Proposal Format

Title of Study:
Exploring key stakeholders' perspectives on effective community engagement strategies to facilitate reporting aggregate genomic results to groups and communities: The Kenya Case Study

Investigators and Institutional Affiliations
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Abbreviations
AMREF- African Medical and Research Foundation
APHRC- African Population and Health Research Center
AWI-Gen- Africa Wits-INDEPTH partnership for Genomic Studies
CE- Community Engagement
CEBioGen- Community Engagement Biobanks and Genomics
CHVs- Community Health Volunteers
DNA-Deoxyribonucleic Acid
FGDs-Focus Group Discussions
H3A-Human Heredity and Health in Africa
HDSS- Health and Demographic Surveillance Systems
HICs- High income countries
NIH- National Institute of Health
ID- Identification
IDIs- In-depth Interviews
OHRP- Office for Human Reearch Protections
KEMRI- Kenya Medical Research Institute

Abstract
Community engagement (CE) has gained prominence as an important ethical practice, for conducting genomic studies and bio-banking, particularly in Africa context. However,

determining the effectiveness of CE strategies in supporting broad sharing of data and samples and the return of both individual genetic findings and aggregate genomic results to communities and groups remain a challenge. The overall goals of the Community Engagement in Biobanks and Genomics (CEBioGen) Collaborative Centre are to address this knowledge gap in CE and to build the capacity of a critical cadre of ethics and community engagement practitioners who can support the implementation of genomic and biobanking projects in the African continent.

The Africa Wits-INDEPTH partnership for Genomic Community Engagement (AWI-Gen-CE) study will (i) elicit key stakeholders' views on the value and purpose of CE in genomics, (ii) identify the core competencies that are required for best CE practices, (iii) examine the key ways in which local communities should be involved in genomics and biobanking in Africa and (iv) which African moral theory should underpin CE in Africa. The findings from this study will also feed into further development of several H3Africa guidelines and policies on consent, CE and feedback of findings. The study will employ a mixed social science methodology to address the study research questions. In Kenya we will conduct this study in three phases over a period of four years. This study budget is $19,008 for one year.

I. Introduction/Background

There is growing recognition that genomic research raises important ethical questions. These include what consent models are appropriate for reuse of archived samples, how samples and data ought to be shared, how privacy and confidentiality should be protected, how communities should be engaged in the research process and how to communicate genetic results to research participants (1–3). Although most of these questions have received considerable attention both through academic discourse and empirical research, very little attention is given to the question of what should count as best ethical practice in communicating research results to individuals, groups, families and communities in genomic research, particularly in Africa where genetic background is fairly new and can have negative social, political and economic consequences. In addition, although CE has been recognised as a process that needs to be carried out before, during and after a research project, there is very little evidence on how communities are engaged beyond the sampling and data collection stages of genomic studies (4). This also includes how individual genetic results and aggregate genomic research results are disseminated to research participants and their communities (5,6).

In most genomic studies several kinds of research results can be fed back. The assessments include blood pressure, lung function, bone density, height, weight, fat, and other measurements taken at baseline or at any subsequent assessment. There are two types of results: (i) Individual research results (which concern an individual participant, and have potential health or reproductive impact); and (ii) Incidental findings (which are unforeseen findings concerning a research participant that have potential health or reproductive importance). Incidental findings are discovered in the course of the research but are outside the research objectives. General research results refer to aggregate results drawn from the analysis of data and samples of a group of research participants (7).

The literature on reporting individual genetic research results to research participants is mainly from high-income countries (HICs) (8–12). The establishment of the H3Africa Consortium has given rise to a limited but growing literature including empirical studies on CE in the context of genomics research in Africa(4) (13,14). However, none of these studies have addressed the question of how CE can facilitate reporting genetic and genomic research results including individual genetic research findings and aggregate genomic results. Marsh et al 2011 conducted a study that explored ways in which community's views can help inform the development of policies on feedback of individual genetic findings. Many studies have not addressed questions related to methods of engagement that could facilitate the return of research results including aggregate genomic results and the obligations of secondary users of data from biobanks to return these results to research participants (15,16). Additionally, no study has explored these views from the perspectives of genomic researchers and research ethics committees in Africa.

II. Problem Statement

Experiences from the first round of H3Africa projects have suggested that there are expectations for return of results from communities that participated in genomic studies, but questions remain about what results ought to be returned to communities and how these results should be presented.

The value of engaging stakeholders in genomic research, particularly on decisions around sample and data sharing as well as feedback of findings is not well understood. The CEBioGen collaborative Centre seeks to address this knowledge gap through empirical research and normative analysis by exploring stakeholders' views and identifying best practices that can support the implementation of genomic studies in Africa.

We expect findings to be highly relevant in our continental context and to contribute insights far more widely. With the advent of genetic and genomic research, there have been recent calls for the development of genuine partnerships with relevant communities including sample donors. The view is that CE in the context of genomic research is an additional layer of protection for researched communities. It is an opportunity to provide information to research participants over a period of time, to enhance research understanding particularly with the complexities involved in genomic studies and provides an avenue for feeding back research findings(17).

