumu Bondo Usenge, African Population and Health Research Center (APHRC), and Kenya Medical Research Institute

Researcher	**Institution**	**Study Role**
Dr. Gershim Asiki, MD, MPH, PhD	APHRC	Site Principal Investigator
Dr. Razak M. Gyasi, MPhil, PhD, PD	APHRC	Co-Principal Investigator
Dr. Sylvia Muyingo, MSc, PhD	APHRC	Co-Principal Investigator
Sharon Mugo	APHRC	Co- Investigator
Dr. Dickens Samuel Aduda, MPH, PhD	JOOUST	Principal Investigator
Prof Ben Muok, MSc, PhD	JOOUST	Co-Principal Investigator
Prof Charles Obonyo, MPH, PhD	KEMRI	Co-Principal Investigator
Dr. Thomas Kwasa, PhD	KEMRI	Co-Principal Investigator
Dr. Juzar Hooker, MD	Khan University	Co-Principal Investigator
Dr. Thomas Kwasa, MD	Khan University	Co-Principal Investigator

Researcher's statement:
I would like to tell you about a study being conducted by researchers from Jaramogi Oginga Odinga University of Science and Technology (JOOUST), the African Population and Health Research Center (APHRC), and the Kenya Medical Research Institute.

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 Kenya
- 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, diagnosis, perceptions, awareness, and care of Parkinson's disease in Kenya to help improve the lives of the people living with Parkinson's disease in these communities. To do this, the head of this household or an adult representative will be interviewed using a standardized Parkinson's disease questionnaire.

How many people will take part in this study?

About 200 adults(100 PD cases and 100 controls) aged 60 years or older who are residents in Kenya will be asked to take part in this study.

What will happen if you 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 Parkinson's disease and in case you or any member of your household has any previous history of the disease, you will be requested to proceed to fill a Parkinson's disease screening questionnaire. If you or any member of your household screen positive for Parkinson's disease, 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 a neurologist and a physician in the primary care facility participating in this study.

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 care of Parkinson's disease. 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. 0722385291/ 0714712834/ 0757895429. You may also contact the Secretary of the Scientific and Ethics Review Unit at the Kenya Medical Research Institute on 020-2722541/ 0722205901/ 0717719477; Email address seru@kemri.org. This committee is concerned with the protection of volunteers in research projects.

Consent
You have been given a copy of this consent form to keep.

PARTICIPATION IN RESEARCH IS VOLUNTARY. You have the right to choose not to be in this study, or to leave the study at any point without penalty or loss of benefits to which you are entitled. **If you wish to participate in this study, you should sign below.**

Do you provide consent to participate in the study? □ Yes □ No _____ DATE

GIVEN BY: _____ _____
NAME OF PARTICIPANT SIGNATURE OF PARTICIPANT

BY: _____ _____
NAME OF STAFF MEMBER SIGNATURE OF STAFF MEMBER

WITNESSED BY: _____ _____

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How many people will take part in this study?
About 1,500 adults aged 60 years or older who are residents in Kenya will be asked to take part in this study.

What will happen if you 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 Parkinson's disease and in case you or any member of your household has any previous history of the disease, you will be requested to proceed to fill a Parkinson's disease screening questionnaire. If you or any member of your household screen positive for Parkinson's disease, 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 a neurologist and a physician in the primary care facility participating in this study.

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NAME OF PARTICIPANT SIGNATURE OF PARTICIPANT

BY: _____ _____
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WITNESSED BY: _____ _____

2. Qualitative interviews: Focus Group Discussions (FGDs)

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- 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 perceptions, awareness, and care of Parkinson's disease in Kenya to help improve the lives of the people living with Parkinson's disease in these communities. To do this, the head of this household or an adult representative will be interviewed through focus group discussions (FGDs). In this regard, we would like to clearly understand the perceptions and attitudes towards people with Parkinson's disease (PD) and how they are cared for by the family and the community at large as well as people living with PD themselves. To obtain data, we will identify caregivers and family members of people with PD and put them into groups of between six and ten members based on gender and age. Each group will be facilitated to discuss the various issues of interest together and the responses would be audio recorded once the approval is provided by the participants.

How many people will take part in this study?

About 50 adults who are residents in Kenya will be asked to take part in this study.

What will happen if you 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 Parkinson's disease and in case you or any member of your household has any previous history of the disease, you will be requested to proceed to fill a Parkinson's disease screening questionnaire. If you or any member of your household screen positive for Parkinson's disease, 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 a neurologist and a physician in the primary care facility participating in this study.

This survey 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 care of Parkinson's disease. 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. 0722385291/ 0714712834/ 0757895429. You may also contact the Secretary of the Scientific and Ethics Review Unit at the Kenya Medical Research Institute on 020-2722541/ 0722205901/ 0717719477; Email address seru@kemri.org. This committee is concerned with the protection of volunteers in research projects.

Consent
You have been given a copy of this consent form to keep.

PARTICIPATION IN RESEARCH IS VOLUNTARY. You have the right to choose not to be in this study, or to leave the study at any point without penalty or loss of benefits to which you are entitled. **If you wish to participate in this study, you should sign below.**

Do you provide consent to participate in the study? □ Yes □ No _____ DATE

GIVEN BY: _____ _____
NAME OF PARTICIPANT SIGNATURE OF PARTICIPANT

BY: _____ _____
NAME OF STAFF MEMBER SIGNATURE OF STAFF MEMBER

WITNESSED BY: _____ _____

3. Qualitative interviews: In-depth Interview (IDI)

Parkinson's Disease Diagnosis, Perceptions, Awareness, and Care in Kenya

Jaramogi Oginga Odinga University of Science and Technology (JOOUST)
Kisumu Bondo Usenge, African Population and Health Research Center (APHRC), and Kenya Medical Research Institute

Researcher	Institution	Study Role
Dr. Gershim Asiki, MD, MPH, PhD	APHRC	Site Principal Investigator
Dr. Razak M. Gyasi, MPhil, PhD, PD	APHRC	Co-Principal Investigator
Dr. Sylvia Muyingo, MSc, PhD	APHRC	Co-Principal Investigator
Sharon Mugo	APHRC	Co-Investigator
Dr. Dickens Samuel Aduda, MPH, PhD	JOOUST	Principal Investigator
Prof Ben Muok, MSc, PhD	JOOUST	Co-Principal Investigator
Prof Charles Obonyo, MPH, PhD	KEMRI	Co-Principal Investigator
Dr. Thomas Kwasa, PhD	KEMRI	Co-Principal Investigator
Dr. Juzar Hooker, MD	Khan University	Co-Principal Investigator
Dr. Thomas Kwasa, MD	Khan University	Co-Principal Investigator

Researcher's statement:
I would like to tell you about a study being conducted by researchers from Jaramogi Oginga Odinga University of Science and Technology (JOOUST), the African Population and Health Research Center (APHRC), and Kenya Medical Research Institute.

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 Kenya
- 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 perceptions, awareness, and care of Parkinson's disease in Kenya to help improve the lives of the people living with Parkinson's disease in these communities. To do this, the head of this household or an adult representative will be interviewed using in-depth interviews (IDI) where each respondent will be engaged one-on-one with the researchers to tease out their detailed understanding of their perceptions and attitudes as well as the burden of care of people living with PD using interview guides. People living with PD will be interviewed in this regard. In this process of data acquisition, the researchers will probe the respondents to further gather the pieces and clarify all the needed issues of interest, particularly

among the immediate family members and caregivers of people with PD. The discussions/interviews will be audio recorded once the approval is provided by the participants.

How many people will take part in this study?
About 40 who are residents in Kenya will be asked to take part in this study.

What will happen if you 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 Parkinson's disease and in case you or any member of your household has any previous history of the disease, you will be requested to proceed to fill a Parkinson's disease screening questionnaire. If you or any member of your household screen positive for Parkinson's disease, 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 a neurologist and a physician in the primary care facility participating in this study.

This survey 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 care of Parkinson's disease. 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. 0722385291/ 0714712834/ 0757895429. You may also contact the Secretary of the Scientific and Ethics Review Unit at the Kenya Medical Research Institute on 020-2722541/ 0722205901/ 0717719477; Email address seru@kemri.org. This committee is concerned with the protection of volunteers in research projects.

Consent
You have been given a copy of this consent form to keep.

PARTICIPATION IN RESEARCH IS VOLUNTARY. You have the right to choose not to be in this study, or to leave the study at any point without penalty or loss of benefits to which you are entitled. **If you wish to participate in this study, you should sign below.**

Do you provide consent to participate in the study? □ Yes □ No _____ DATE

GIVEN BY: _____ _____
NAME OF PARTICIPANT SIGNATURE OF PARTICIPANT

BY: _____ _____
NAME OF STAFF MEMBER SIGNATURE OF STAFF MEMBER

WITNESSED BY: _____ _____

Appendix B1: Parkinson's Disease (PD) Questionnaire (PDQ) for screening PD


Parkinson's Disease Diagnosis, Perceptions, Awareness, and Care in Kenya

[THE PERSON COMPLETING THIS HOUSEHOLD QUESTIONNAIRE SHOULD BE THE HEAD OF HOUSEHOLD IF AVAILABLE. WHERE UNAVAILABLE, ANY SPOUSE OF THE HEAD OF HOUSEHOLD SHOULD BE SELECTED TO COMPLETE THE HOUSEHOLD QUESTIONNAIRE. IN THE CASE THAT NEITHER THE HEAD OF HOUSEHOLD NOR ANY SPOUSE IS AVAILABLE, PLEASE COMPLETE THE HOUSEHOLD QUESTIONNAIRE WITH ANY OTHER AVAILABLE CREDIBLE ADULT AGED 18+]				
1.0 Background				
1.1 Start Time	[ ]			
1.2 Interviewer's Code	[ ]			
1.3 Date of Interview	[ ]			
1.4 Structure no.	[ ]			
1.5 Room no.	[ ]			
1.6 Household ID	[ ]			
1.7 Household head name	[ ]			
1.8 ID of the room where the household head sleeps	[ ]			
1.10 Household head's ID	[ ]			
2.0 Introduction and Consent				
Hello, my name is……and I am working with the African Population and Health Research Center (APHRC). We are conducting a research study to assess the prevalence and diagnosis of Parkinson's disease (PD) and explore the awareness, perceptions, and care for people with PD in this community. To do this, the head of this household or an adult representative will be interviewed using a standardized PD questionnaire. Your participation in this research is completely voluntary. You may also refuse to answer any question which you do not want to answer, and no harm will occur to you or anyone in your family regardless of your participation decision. The information that you provide will be completely confidential. Your responses will be combined with the answers of other respondents involved in the study and reported in such a way that you will be identified. The interview will take less than 20 minutes.				
	Response option			
Item	**No**	**Yes**	**Don't know**	
2.1. Have you ever noticed stiffness in your legs?	[ ]	[ ]	[ ]	
2.2. Have you ever had tremors of your head, arm, or legs that lasted more than 1 day?	[ ]	[ ]	[ ]	
2.3. Do you have trouble buttoning buttons or dressing?	[ ]	[ ]	[ ]	
2.4. Have you or others noted that you do not swing one arm when you walk?	[ ]	[ ]	[ ]	
2.5. Do your feet seem to get stuck to the floor when walking or turning?	[ ]	[ ]	[ ]	
2.6. Have you become slower in your usual daily activities?	[ ]	[ ]	[ ]	

Appendix B2: Parkinson's disease questionnaire (PDQ)

Parkinson's Disease Diagnosis, Perceptions, Awareness, and Care in Kenya

Assessment of Service Availability for Parkinson's Disease in Kenya
(Using ACIC-S, Short form Version)

Please complete the following information about you and your organization. This information will not be disclosed to anyone besides the Parkinson's research team. We would like to get your phone number and e-mail address in the event that we need to contact you/your team in the future. Please also indicate the names of persons (e.g., team members) who complete the survey with you. Later on in the survey, you will be asked to describe the process by which you complete the survey.

Your name:	Date: _____/_____/_____ **Month Day Year**
Health facility name: _____ Type of facility (public or private): _____ Ministry of Health category: _____ ***(e.g., Primary Level (I – III); Tertiary Level (IV – V); National Level)*** County: _____; S/County: _____ Address: _____ _____ _____.	Names of other persons completing the survey with you: **1.** **2.** **3.** **4.**
Your phone number: **(_____)** __ __ __ - __ __ __ __	Your e-mail address:

Directions for Completing the Survey

This survey is designed to help systems and provider practices move toward the "state-of-the-art" in managing Parkinson's disease chronic illness. The results can be used to help your team identify areas for improvement. Instructions are as follows:

1. **Answer each question** from the perspective of one physical site (e.g., a practice, clinic, hospital, health plan) that supports care for chronic illness.

2. **Answer each question** regarding how your organization/institution is doing with respect to Parkinson's Disease.

3. For each row, **circle the point value** that best describes the level of care that currently exists in the site and condition you chose. The rows in this form present key aspects of chronic illness care. Each aspect is divided into levels showing various stages in improving chronic illness care. The stages are represented by points that range from 0 to 11. The higher point values indicate that the actions described in that box are more fully implemented.

4. **Sum the points in each section** (e.g., total part 1 score), calculate the average score (e.g., total part 1 score / # of questions), and enter these scores in the space provided at the end of each section. Then sum all of the section scores and complete the average score for the program as a whole by dividing this by 7.

5. Teams are instructed to complete the ACIC as a ''group'' using input from each team member to arrive at a consensus rating for each item. This enables input from all team members in assessing their system's approach to chronic illness care.