III. Review of Literature

Community engagement is generally defined as a process of working collaboratively with a group or groups of people on a shared goal or common interest [4] and has been recognized as an important requirement for the ethical conduct of biomedical research, particularly in resource-constrained settings where the commuites are vulnerable. Many have argued that CE can support the successful implementation of research by ensuring that research is locally relevant. It is also an important step to extending the ethical principle of respect for persons to communities, ensuring the protection of individuals and their communities and building a trusting relationship between

researchers and communities as well as facilitating the smooth conduct of research (4,18,19).

It is generally acknowledged, in the literature, that genomic studies raise important ethical issues related to seeking culturally appropriate consent, determining the effectiveness of CE, maintaining privacy, determining ownership and control of samples and associated data(1,2,20). Recently, CE has gained prominence as an important ethical practice that can support the successful implementation of genomic research in Africa with key funders such as the US National Institutes of Health and the Wellcome Trust making community engagement a requirement for funding.

While there is extensive literature on feedback of individual genetic research findings including how to handle incidental findings(3,21–23), discussions on these issues have only evolved recently within the H3Africa Consortium in Africa. In the context of biobanks, empirical studies have suggested that despite the growing acceptance of broad consent for genomics and biobanking, there is also an expectation from research participants and sample donors for some feedback on the range of projects in which their samples and data will be used (24–28). In a recent publication, the H3Africa CE working group suggested that given the increasing interest and investments on CE from the key funders of the H3Africa Consortium, it is important for research projects to be able to demonstrate the impact of their CE strategy and justify the expenditure to funders (29).

Increasingly, research community has argued that researchers have an ethical obligation to share research results to participants based on the principles of respect, beneficence and reciprocity (30–32). Communicating research results does not only demonstrate respect to participants but also acknowledges their important contribution to science. Feedback is also about sharing knowledge which could help participants and their communities live healthier lifestyles which could contribute to positive health outcomes. For example, Kerasidou has recently proposed that communicating aggregate findings from genomic studies should be perceived as ‘sharing knowledge’ and not ‘returning results’. She argues that the dissemination of ‘aggregate findings as sharing of knowledge not only describes the exercise more accurately but can also help mitigate some of the risks involved with returning non-individual aggregate results’ (33). A key challenge to sharing such aggregate knowledge is finding the appropriate methods and how the views of communities ought to be incorporated into policies guiding decisions on when, how and what to feedback to research participants and communities participating in genomic studies. The impact of genomic research will be enhanced when communities embrace the results and fully understand its value to their families and future generations. If appropriately communicated, the results could foster a sense of uniqueness in the context of a larger whole and also has historical value (e.g. population genetic findings).

The proposed CE component of the study will seek to address this knowledge gap through empirical research and normative analysis by exploring stakeholders' views and identifying best practices that can support the implementation of genomic studies in Africa.

IV. Research Objectives

General Objectives

This study aims at identifying innovative CE models for returning aggregate genomic results to groups and communities in Africa

Specific objectives

1. To explore key stakeholders' views on the role of CE in feeding back genomic results.
2. To identify best methods of feeding back research results to communities.
3. To explore community perspectives on participation in genomic cohort studies.

V. Conceptual Framework and Operationalization

Figure 1 is a schematic representation of the AWI-Gen phase 1 CE model. In this study, there will be an emphasis on CE before, during and after the second wave (AWI-Gen II) of data collection. These engagements will be informed by the work of the present study. In AWI-Gen II the participants will be re-consented and once again the model of broad consent will be used. Five of the six participating AWI-Gen sites are Health and Demographic Surveillance Systems (HDSS) sites and this partnership leverages their infrastructure and data to identify the participants for follow-up research. Several of the HDSSs already have divisions that specialize in CE, but the emphasis has not been on genomic studies and feedback of data.