For more information about how to complete the survey, please contact: Dr Dickens S. Omondi Aduda, omondisda@gmail.com; Dr Muthoni Gichu, muthonigichu@gmail.com

PACKS Study Primary Health Facility (Level 4) Readiness Assessment

Module	No.	Question	Results	Skip
		Cover		
		1.1. COVER PAGE AND FACILITY IDENTIFIER		
		1.1.1. FACILITY IDENTIFIERS		
		ADAPT NUMBERING FOR COUNTIES AND HEALTH FACILITIES		
All	100	Facility code	----------	
All	101	Name of facility	----------	
All	102	Is this facility known by any other names? IF YES, PLEASE SPECIFY	YES ..... 1 NO..... 2 IF YES, SPECIFY:_____	
All	103	Name of County and code	----------/---	
All	104	Interview date	Visit No. ----- Date: DD MM YYYY Interviewer code Result Code	
			*RESULT CODE 1 = INTERVIEW STARTED 2 = POSTPONED 3 = FACILITY CLOSED 4 = FACILITY DESTROYED 5 = FACILITY NOT FOUND 6 = OTHER COMPLETE GPS COORDINATES FOR RESULTS CODES 1 THROUGH 4	
		1.1.2. GEOGRAPHIC COORDINATES – of study sites		

	105	**1.1.3. CONSENT:** **Jaramogi Oginga Odinga University of Science and Technology in collaboration with Ministry of Health is conducting** is conducting a study on Parkinson's Disease. The objective is to assess the availability of key health services for Parkinson's Disease (PD) in different facilities. This information will be collected in selected primary healthcare and secondary referral facilities across the country. The survey is part of the PACKS study to understand what services are being offered and where they are being offered. The present study will be conducted across the country. The facilities included in the survey were selected randomly from a list of all facilities at Subcounty level. The facilities included in this study were sampled from among level 2 – 4 by the sub-counties. The sampling process was done in a manner that ensured equal opportunity for all level 2 - 4 facilities in each sub-county to be included in the sample. As the in charge of this facility, we are asking you to help us to collect the information from the persons who are most knowledgeable about the services. For any questions we ask, if there is another person who is in a better position to provide details, please feel free to refer us to that person. We will want to speak with persons familiar with the various outpatient services and rehabilitation services if these are offered so that we can correctly identify the components of these services that are offered to PD patients in this facility. We anticipate that the time required from an individual respondent to complete data collection from a service site may take from 40 to 50 minutes, depending on how busy each separate site is. Your participation in this survey is voluntary and at no cost to you as an individual. You may choose not to participate at all or to stop at any time before the end of the survey. You may also choose not to answer any question that you are not comfortable with. The information on service availability will be shared with the Ministry of Health (MOH) and other relevant stakeholders who support the MOH, to provide information for planning improvement of services availability for patients living with Parkinson's Disease. No names of any respondents will be shared. In case you have any questions about this survey at any time, please feel free to contact any of the following people: [LIST NAMES AND PHONE NUMBERS OF SURVEY MANAGEMENT PERSONS WHO CAN BE CONTACTED] At this point do you have any questions about the study? Do I have your agreement to proceed?		
		Signature (Study leader)_____	Signature (Facility staff) _____	
		1.1.4. FACILITY CHARACTERISTICS		
ALL	113	Facility level	sub-County hospital .....1 HEALTH CENTRE ..... 2 CLINIC/DISPENSARY 3	

ALL	114	Which of the responses best describes the ownership of this facility? That is, the authority that makes policy decisions and provides supervision for the facility.	GOVERNMENT/PUBLIC: MINISTRY OF HEALTH ..... 1 MISSION/FAITH-BASED ..... 2 Other .....3 (specify: ..... .)	

Module	No.	Question	Results				Skip
ALL	117	RECORD FACILITY LOCATION: URBAN OR RURAL OR PERIURBAN (FROM SURVEY LIST)	URBAN ..... 1 RURAL ..... 2 PERIURBAN 3				
ALL	118	Service levels available	OUTPATIENT ONLY..... 1 *INPATIENT ONLY ..... 2 BOTH OUT AND INPATIENT..... 3				
		2. CLIENT SERVICES					
		2.1. SERVICES PROVIDED FOR CHRONIC DISEASES BY THE FACILITY					
		2.1.1. NONCOMMUNICABLE DISEASES (NCDs) SERVICE AVAILABILITY					
			Out-patient (OP) only	In-patient (IP) only	Both OP&IP	Service not available	
A_C	01	Any services for chronic diseases (diabetes, cardiovascular, cancer)	1	2	3	4	
A_C	02	Movement disorders	1	2	3	4	
A_C	03	Neurological diseases, specifically Parkinson's Disease; Dementia	1	2	3	4	
		2.1.2. SPECIALTY MEDICAL SERVICES					
A_C	01	Does this facility offer any specialty medical services? ***By this I mean that there is a specialist doctor who provides the service and medical equipment for diagnosis and treatment (including outreach).***	1	2	3	4	
A_C	02	Providers in this facility diagnose, prescribe treatment for, or manage patients with Parkinson's Disease.	YES..... .....1 NO 2				

A-C	03	Does this facility dispense basic medication for Parkinson's disease (e.g. Levodopa)	YES..... .....1 NO 2	
		2.1.2 SYSTEMS TO SUPPORT QUALITY SERVICES FOR CHRONIC DISEASES:		
R_C	69 01	Is there a register or database for patients who are diagnosed with PD or other NCDs where information such as when patients start treatment, compliance and outcomes are recorded? **IF YES, ASK TO SEE THE REGISTER.**	YES, START AND OUTCOMES/COMPLIANCE INFORMATION RECORDED .....1 YES, START RECORDED.....2 NO..... 3	
R_C	69 02	Does the facility have an appointment system for routine follow-up for patients diagnosed with NCDs? **IF YES, ASK TO SEE AN APPOINTMENT SCHEDULE FOR ANY NCD.**	YES, REGISTER/SCHEDULE OBSERVED .....1 YES, REPORTED, NO REGISTER/SCHEDULE SEEN.... ....2 NO 3	
R_C	69 03	Are individual patient treatment cards/files maintained for patients with chronic diseases? **IF YES, ASK TO SEE A PATIENT TREATMENT CARD.**	YES, REGISTER/SCHEDULE OBSERVED .....1 YES, REPORTED, NO SEEN.....2 NO 3	
		2.2. SERVICES FOR SPECIAL NEEDS		
		2.2.1. MENTAL AND/OR NEUROLOGICAL SERVICES:		
R_C	78 00	Does this facility offer any services for mental health related conditions	YES..... .....1 NO 2	
		Does this facility offer any services for neurological conditions such as epilepsy or dementia?	YES..... .....1 NO 2	
R_C			YES OFFERED	