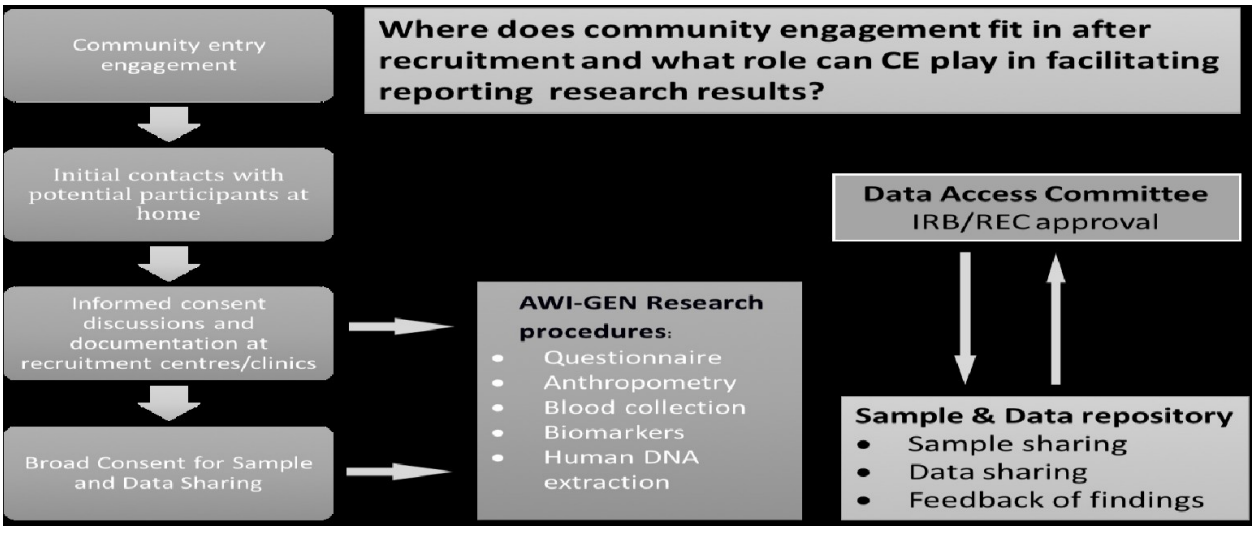

Figure 1: A schematic representation of the AWI-Gen CE model

One obvious challenge with this model is the extent to which CE should be carried out beyond the recruitment stage and how CE can support the return of research results to communities. Given the growing expectation of community members for some feedback from the AWI-Gen study, it will be important to gauge community views on what they consider to be good ethical practices for returning research results. Embedding this ethics research in an ongoing scientific project like AWI-Gen will ensure that the recommendations drawn from this research informs research practice. Key stakeholders will be drawn from three of the six sites to address our research questions: Navrongo in northern Ghana, Agincourt in South Africa and Nairobi in Kenya.

VI. Hypotheses

The ideal model for community engagement for genomic work in this community is not known.

VII. Study Design and Sampling Strategy

a) Study design:

We will employ a mixed social science methodology to address our research questions. Drawing insights from Creswell's interpretation of pragmatism, we will adopt this approach for this study. In this approach, individual researchers have a "freedom of choice and are free to choose the methods, techniques, and procedures of research that best meet their needs and purposes" (28,29). This will include qualitative study that will utilize in-depth interviews (IDIs), focus group discussions (FGDs) and deliberative workshops and interviewing of various key stakeholders including members of research ethics committees, genomic researchers, community gatekeepers, fieldworkers and community facilitators. The quantitative strategies will involve simultaneous or sequential collection of both numerical and textual information to best understand the research problem. The quantitative arm will test the general acceptabilityof various of the various CE methods feedback.

b) Study site (geographical)

The study in Kenya will be conducted in Nairobi, specifically in Korogocho and Viwandani urban informal settlements whose populations have been under surveillance since 2003 as part of the Nairobi Urban Health and Demographic Surveillance System (NUHDSS) project.

c) Sampling

The AWI-Gen study collected data and DNA samples from 2006 individuals, aged between 40 and 60 years from 2014-2016. We will first approach 56 of these participants, 20 of these will be involved in IDIs, while 36 will be involved in FGDs. Interviews will continue until we have either contacted all 56 individuals or reached saturation. We will obtain the contact information of those who refused participation from the AWI-Gen research team. Depending on the numbers involved, we will purposively approach all (if they are less than 10-15 people) or randomly approach a

percentage of them until we have reached 10-15 people or a point of saturation. The 56 participants, who reside in the NUDSS sites, will be traced using phone calls (their phone numbers were documented during AWI-Gen I) and by visiting their structure with help of community health volunteers (CHVs). We will also conduct IDIs with these individuals who declined to participate in the AWI-Gen study.

VIII. Data Collection

Data will be collected using IDIs and FGDs by trained interviewers among community members, study coordinator/fieldworkers and the research ethics committees using a semi-structured interview guides. The interviews will be collected in both English and Kiswahili. IDIs and FGDs will be conducted in a private location. The IDIs will take about 40-60 minutes of a participant's time. Focus groups will include 8-10 participants each and will take between 90-120 minutes.

a) Qualitative data collection

Field workers will be recruited and trained to collect data, supervised closely by APHRC researchers. We will conduct the study in three phases over a period of four years:

Phase One: Following ethical approval for this study, we will conduct a scoping exercise in each of the two slums in Nairobi (Korogocho and Viwandani) to document the CE activities of the studies and to conduct preliminary interviews with research participants on their expectations and preferences for receiving feedback.

Phase Two: This will involve qualitative research to elicit the views of key stakeholders on genomic research more broadly and the perceptions about returning research results, and to identify innovative methods of approaching and returning genomic results to various constituencies within research communities.

Data will be collected from three main sources; document review, semi-structured interviews and FGDs. We will conduct a review of existing international guidelines and policies on feedback of genetic results as well as consent forms for the AWI-Gen studies across the three sites. The aim of this review is to understand the key scientific rationale for feedback.

Semi-structured interviews and Group discussions with key stakeholders:

Deliberative workshops have become popular for soliciting public views and enhancing understanding of complex issues, encouraging public engagement and participation in research (29,32). They also allow for a deeper understanding of the key values underlying the participants' perception of a research practice or policy. They often involve the use of qualitative methods including small group discussions and mini-workshops. Three categories of stakeholders will be targeted for this study, namely (i) community members and research participants, (ii) fieldworkers and study coordinators and (iii) members of research ethics committees as outlined below:

1. ***Community members:*** We will recruit two different groups of community members for this first phase of the study.
   The first group will include those that participated in the first phase of the AWI-Gen study and the second group will be prospective participants in H3Africa AWI-Gen 2.

Semi-structured individual interviews will be conducted among those who have participated in H3Africa AWI-Gen.

These interviews are likely to take place between three to six months after their participation in AWI-Gen. For participants who consented, we will explore views on their experiences and understandings of the consent process, as well as their views on the value of receiving feedback of results. For those who refused to participate, we will seek insights into the main reasons for refusal and whether these reasons are related to the lack of feedback.

2. ***Study Coordinators/Fieldworkers*:** We will purposively select all the study coordinators and fieldworkers who participated in AWI-Gen I in Nairobi for FGDs. These frontline staff often work closely with research participants and serve as a link between the local community and the research institutions. Their interactions with these communities provide an important opportunity to understand the key ethical and practical issues that often arise during the consent process and the local concerns around some of the scientific practices of biological samples and data collection. These group discussions will aim at understanding how the issue of feedback of results was discussed with participants, the expectations of the participants, challenges arising in practice and proposed solutions.
3. ***Research Ethics Committees*:** We will also purposively select members of the ethics committees of AMREF and KEMRI in Nairobi. We will conduct IDIs with members of these committees to deliberate on the key ethical concerns around feedback of research results in order to identify what counts as good ethical practice.

The four categories of stakeholders for interviews at each research site will include the following:

Stakeholders	**Data collection methods**	**Estimated Number of interviews/group discussions**
1. Study scientist (Nairobi site)	Semi-structured interview	1-2
2. Members of research ethics Committees	IDIs	1-2 deliberative consultations in Kenya
3. AWI-Gen Research Participants	In-depth interviews	20 interviews at each site - Nairobi
4. AWI-Gen research Participants	Focus group discussions	4 FGDs in Nairobi
5. Fieldworkers/field Coordinators	Focus group discussions	1 in Nairobi

Total number of interviews		**20-22 interviews and 5 FGDs**

Table 1: Proposed Sample for semi-structured interviews and focus group discussions

Phase Three: CE evaluation
Aim 2 of this study seeks to identify best practices of reporting genomic research results. Under this aim, we will seek to conduct an evaluation of CE methods that will be developed based on the results from Phase One of the study Working in collaboration with the AWI-Gen study, we will carry out a feedback session with various communities within the selected HDSSs. The design of this community feedback will be based on recommendations from Phase Two of the study. Based on the recommendations that will be drawn from the interviews and FGDs, we will design a CE model that will involve reporting aggregate results from the AWI-Gen study.

Following the series of community feedback, we will seek the views of community members on the approach used for the feedback, what worked and what can be done to improve the process. This phase will employ both quantitative and qualitative research methods. We will develop a survey instrument to assess the acceptability of various CE models that have been proposed by research participants in Phase Two using the results of the qualitative arm of the study in Phase One. The instrument will be refined and validated through a pilot study involving a small number of participants, before being used more widely. We will randomly select 60 community members (including roughly equal groups of AWI-Gen and study-naive participants) between the ages of 20 and 60 years with an equal representation of both men and women in four age categories: 20-29, 30-39, 40-49 and 50-60 from the NUHDSS. We also aim to conduct 2 FGDs in Nairobi (Korogocho and Viwandani) to explore community views on the acceptability of the method of feedback.

b) Training of research assistants and piloting
Training of the field team will include the study rationale, objectives, study approach and the data collection procedures. In addition, the training will cover ethical issues, specifically confidentiality, privacy and voluntary participation.

The team will also be taken through informed consent, to explain the key elements and clarify any issues that may not be clear. They will also be taken through every question to understand its purpose, the data it is intended to collect, and the objective it answers. The training will involve lectures, open discussions, demonstrations and role plays. A 2-day pilot will be undertaken outside the study areas. A one-day debriefing session will be held to discuss any questions that are unclear, wrong instructions, questions respondents struggled with etc. Thereafter the tools will be revised and printed.