	7801	For each service I ask about, please tell me if the service is offered in this facility. If yes, is it offered as an inpatient, an outpatient or both as an in- and out-patient service?	*IN-PATIENT ONLY	OUT-PATIENT ONLY	BOTH IN- AND OUT-PATIENT	NOT OFFERED	
R_C	01	Mental disorders (depression, psychosis and bipolar disorder)	1	2	3	4	
R_C	04	Dementia	1	2	3	4	
R_C	05	Parkinson's Disease	1	2	3	4	
R_C	03	Neurological inpatient services	1			4	
		ASK TO BE SHOWN THE LOCATION IN THE FACILITY WHERE OUTPATIENT MENTAL HEALTH SERVICES ARE PROVIDED. FIND THE PERSON MOST KNOWLEDGEABLE ABOUT MENTAL HEALTH SERVICES IN THE FACILITY. INTRODUCE YOURSELF, EXPLAIN THE PURPOSE OF THE SURVEY AND ASK THE FOLLOWING QUESTIONS.					
R_C	7802	Now I would like to know about specific types of mental health services offered. For each diagnosis I mention, please tell me if this facility diagnoses and/or provides patient follow-up for the condition.	DIAGNOSES ONLY	PROVIDES PATIENT FOLLOW-UP ONLY	DIAGNOSES AND PROVIDES PATIENT FOLLOW-UP	NO SERVICE	
R_C	01	Depression	1	2	3	4	
R_C	02	Psychosis	1	2	3	4	
R_C	03	Bipolar disorder	1	2	3	4	
R_C	7803	Does this facility have health guidelines for diagnosis and management of patients with neurological conditions? **IF YES, ASK: May I see the guidelines?**	YES, OBSERVED.....1 YES, REPORTED, NO SEEN.....2 NO .....3 **Date of publication: of guideline: .....**				
R_C	7804	Have you or any provider(s) of mental health services received training related to diagnosis,	YES 1				

		counselling or treatment for mental health in the past 2 years?	If YES, specify duration of training ..... NO 2		
R_C	7805	Have you or any provider(s) of neurological health services received training related to diagnosis, counselling or treatment for neurological conditions in the past 2 years?	YES .....1 NO 2		
		2.2.2. REHABILITATIVE CARE:			
R_C	8000	Does this facility offer any rehabilitative care or physical therapy care services?	YES..... .....1 NO 2		
R_C	8001	Next, I want to know about the trained rehabilitation staff who are available for services in this facility. For each qualification I mention, please tell me how many full-time and part-time persons with the qualifications are employed by this facility.	**A** **Full time** ----------	**B** **Part Time** --------	
R_C	01	Registered physical therapist			
R_C	02	Registered occupational therapists			
R_C	03	Registered speech/language therapists			
R_C	04	Orthopedic technicians / assistants			
R_C	05	Plaster technicians			
R_C	06	Psychologist			
R_C	07	Audiologist			
R_C	8002	Is there a space specific for rehabilitation or physical therapy services?	**Yes:.....** **.....1** **No:** **.....2**		
		2.3. FORMAL LINKAGES WITH SERVICES OUTSIDE THE FACILITY			
		2.3.1. LINKAGES WITH TRADITIONAL, COMPLEMENTARY AND INTEGRATIVE (TCI) MEDICINE			

M_C	400	Does this facility have formal linkages with outside resources, e.g. providers of traditional, complementary or other integrative types of medicine (TCI)? **This may be facility wide, or service specific.**	YES .....1 (*if yes, specify:* .....) NO 2	
		2.3.2. COMMUNITY LINKAGES		
M_C	402	Does this facility have any formal systems for linking with community health workers or community volunteers for any services related to non-communicable disease care, including neurological?	YES, neurological diseases includes.....1 YES, Neurological disease, not include.....2 NO 3	
M_C	403	Does this facility have any formal systems for linking with other organizations providing home-based palliative care	YES .....1 NO 2	

Table Legend:

• Column 1 - Mod/Ind: The first letter in Column 1 shows the module to which the question belongs: A for Availability, R for Readiness, M for Management and finance, or Q for Quality of care. The second letter (after the underscore symbol) denotes the kind of question: C for Core or A for Additional.

• Column 2 – No: Column 2 contains the number of the HHFA question. There may be a single number per question, or a main number with sub-questions below it, e.g., Q2401 (main question), Q2401_01 (sub-question).

• Column 3 - Question: Column 3 contains the question that is read to the respondent by the interviewer. It may also contain additional clarifying information (in non-capitalized font) that the interviewer reads to the respondent. This column may also include instructions (in CAPITALS) to the interviewer. (These instructions are not read to the respondent.)

• Column 4 - Result: Column 4 contains the response options. Different types of response options are used for different types of questions, e.g., pre-coded responses where one or more options are selected, fields requiring entry of a number or text, or combinations of these.

• Column 5 - Skip: This column contains arrows that instruct the interviewer to skip to a specific question or to other instructions, if necessary.

**Note: Patients who stay at the facility overnight are in-patients.*

Interviewer's Notes:

Supervisors Notes:

<table>
<tr><td colspan="2">Assessment of Service Availability for Parkinson's Disease (PD) in Kenya
(ACIC Version 3.5)</td></tr>
<tr><td colspan="2">Please complete the following information about you and your organization. This information will not be disclosed to anyone besides the Parkinson's research team. We would like to get your phone number and e-mail address in the event that we need to contact you/your team in future. Please also indicate the names/roles of persons (e.g., team members) who complete the survey with you. Later on in the survey, you will be asked to describe the process by which you complete the survey.</td></tr>
<tr><td>Your name and Substantive Position:</td><td>Date:
_____/_____/_____
Month Day Year</td></tr>
<tr><td rowspan="5">Health facility name:
_____
Type of facility (public or private):
_____
Ministry of Health category:
_____ (e.g., Primary Level (I – III); Tertiary Level (IV – V); National Level)
County: _____; S/County:
_____
Address:
_____
_____
_____.</td><td>Names/roles of other persons completing the survey with you:</td></tr>
<tr><td>1.</td></tr>
<tr><td>2.</td></tr>
<tr><td>3.</td></tr>
<tr><td>4.</td></tr>
<tr><td>Your phone number: (_____) __ __ __ - __ __ __ __</td><td>Your e-mail address:</td></tr>
<tr><td colspan="2">Directions for Completing the Survey</td></tr>
</table>

This survey is designed to help systems and provider practices move toward the "state-of-the-art" in managing Parkinson's disease which is a chronic illness. The results can be used to help your team identify areas for improvement. Instructions are as follows:

1. **Answer each question** from the perspective of one physical site (e.g., a practice, clinic, hospital, health plan) that supports care for chronic illness.

2. **Answer each question** regarding how your organization / institution is doing with respect to Parkinson's Disease.

3. For each row, **circle the point value** that best describes the level of care that currently exists in the site and Parkinson's Disease. The rows in this form present key aspects of chronic illness care. Each aspect is divided into levels showing various stages in improving chronic illness care. The stages are represented by points that range from 0 to 11. The higher point values indicate that the actions described in that box **are more fully implemented**.

4. **Sum the points in each section** (e.g., total part 1 score), calculate the average score (e.g., total part 1 score / # of questions), and enter these scores in the space provided at the end of each section. Then sum all of the section scores and complete the average score for the program as a whole by dividing this by 7.

5. Teams are instructed to strive to complete the ACIC as a ''group'' using input from each team member to arrive at a consensus rating for each item. This enables input from all team members in assessing their system's approach to chronic illness care.