Ethical considerations

We will seek ethics approval from AMREF Institutional Review Board in Kenya before approaching potential research participants for this study. This committee has an active federal wide assurance with the United States Office for Human Research Protections (OHRP). All data collection tools, guides, participant information sheets, and consent

forms will be translated into Swahili. This will allow for participants whose preference is Swahili to participate with ease.
All participants will receive an information sheet and a clear verbal explanation of the different steps of the research process prior to signing or applying thumbprints to the consent forms. Written informed consent will be obtained from all research participants that will be approached to participate in the study. This will involve explaining the aim and procedures of the study to them, emphasizing that their participation is voluntary, assuring them of confidentiality and addressing any questions that may arise during the consent process.

IX. Data Processing and Analysis

To facilitate the management and analysis of the data, all the interviews will be audio recorded and transcribed, where interviewees consent to the use of recorders. Where permission to record is not granted, notes will be taken during the interview and an account of the interview prepared immediately afterwards. Interviews that are not conducted in English will be translated into English by trained translators. All interviewees will be assigned a unique identifier (an ID number) which will be used on all transcripts. Real personal names and names of places of residence will not be included in any data. A database linking real names and ID numbers will be stored securely and separately from the data and will be accessible only to the PIs. To protect against potential data loss, backup data files will be prepared weekly in the field. Audio recordings will be deleted at the end of the study

Data analysis will be an ongoing process during the course of the study. We will follow the steps used across many different qualitative analytical traditions with a particular focus on *thematic* analysis, which will focus on an in-depth description and conceptual interpretation of the entire data set (30,33). Qualitative data will be transcribed verbatim. Rapid analysis of the transcribed qualitative data will be done through systematic reading through the transcripts. A qualitative software package (Nvivo 11) will be used to aid in the management and support analyses. Thematic content analysis will be used to identify specific themes used to guide data collection, and then augmented by themes emerging from the data.

The quantitative arm of the study will be analysed using stata 15.0. The qualitative arm will test the general acceptability of the various CE methods for feedback. The quantitative analysis will be developed based on the results of qualitative arm of the study in phase one and two.

X. Plan for Communicating Findings of the Study

Community engagement (CE) will be an integral part of the proposed study and will be carried out before, during and after the study. Each of the participating AWI-Gen sites have established CE methods that have proved successful for the conduct of research for many years. These methods include initial community entry processes with community gatekeepers and meetings with various constituencies within the target communities including women groups and youth groups. The CE methods will be

complemented by the development of educational tools, information leaflets and radio discussions.

The main goal of the CE strategy for this study will be to improve general understanding of genomics and non-communicable diseases among participating communities. We will develop information leaflets that will be disseminated to various communities members. These leaflets will contain key messages of clinical utility and advice on a healthy lifestyle. To ensure that we are giving back to the community, we will aim at developing other educational materials such as a video documentary dubbed 'The Journey of my Sample' which will illustrate how human biological samples that are collected at the community level are handled, how DNA is extracted, and how aliquots are transported. This CE tool will be developed in collaboration with the team to support an ongoing engagement with the various communities that will be involved in the collaborative studies. The planned community engagement strategy for this study is illustrative in

Figure 2:

Figure 2: Community engagement strategy

Expected output

The study will generate valuable insights into what will count as best ethical practice in returning aggregate genomic results to groups and to communities. Stakeholders' recommendations are expected to feed into H3A policies on CE and guide findings. Findings from this study will support the development of innovative CE models that can be adopted for various genomic studies in Africa. We will also develop two key manuscripts that report the findings from the study in international peer reviewed journals.

XI. Study Limitations and Risks

One limitation of this study is that we may not be able to reach all the proposed study participants as time has passed since data was collected in 2014-2016. There maybe participated in recall bias as the study particpants may have forgotten the genomic study they participated in. Also there is a likelihood of getting desirable answers from the fieldworkers involved in AWI-Gen I data collection.

XII. Management and Organization of the Study

a) Role of each Investigator

Catherine Kyobutungi, the Kenya site PI is an executive director at APHRC. Her role is to provide overall intellectual guidance and coordination of the study, supervise the research officers' activities, and provide the external reporting needed by the funder. She will participate in data analyses and will lead the site-specific scientific publications

Gershim Asiki is a research scientist at APHRC. His role will be to manage the study hence will be in charge of overall coordination of the study including overseeing the research activities, dissemination and policy engagement and reporting. He will be leading the quantitative and qualitative aspect of the study. He will participate in the analyzing the data and writing scientific outputs.

Shukri Mohamed is a research officer at APHRC. Her role will be to coordinate the activities for the study. She will manage the day to day study management and will be primarily responsible for the quality of the data and samples collected in Kenya. She will participate in data analysis and scientific writing.

Isaac Kisiangani is a research officer at APHRC. His role will be to oversee the study activities. He will manage the day to day study management and will be primarily responsible for the quality of the data and samples collected in Kenya. He will supervise the research assistant and participate in data analysis and scientific writing.

A research assistant will also coordinate the day to day data collection activities, organize field logistics and oversee data collection work. This person will participate in data analysis and scientific writing.

b) Time Frame/Duration of the Study

AWI-Gen study II is expected to last four years, with the ethics approval taking place at the onset of year 1. Following ethics approval for this study, (April/June), the recruitment and training of the data collectors will be conducted in June. Thereafter community engagement as well as the scoping exercise will be conducted at each of the participating AWI-Gen sites in Korogocho and Viwandani slums in Nairobi to document the CE activities of the study and conduct preliminary interviews with research participants. Data collection will begin in June/July and is expected to last two months. The data management component will take about 2-3 months and will take place in year two of the study. Follow-up interviews will be done during the presentation of preliminary findings in year 2. Formal data analysis, dissemination of findings, manuscript development and submission of the final report to the NIH will occur in years 3 and 4.

CEBioGen Study Timeline

Activity	Year 1	Year 2	Year 3	Year 4
Obtain ethics approvals				
Community engagement				
Phase 1: scoping visits				
Participant identification and preliminary interviews				
Phase 2: CE evaluation qualitative interviews				
Formal data analysis of survey				
Follow-up interviews during presentation of preliminary findings				
Dissemination of findings/ public engagement activities				
Develop two manuscripts for publication				
Submission of final report to the NIH, Developing manuscripts for publication				

- **1) Summary Budget**

Item	Sub-total (USD)	Sub-total (KES)
Personnel costs	$11,000	1,100,000
Materials and Office Consumables	$1,500	150,000
Field work and Data Collection	$2,500	250,000
Community engagement (CE)	$2,100	210,000
Ethics review	$500	50,000
Indirect costs	$1,408	140,800
Total	**$19,008**	**1,900,800**

*exchange rate of KES 100= 1USD

2) Justification of the budget

The budget is based onthe current estimates of prices and wages and includes, competitive field allowances, and estimated institutional administrative overheads. The personnel salaries and benefits costs cover the facilitative fee for the proportion of time that the Principal Investigators, Co-Investigators, data systems manager, program assistant and community relations office will devote to the activity. Community meetings to sensitize the community on the study and disseminate findings have also been budgeted for. Data collection costs include; training costs for the field team, fieldwork costs and consumables costs. The budget also includes materials, office consumables costs and equipment to facilitate data collection. The institutional administrative overheads (indirect costs) are calculated at 8% of the total costs.

XIII. Appendices and References

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b) Appendices

Appendix 1: Curriculum Vitae of Investigators

CV of (Dr. Kyobutungi Catherine)

Proposed Position in Research:	Kenya Site Principal Investigator
Proposed role in the study:	Technical oversight
Organisation:	African Population & Health Research Center
Name of Staff:	Dr. Kyobutungi Catherine
Profession:	Epidemiologist, Executive Director
Date of Birth:	January 7th 1972
Years with Organisation:	Ten
Nationality:	Ugandan
Membership in Professional Societies:	International Epidemiology Association Global Health Systems
Detailed Tasks Assigned in Study:	She is will be the Kenya Site PI and will offer overall technical direction to the study and be the main contact person for any correspondence.

Education & Qualifications:

Qualification	Awarding Institution	Country	Year
PhD – Epidemiology	Medical faculty of the Ruprecht-Karls-University, Heidelberg	Germany	Jan 2006
MSc – Community Health and Health Management (CHHM)	Ruprecht-Karls-University, Heidelberg,	Germany	Sept 2002
MBChB	Makerere University Kampala,	Uganda	1995

Employment Record:

From (year)	To (Year)	Position	Employer
October 2017	To-date	Executive director	African Population and Health Research Center
20th Nov 2014	October 2017	Director of Research	African Population and Health Research Center
Jan 2013	2014	Senior Research Scientist: Head, Health Challenges and Systems Research Program and Head of Policy Engagement and Communications	African Population and Health Research Center
Jan 2010	Dec 2012	Research Scientist	African Population & Health Research Center, in Nairobi Kenya
Nov 2007	Dec 2009	Associate research Scientist	African Population & Health Research Center, in Nairobi Kenya
May 2006	Oct 2007	Post-doctoral fellow	African Population & Health Research Center, in Nairobi Kenya

Summary of research experience:

I have been involved in research since 2002 when I embarked on my PhD studies. Soon after my PhD studies, I joined APHRC in 2006 as a post-doctoral fellow where I have been involved in research on a full time basis. Since 2006, I have been a research project manager of more than 14 projects and a principal investigator on more than 10 projects. I have published more than 60 peer-reviewed papers.