6. You will be required to briefly describe the process used to complete this survey (e.g. reached consensus in a face-to-face meeting; filled out by the team leader in consultation with other team members as needed; each team member filled out a separate form and the responses were averaged):

For more information about how to complete the survey, please contact: Dr Dickens S. Omondi Aduda, omondisda@gmail.com; Dr Muthoni Gichu, muthonigichu@gmail.com

Part 1: Organization of the Healthcare Delivery System. *Chronic illness management programs for PD can be more effective if the overall system (organization) in which care is provided is oriented and led in a manner that allows for a focus on chronic illness care.*

Components	Level D	Level C	Level B	Level A
1.1. Overall Organizational Leadership in Chronic Illness Care	…does not exist or there is a little interest.	…is reflected in vision statements and business plans, but no resources are specifically earmarked to execute the work.	…is reflected by senior leadership and specific dedicated resources (Money and personnel).	…is part of the system's long term planning strategy, receive necessary resources, and specific people are held accountable.
Score	0 1 2	3 4 5	6 7 8	9 10 11
1.2 Organizational Goals for Chronic Care	…do not exist or are limited to one condition.	…exist but are not actively reviewed.	…are measurable and reviewed.	…are measurable, reviewed routinely, and are incorporated into plans for improvement.
Score	0 1 2	3 4 5	6 7 8	9 10 11
1.3 Improvement Strategy for Chronic Illness Care	…is ad hoc and not organized or supported consistently.	…utilizes ad hoc approaches for targeted problems as they emerge.	…utilizes a proven improvement strategy for targeted problems.	…includes a proven improvement strategy and uses it proactively in meeting organizational goals.
Score	0 1 2	3 4 5	6 7 8	9 10 11

Total Health Care Organization Score _____ Average Score (Health Care Org. Score / 3) _____

Part 2: Community Linkages. Linkages between the health delivery system (or provider practice) and community resources play important roles in the management of chronic illness: e.g. community-based self-management programs.

Components	Level D	Level C	Level B	Level A
2.1 Linking Patients to Outside Resources **Score**	…is not done systematically. 0 1 2	…is limited to a list of identified community resources in an accessible format. 3 4 5	…is accomplished through a designated staff person or resource responsible for ensuring providers and patients make maximum use of community resources. 6 7 8	… is accomplished through active coordination between the health system, community service agencies and patients. 9 10 11
2.2 Partnerships with Community Organizations **Score**	…do not exist. 0 1 2	…are being considered but have not yet been implemented. 3 4 5	…are formed to develop supportive programs and policies. 6 7 8	…are actively sought to develop formal supportive programs and policies across the entire system. 9 10 11
2.3 Regional Health Plans **Score**	…do not coordinate chronic illness guidelines, measures or care resources at the practice/facility level. 0 1 2	…would consider some degree of coordination of guidelines, measures or care resources at the practice/facility level but have not yet implemented changes. 3 4 5	…currently coordinate guidelines, measures or care resources in one or two chronic illness areas. 6 7 8	…currently coordinate chronic illness guidelines, measures and resources at the practice level/facility for most chronic illnesses. 9 10 11

Total Community Linkages Score _____ Average Score (Community Linkages Score / 3) _____

Part 3: Practice Level. Several components that manifest themselves at the level of the individual provider practice (e.g. individual clinic) have been shown to improve chronic illness care. These characteristics fall into general areas of self-management support, delivery system design issues that directly affect the practice, decision support, and clinical information systems.

Part 3a: Self-Management Support. Effective self-management support can help patients and families cope with the challenges of living with and treating chronic illness such as PD and reduce complications and symptoms, **e.g., integration of self-management support for PD into routine care**

Components	Level D	Level C	Level B	Level A
3a.1 Assessment and Documentation of Self-Management Needs and Activities Score	…are not done. 0 1 2	…are expected. 3 4 5	…are completed in a standardized manner. 6 7 8	…are regularly assessed and recorded in standardized form linked to a treatment plan available to practice and patients. 9 10 11
3a.2 Self-Management Support **Score**	…is limited to the distribution of information (pamphlets, booklets). 0 1 2	…is available by referral to self-management classes or educators / life coach. 3 4 5	…is provided by trained clinical educators who are designated to do self-management support, affiliated with each practice/facility, and see patients on referral. 6 7 8	…is provided by clinical educators affiliated with each practice/facility, trained in patient empowerment and problem-solving methodologies, and see most patients with chronic illness. 9 10 11
3a.3 Addressing Concerns of Patients and Families	…is not consistently done.	…is provided for specific patients and families through referral.	…is encouraged, and peer support, groups, and mentoring programs are available.	…is an integral part of care and includes systematic assessment and routine involvement in peer support,

Score	0 1 2	3 4 5	6 7 8	groups or mentoring programs. 9 10 11

Total Self-Management Score_____ Average Score (Self Management Score / 3) _____

Part 3b: Decision Support. Effective chronic illness management programs assure that providers have access to evidence-based information necessary to care for PD patients-decision support**,** linkages between primary and specialty care and; integration of clinical guidelines).

Components	**Level D**	**Level C**	**Level B**	**Level A**
3b.1 Evidence-Based Guidelines **Score**	…are not available. 0 1 2	…are available but are not integrated into care delivery. 3 4 5	…are available and supported by provider education. 6 7 8	…are available, supported by provider education and integrated into care through reminders and other proven provider behavior change methods. 9 10 11
3b.2 Provider Education for Chronic Illness Care **Score**	…is provided sporadically. 0 1 2	…is provided systematically through traditional methods. 3 4 5	…is provided using optimal methods (e.g. academic detailing). 6 7 8	…includes training all health facility teams in chronic illness care methods such as population-based management, and self-management support. 9 10 11
3b.3 Informing Patients about Guidelines	…is not done.	…happens on request or through system publications.	…is done through specific patient education materials for each guideline.	…includes specific materials developed for patients which describe their role in

Components	Level D	Level C	Level B	Level A
Score	0 1 2	3 4 5	6 7 8	achieving guideline adherence. 9 10 11

Total Decision Support Score_____ Average Score (Decision Support Score / 3) _____

Part 3c: Delivery System Design. Evidence suggests that effective chronic illness management involves more than simply adding additional interventions to a current system focused on acute care. It may necessitate changes to the organization of practice that impact provision of care e.g. use of telephone or SMS follow-up reminders; nurse case manager support.

Components	Level D	Level C	Level B	Level A
3c.1 Follow-up **Score**	…is scheduled by patients or providers in an *ad hoc* fashion. 0 1 2	…is scheduled by the health facility service provider in accordance with guidelines. 3 4 5	…is assured by the health facility team by monitoring patient utilization. 6 7 8	…is customized to patient needs, varies in intensity and methodology (phone, in person, email) and assures guideline follow-up. 9 10 11
3c.2 Planned Visits for Chronic Illness Care	…are not used.	…are occasionally used for complicated patients.	…are an option for interested patients.	…are used for all patients and include regular assessment, preventive interventions and attention to self-management support.