Selected Peer-Reviewed Publications:

1. Haregu TN, Oti S, Ngomi N, Khayeka-Wandabwa C, Egondi T, **Kyobutungi C.** Interlinkage among cardio-metabolic disease markers in an urban poor setting in Nairobi, Kenya. Glob Health Action. 2016 Feb 9;9:30626. doi: 10.3402/gha.v9.30626. eCollection 2016. PubMed PMID: 26864740.
2. Atela M, Bakibinga P, Ettarh R, **Kyobutungi C**, Cohn S. Strengthening health system governance using health facility service charters: a mixed methods assessment of community experiences and perceptions in a district in Kenya. BMC Health Serv Res. 2015 Dec 4;15(1):539. doi: 10.1186/s12913-015-1204-6. PubMed PMID: 26637186; PubMed Central PMCID: PMC4670501.
3. Werner ME, van de Vijver S, Adhiambo M, Egondi T, Oti SO, **Kyobutungi C**. Results of a hypertension and diabetes treatment program in the slums of Nairobi: a retrospective cohort study. BMC Health Serv Res. 2015 Nov 17;15(1):512. doi: 10.1186/s12913-015-1167-7. PubMed PMID: 26577953; PubMed Central PMCID: PMC4650397.
4. van de Vijver S, Oti S, Oduor C, Ezeh A, Lange J, Agyemang C, **Kyobutungi C**. Challenges of health programmes in slums. Lancet. 2015 Nov 21;386(10008):2114-6. doi: 10.1016/S0140-6736(15)00385-2. Epub 2015 Oct 6. PubMed PMID: 26452707.
5. Oti, S., van de Vijver, S., **Kyobutungi, C**., Gomez, G.B., Agyemang, C., Eric P. Moll van Charante, E.P., Brewster, L.M., Hendriks, M.E., Schultsz, C., Ettarh, R., Ezeh, A., and Lange, J (2013). A community-based intervention for primary prevention of cardiovascular diseases in the slums of Nairobi: The SCALE UP Study protocol. *Trials* Dec 1; 14:409.
6. Ettarh, R., van de Vijver, S., Oti, S., and **Kyobutungi, C** (*2013*). Overweight, obesity and perception of body image among slum residents in Nairobi, Kenya. *Preventing Chronic Disease* Dec 19; 10:

7. **Oti, S.O., van de Vijver, S.,** Agyemang, C., & **Kyobutungi, C** (2013). The magnitude of diabetes and its association with obesity in the slums of Nairobi, Kenya: results from a cross-sectional survey. *Tropical Medicine and International Health* Dec;18(12):1520-30
8. Egondi, T., **Kyobutungi, C**., Ng, N., Muindi, K., Oti, S., van de Vijver, S., Remare, E. and J. Rocklöv, (2013). "Community Perception of Air Pollution and Related Health Risks in Nairobi Slums" International Journal of Environment Research and Public Health, Vol. 10 4851-4868.
9. **Van de Vijver, S., Oti, S.O.,** Cohen, T., Hankins, C., **Kyobutungi, C**., Gomez, G. B., Brewster, L., Agyemang, C., and Lange, J (2013). Introducing a model of cardiovascular prevention in Nairobi's slums by integrating a public health and private sector approach: the SCALE UP study. *Global Health Action* Oct 21;6:
10. Van de Vijver, S., & Oti, S.O., Agyemang, C., Gomez, G., & **Kyobutungi, C (2013)**. Prevalence, awareness, treatment and control of hypertension among slum dwellers in Nairobi Kenya. *Journal of Hypertension.* May; 31(5): 1018-24
11. Di Cesare, M., Khang, Y., Asaria, P., Blakely, T., Cowan, M.J., Farzadfar, F., Guerrero, R., Ikeda, N., Kyobutungi, C. Msyamboza, K.P., Oum, S., Lynch, J.W., Marmot, M.G., & Ezzati, M on behalf of the Lancet NCD Action (2013). Group Inequalities in non-communicable diseases: challenges and opportunities for action. *The Lancet.* February; 381 (9866): 585-597
12. Ye Y, **Kyobutungi C**, Ogutu B et al (2013) Malaria mortality estimates: need for agreeable approach - Editorial- *Tropical Medicine and International Health*, DOI: http://dx.doi.org/10.1111/tmi.12020. February; 18(2): 219-221
13. Egondi, T., **Kyobutungi**, **C.,** Kovats, S., Muindi, K., Ettarh, R., Rocklöv, J (2012). Time-series analysis of weather and mortality patterns in Nairobi's informal settlements. *Global Health Action 5: 19065*
14. Ekirapa A, Mgomella GS, **Kyobutungi C** (2012). Civil society organizations: Capacity to address the needs of the urban poor in Nairobi**.** *J Public Health Policy*. Nov;33(4):404-22
15. Ettarh, R., Mutua, M.K., **Kyobutungi, C.** (2012). Ethnicity and delay in measles vaccination in a Nairobi slum. *Tropical Medicine and Health*, *40*(2): 59-62
16. Ettarh R. Kimani, J.K., & **Kyobutungi, C.** Correlates of HIV status awareness among adults in Nairobi slums. *African Journal of AIDS Research. 11(4): 337-342*
17. Ettarh, R., & **Kyobutungi, C** (2012). Physical access to health facilities and family planning in Kenya. *Journal of Family Planning and Reproductive Health Care, 16[3]: 47-55*
18. Bellows B, **Kyobutungi C**, Mutua MK, Warren C, Ezeh A (2012). Increase in facility-based deliveries associated with a maternal health voucher programme in informal settlements in Nairobi, Kenya. *Health Policy and Planning*. 27(4),1-9
19. Kimani JK, Ettarh R, **Kyobutungi C**, Mberu B, Muindi K (2012).. Determinants for participation in a public health insurance program among residents of urban slums in Nairobi, Kenya: results from a cross-sectional survey. *BMC Health Service Research*. 19; 12 :66.
20. Karanja S, Mbuagbaw L, Ritvo P, Law J, **Kyobutungi C**, Reid G. Ram R, Estambale B. and Lester R. (2011). A workshop report on HIV mHealth synergy and strategy meeting to review emerging evidence-based mHealth interventions and develop a framework for scale-up of these interventions. *The Pan African Medical Journal, 10*, 37.