Components	Level D	Level C	Level B	Level A
Score	0 1 2	3 4 5	6 7 8	9 10 11
3c.3 Continuity of Care **Score**	…is not a priority. 0 1 2	…depends on written communication between primary care providers and specialists, case managers or disease management companies. 3 4 5	…between primary care providers and specialists and other relevant providers is a priority but not implemented systematically. 6 7 8	…is a high priority and all chronic disease interventions include active coordination between primary care, specialists and other relevant groups. 9 10 11

(From Previous Page)

Total Delivery System Design Score_____ Average Score (Delivery System Design Score / 3) _____

Part 3d: Clinical Information Systems. Timely, useful information about individual patients and populations of patients with chronic conditions is a critical feature of effective programs, especially those that employ population-based approaches e.g., chronic illness registry, reminders.[7, 8]

Components	Level D	Level C	Level B	Level A
3d.1 Feedback **Score**	…is not available or is non-specific to the team. 0 1 2	…is provided at infrequent intervals and is delivered impersonally. 3 4 5	…occurs at frequent enough intervals to monitor performance and is specific to the team's population. 6 7 8	…is timely, specific to the team, routine and personally delivered by a respected opinion leader to improve team performance. 9 10 11
3d.2 Information about Relevant Subgroups of	…is not available.	…can only be obtained with special efforts or additional programming.	…can be obtained upon request but is not routinely available.	…is provided routinely to providers to help them deliver planned care.

Components	Level D	Level C	Level B	Level A
Patients Needing Services Score	0 1 2	3 4 5	 6 7 8	9 10 11
3d.3 Patient Treatment Plans **Score**	…are not expected. 0 1 2	…are achieved through a standardized approach. 3 4 5	…are established collaboratively and include self management as well as clinical goals. 6 7 8	…are established collaborative an include self management as well as clinical management. Follow-up occurs and guides care at every point of service. 9 10 11

Total Clinical Information System Score_____ Average Score (Clinical Information System Score / 3) _____

Part 7: Integration of Components for the Chronic Care Model into PD care

Integration of Chronic Care into Routine Care

Components	Level D	Level C	Level B	Level A
Informing Patients about Guidelines **Score**	…is not done. 0 1 2	…happens on request or through system publications. 3 4 5	…is done through specific patient education materials for each guideline. 6 7 8	…includes specific materials developed for patients which describe their role in achieving guideline adherence 9 10 11
Routine follow-up for appointments, patient	…is not ensured.	…is sporadically done, usually for appointments only.	…is ensured by assigning responsibilities to specific staff (e.g., nurse case	… ensured by assigning responsibilities to specific staff (e.g., nurse case

Components	Level D	Level C	Level B	Level A
assessments and goal planning **Score**	0 1 2	3 4 5	manager, outreach manager, social worker). 6 7 8	manager, etc.) who uses the registry and other prompts to coordinate with patients and the entire health facility team. 9 10 11
Guidelines for chronic illness (PD) care **Score**	…are not shared with patients. 0 1 2	…are given to patients who express a specific interest in self- management of their condition. 3 4 5	…are provided for all patients to help them develop effective self- management or behavior modification programs, and identify when they should see a provider. 6 7 8	…are reviewed by the health facility care team with the patient to devise a self-management or behavior modification program consistent with the guidelines that takes into account patient's goals and readiness to change. 9 10 11

Total Integration Score (SUM items): _____ ➢ **Average Score (Integration Score/3)** = _____

Briefly describe the process you used to fill out the form (e.g., reached consensus in a face-to-face meeting; filled out by the team leader in consultation with other team members as needed; each team member filled out a separate form and the responses were averaged).

Description: _____

_

Scoring Summary
(bring forward scoring at end of each section to this page)

Total Org. of Health Care System Score _____
Total Community Linkages Score _____
Total Self-Management Score _____
Total Decision Support Score _____
Total Delivery System Design Score _____
Total Clinical Information System Score _____
Total Integration Score _____

Overall Total Program Score (Sum of all scores) _____

Average Program Score (Total Program / 6) _____

What does it mean?

The ACIC is organized such that the highest "score" (an "11") on any individual item, subscale, or the overall score (an average of the six ACIC subscale scores) indicates optimal support for chronic illness. The lowest possible score on any given item or subscale is a "0", which corresponds to limited support for chronic illness care. The interpretation guidelines are as follows:

Between "0" and "2" = limited support for Parkinson's Disease care
Between "3" and "5" = basic support for Parkinson's Disease care
Between "6" and "8" = reasonably good support for Parkinson's Disease care
Between "9" and "11" = fully developed Parkinson's Disease care

Parkinson's Disease Caregiver Burden Questionnaire

PART A: PLEASE TICK one of the following options for each statement. You must rate the degree to which you currently agree to the following statements regarding yourself and the person you are caring for.

1) I have been injured as a result of caring for him/her, e.g. back strain as a result of lifting.

Strongly Disagree	Somewhat Disagree	Maybe	Somewhat Agree	Strongly Agree
☐	☐	☐	☐	☐

2) I feel physically capable to help him/her with activities of daily living such as toileting, dressing, showering, bathing, and lifting.

Strongly Disagree	Somewhat Disagree	Maybe	Somewhat Agree	Strongly Agree
☐	☐	☐	☐	☐

3) I feel annoyed or frustrated because my sleep is disturbed by him/her at night.

Strongly Disagree	Somewhat Disagree	Maybe	Somewhat Agree	Strongly Agree
☐	☐	☐	☐	☐

4) I think I get enough sleep at night, and I feel awake during the day.

Strongly Disagree	Somewhat Disagree	Maybe	Somewhat Agree	Strongly Agree
☐	☐	☐	☐	☐

5) Dealing with the day-to-day unpredictability of symptoms makes it frustrating and difficult.

Strongly Disagree	Somewhat Disagree	Maybe	Somewhat Agree	Strongly Agree

☐ ☐ ☐ ☐ ☐

6) I am fine with how slowly he/she moves and does things.

Strongly Disagree | Somewhat Disagree | Maybe | Somewhat Agree | Strongly Agree

☐ ☐ ☐ ☐ ☐

7) He/she has trouble with urinary urgency, and helping with toileting is very difficult for me.

Strongly Disagree | Somewhat Disagree | Maybe | Somewhat Agree | Strongly Agree

☐ ☐ ☐ ☐ ☐

8) I have had trouble coping with his/her compulsive behaviours (such as gambling, sexual hyperactivity, hobbies, and hoarding).

Strongly Disagree | Somewhat Disagree | Maybe | Somewhat Agree | Strongly Agree

☐ ☐ ☐ ☐ ☐

PART A (continued):

9) I feel anxious or confused because I am unsure whether he/she is suffering from depression.

Strongly Disagree | Somewhat Disagree | Maybe | Somewhat Agree | Strongly Agree

☐ ☐ ☐ ☐ ☐

10) I am okay with having to take care of our responsibilities, such as decision making, chores and appointments.

Strongly Disagree | Somewhat Disagree | Maybe | Somewhat Agree | Strongly Agree

☐ ☐ ☐ ☐ ☐

11) I get upset because it seems he/she can't be bothered to take responsibility of his/her health.

Strongly Disagree	Somewhat Disagree	Maybe	Somewhat Agree	Strongly Agree
☐	☐	☐	☐	☐

12) I feel anxious because I need to be aware of what he/she is doing all the time.

Strongly Disagree	Somewhat Disagree	Maybe	Somewhat Agree	Strongly Agree
☐	☐	☐	☐	☐

13) I am worried when he/she wants to take more Parkinson's medicine than the doctor prescribed.

Strongly Disagree	Somewhat Disagree	Maybe	Somewhat Agree	Strongly Agree
☐	☐	☐	☐	☐

14) I find it very easy to deal with his/her medications.

Strongly Disagree	Somewhat Disagree	Maybe	Somewhat Agree	Strongly Agree
☐	☐	☐	☐	☐

15) I feel embarrassed because of his/her behaviours or comments.

Strongly Disagree	Somewhat Disagree	Maybe	Somewhat Agree	Strongly Agree

☐ ☐ ☐ ☐ ☐

16) I am comfortable going out with him/her.

Strongly Disagree Somewhat Disagree Maybe Somewhat Agree Strongly Agree

☐ ☐ ☐ ☐ ☐

PART A (continued):

17) I don't like it when people notice his/her tremor or dyskinesia (abnormal involuntary movements).

Strongly Disagree Somewhat Disagree Maybe Somewhat Agree Strongly Agree

☐ ☐ ☐ ☐ ☐

18) I feel that he/she is still my friend.

Strongly Disagree Somewhat Disagree Maybe Somewhat Agree Strongly Agree

☐ ☐ ☐ ☐ ☐

19) I miss the good times we used to have together.

Strongly Disagree Somewhat Disagree Maybe Somewhat Agree Strongly Agree

☐ ☐ ☐ ☐ ☐

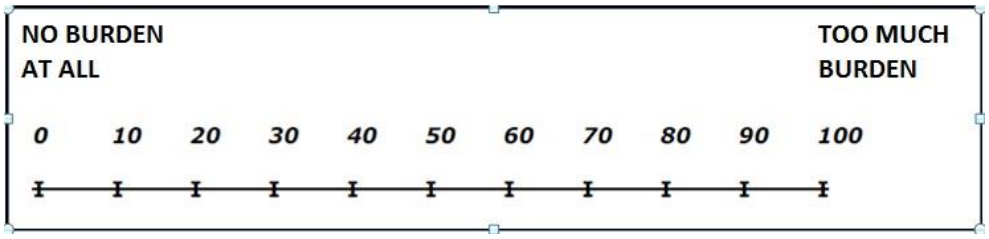
20) I am still able to make plans for the future, or to pursue my dreams.

Strongly Disagree Somewhat Disagree Maybe Somewhat Agree Strongly Agree

☐ ☐ ☐ ☐ ☐

* * * * * * *

<u>PART B:</u> PLEASE INDICATE WITH AN "X" on the scale below *how burdensome you generally feel caring your partner/family member is at the moment.* "0" means that you feel that your role as a caregiver is not hard at all, whereas "100" means that you feel it is much too hard. Please indicate with an 'X' on the scale:



Appendix B3: Parkinson's disease Interview Guide
Knowledge and practices of influential people (traditional healers, medicine sellers, religious leaders, and community health volunteers) regarding PD

Domains:
Diagnosis; therapeutic options; Disease course
Awareness of and experience in making PD Diagnosis:
How many years have you been practicing medicine /healing?
Have you heard about PD?
What terms are used for the disease
What are the common symptoms you associate with PD?
How common is the problem in the community?
Is it possible to identify the symptoms early before the patient develops complications?
How confident are you of making the diagnosis of Parkinson's disease?

Disease course
What is your opinion about Parkinson's disease' [what about those who have the disease?]
Can you share with us your experiences of PD prevention and management, and if this has been successful?
What questions do you ask patients (what would you like to know) from patients who come to you with these symptoms?
What is your opinion makes patients with PD symptoms come to you and (as well as, or) not attend the hospital?
How do you educate the community about the condition? What do you tell them?
What skills/information would you need to improve your ability to identify and manage PD?

Therapeutic options / methods and additional management strategies / package:
What are the roles of traditional healers and medical science in the treatment of PD?
What medicines or treatment methods are used?
Do you do follow-ups? How frequent?
Do you work in partnership/collaboration with medical doctors? Referrals, (e.g. to your fellow healers, medical officers?), etc.? how do you conduct referrals? How does it work?
What health information do you provide them with, if at all?
Is the information only for patients visiting your clinic? Do you teach the community about the disease?

What are some of the ways by which you make decisions on what treatment to use?
How do you assess treatment success?

Appendix B1: Parkinson's Disease (PD) Questionnaire (PDQ) for screening PD

Parkinson's Disease Diagnosis, Perceptions, Awareness, and Care in Kenya				
[THE PERSON COMPLETING THIS HOUSEHOLD QUESTIONNAIRE SHOULD BE THE HEAD OF HOUSEHOLD IF AVAILABLE. WHERE UNAVAILABLE, ANY SPOUSE OF THE HEAD OF HOUSEHOLD SHOULD BE SELECTED TO COMPLETE THE HOUSEHOLD QUESTIONNAIRE. IN THE CASE THAT NEITHER THE HEAD OF HOUSEHOLD NOR ANY SPOUSE IS AVAILABLE, PLEASE COMPLETE THE HOUSEHOLD QUESTIONNAIRE WITH ANY OTHER AVAILABLE CREDIBLE ADULT AGED 18+] **Mtu anayefaa kujaza hili dodoso la jamii yapasa awe ndiye kichwa au kiongozi wa jamii lengwa akiwa karibu. Kama hatapatikana, basi mchumba wake ndiye anayefaa kulijaza. Katika hali ambapo kichwa cha hiyo jamii wala mchumba wake hatapatikana, tafadhali chagua mwakilishi wa kuaminika na aliye na umri wa miaka 18 na zaidi ili kujaza hili dodoso**				
1.0 Background ***Utangulizi***				
1.1 Start Time Saa ya kuanza	[ ]			
1.2 Interviewer's Code Kitambulisho cha mwenye kuuliza maswali (mtafiti)	[ ]			
1.3 Date of Interview Tarehe	[ ]			
1.4 Structure no. Namba ya mpangilio	[ ]			
1.5 Room no. Namba ya chumba cha utafiti	[ ]			
1.6 Household ID Namba ya Kitambulisho cha nyumba au jamii	[ ]			
1.7 Household head name Jina la mwenye nyumba/kichwa cha familia	[ ]			
1.8 ID of the room where household head sleeps namba ya kitambulisho cha chumba cha kulala cha mwenye nyumba	[ ]			
1.10 Household head's ID kitambulisho cha mwenye nyumba	[ ]			

2.0 Introduction and Consent- Utangulizi na ridhaa

Hello, my name is……and I am working with the African Population and Health Research Center (APHRC). We are conducting a research study to assess the prevalence and diagnosis of Parkinson's disease (PD) and explore the awareness, perceptions, and care for people with PD in this community. To do this, the head of this household or an adult representative will be interviewed using a standardized PD questionnaire. Your participation in this research is completely voluntary. You may also refuse to answer any question which you do not want to answer, and no harm will occur to you or anyone in your family regardless of your participation decision. The information that you provide will be completely confidential. Your responses will be combined with the answers of other respondents involved in the study and reported in such a way that you will be identified. The interview will take less than 20 minutes.

Hujambo, jina langu ni…… na nafanya kazi na shirika la African Population and Health Research Center (APHRC). Tunafanya utafiti ili tuweze kutadhmini kuenea na kutambulika kwa ugonjwa wa Parkinson (PD). Tungependa kuchunguza kuelewa kwa watu kuhusu huu ugonjwa, mtazamo wao na, usaidizi wa kiafya wanaopata wenye huu ugonjwa katika jumuiya.
Ili kufanya hivyo, mwenye hii nyumba ama kichwa cha hii familia au mwakilishi wake aliye komaa, ataulizwa na kujibu maswali yaliyoandaliwa awali. Kumbuka kuhusika kwako kwa huu utafiti ni uamuzi wako na kupenda kwako. Pia, unaweza amua kutojibu swali lolote lile ambalo hutaki na hakuna madhara yoyote yatakayokupata wewe ama jamaa yako kutokana na uamuzi huo wako. Majibu utakayotoa kwetu yatahifadhiwa kwa siri kubwa. Majibu utakayotoa kwetu yataunganishwa na majibu mengine sawia tutakayopata kutoka kwa wahusika wengine na yaripotiwe kwa njia ambayo itatuwezesha kukutambua. Mahojiano haya yatachukwa chini ya dakika 20.

	Response option		
Item	**No La**	**Yes ndio**	**Don't know sijui**
2.1. Have you ever noticed stiffness in your legs? *Je ushapata miguu yako imekuwa ngumu kama kuganda hivi?*	[ ]	[ ]	[ ]
2.2. Have you ever had tremors of your head, arm, or legs that lasted more than 1 day? *Je ushawahi patwa na mtetemeko wa kichwa, mikono au miguu ambao ulidumu kwa muda wa zaidi ya siku moja?*	[ ]	[ ]	[ ]
2.3. Do you have trouble buttoning buttons or dressing? *Je una shida ya kufunga vitaki vya vazi lako au kuvaa nguo?*	[ ]	[ ]	[ ]
2.4. Have you or others noted that you do not swing one arm when you walk? *Je wewe ama wengine wamepata kujua kuwa mkono wako mmoja haubembei unapotembea?*	[ ]	[ ]	[ ]
2.5. Do your feet seem to get stuck to the floor when walking or turning? *Je unahisi kama miguu yako inakwama kwa sakafu ukitembea au ukigeuka?*	[ ]	[ ]	[ ]
2.6. Have you become slower in your usual daily activities? *Je umepata unafanya polepole mambo yako ya kila siku ambayo ulikuwa ukiyafanya kwa kasi hapo mbeleni?*	[ ]	[ ]	[ ]

Appendix B3: Parkinson's disease Interview Guide - maelezo kuhusu mahojiano ya ugonjwa wa Parkinson

Knowledge and practices of influential people (traditional healers, medicine sellers, religious leaders, and community health volunteers) regarding PD

Maarifa na mazoea ya watu wenye ushawishi (madaktari wa kienyeji, wauzaji madawa, viongozi wa dini, wajitolea wa afya ya jamii)

Domains: Vikoa

Diagnosis; therapeutic options; Disease course

Utambuzi; chaguzi za matibabu, mkondo wa ugonjwa

Awareness of and experience in making PD Diagnosis: Kuelewa na uzoefu wa kutambua PD

How many years have you been practicing medicine /healing? *Ni kwa miaka ngapi umefanya kazi ya utabibu?*

Have you heard about PD? *Ushawahi sikia kuhusu ugonjwa wa Parkinson - PD?*

What terms are used for the disease *Ni majina yapi hutumika kwa huu ugonjwa*

What are the common symptoms you associate with PD? *Ni dalili gani unahusisha na PD?*

How common is the problem in the community? *Je hii shida imeenea kwa kiasi gani katika jamii?*

Is it possible to identify the symptoms early before the patient develops complications? *Je kuna uwezekano wa kutambua dalili zake mapema kabla ugonjwa hujajitokeza?*
How confident are you of making the diagnosis of Parkinson's disease? *Je unauhakika gani wa kutambua huu ugonjwa wa Parkinson's?*

Disease course
What is your opinion about Parkinson's disease' [what about those who have the disease?] *Maoni yako kuhusu Parkinson's disease' (ama wale walio na huu ugonjwa?)*
Can you share with us your experiences of PD prevention and management, and if this has been successful? *Tafadhali elezea kuhusu uzoefu wako katika kuzuia na kudhibiti PD; Je, umepata kufanikiwa?*
What questions do you ask patients (what would you like to know) from patients who come to you with these symptoms? *Je wewe huwauliza wagonjwa maswali gani yaani ungependa kujua nini kutoka kwa wagonjwa wanaokuja kwako wakiwa na hizi dalili?*
What is your opinion makes patients with PD symptoms come to you and (as well as, or) not attend the hospital? *Kwa maoni yako nini hufanya wagonjwa wenye dalili za PD waje kwako ama wasije kwenye hospitali?*
How do you educate the community about the condition? What do you tell them? *Je wewe huelimisha jamii aje kuhusu hii hali? Je wewe huwaambia nini?*
What skills/information would you need to improve your ability to identify and manage PD? *Ni ujuzi au ufahamu gani ungehitaji ili uweze kuimarisha uwezo wako wa kutambua na kudhibiti PD*

Therapeutic options / methods and additional management strategies / package:
What are the roles of traditional healers and medical science in the treatment of PD? *Majukumu ya matabibu wa kiasili na tiba za kisayansi ni yapi?*
What medicines or treatment methods are used? *Dawa gani au mbinu gani za matibabu hutumika?*
Do you do follow-ups? How frequent? *Je wewe hufuatilia wagonjwa katika jamii? Kwa mara ngapi?*
Do you work in partnership/collaboration with medical doctors? Referrals, (e.g. to your fellow healers, medical officers?), etc.? how do you conduct referrals? How does it work? *Je wewe hufanya kazi kwa ushirikiano na madaktari? Wewe hutuma wagonjwa wako kwa tabibu wenzako, madaktari na kadhalika? Kutuma kwako kwa wagonjwa wakatibiwe kwingine hufanyikaje? Huwa inawezekanaje?*
What health information do you provide them with, if at all? *Wewe hupatiana maelezo gani ya kiafya kwa wagonjwa kama wewe huwapa?*
Is the information only for patients visiting your clinic? Do you teach the community about the disease? *Haya maelezo unayotoa, ni kwa wagonjwa wanaokuja kwako hospitalini tu? Je, wewe hufunza jamii nzima kuhusu huu ugonjwa?*
What are some of the ways by which you make decisions on what treatment to use? *Ni baina ya njia gani wewe hutumia kufikia uamuzi wa matibabu utakayotoa?*
How do you assess treatment success? *Wewe hutumia vipimo vipi kupima ufanisi wako?*