21. Ziraba, A.K., **Kyobutungi, C.,** & Zulu, E.M. (2011). Fatal injuries in the slums of Nairobi and their risk factors: results from a matched case-control study. *Journal of Urban Health, 88* (Suppl 2), 256-265.

22. Kimani-Murage EW, Madise NJ, Fotso JC, **Kyobutungi C**, Mutua MK, Gitau TM, Yatich N (2011). Patterns and determinants of breastfeeding and complementary feeding practices in urban informal settlements, Nairobi Kenya, *BMC Public Health* May 26; 11: 396

23. Falkingham JC, Chepngeno-Langat G, **Kyobutungi C**, Ezeh A, and Evandrou M (2011). Does Socioeconomic Inequality in Health Persist among Older People Living in Resource-Poor Urban Slums? *Journal of Urban Health 88* (Suppl 2), 381-400

24. Ng N., Kowal, P., Kahn, K., Naidoo, N., Abdullah, S., Bawah, A., Binka, F., Chuc, N.T., Debpuur, C., Egondi, T., Xavier Gómez-Olivé, F., Hakimi, M., Hirve, S., Hodgson, A., Juvekar, S., **Kyobutungi, C.,** Van Minh, H., Mwanyangala, M.A., Nathan, R., Razzaque, A., Sankoh, O., Kim Streatfield, P., Thorogood, M., Wall, S., Wilopo, S., Byass, P., Tollman, S.M., & Chatterji, S. (2010) Health inequalities among older men and women in Africa and Asia: evidence from eight Health and Demographic Surveillance System sites in the INDEPTH WHO-SAGE Study. *Global Health Action.* 27: 3

Selected Successful Grant Applications

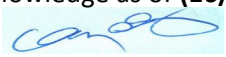
1. IDRC: **Principal Investigator**; *Building Research Capacity and the evidence base for Multi-Sectoral Action for NCD prevention in SSA*; Jan 2013-Dec 2016. (**Grant amount: USD 1,726,534**)
2. Comic Relief: **Principal Investigator**; *Partnerships for Maternal, newborn and child health in Nairobi's slum settlements;* Jul 2012-Dec 2015. **(Grant amount: GBP £1,525,191)**
3. NIH**: Co-applicant;** *Genomic and environmental risk factors for cardiometabolic disease in Africans (H3Africa)*; Aug 2012-Jul 2015. **(Grant amount: USD 240,000)**
4. ESRC: **Co-applicant**; *Understanding resilience in later life in a low resource setting*; Jan 2013-Dec 2014. (Grant amount:~GBP 84,500)
5. MRC/ESEI: **Co-PI**; *Epidemiology, Ecology and Socio-Economics of Disease Emergence in Nairobi*; Aug 2012 – Jul 2017. **(Grant amount: USD 404,000)**
6. Wellcome Trust: **Supervisor**; *Assessing the impact of personalized home-based counselling on MIYCN in Nairobi's slum settlements*; Mar 2012 – Feb 2015. **(Grant amount: USD 684,111)**
7. GlaxoSmithKline Oncology Ethnic Research Initiative (GSK ERI): **Co-PI**; *Triple Negative Breast Cancer (TNBC) in Kenya – A centrally coordinated approach to determine prevalence and clinico-pathologic characteristics of high risk breast cancer in distinct ethnic groupings*; Mar 2012-Feb 2014; **(Grant amount: ~USD 57,000)**
8. Amsterdam Medical Center (AMC) Foundation; **Co-PI** *Scalable models for primordial and primary prevention of CVD in slum populations in Nairobi; Kenya*; Aug 2011 – Jul 2014. **(Grant amount: 1m Euros)**
9. Office of U.S. Foreign Disaster Assistance (OFDA): **Co-PI**; Sep 2010 to Sep 2013; *Development of Indicators for Urban Humanitarian Emergencies*. **(Grant amount: USD 812,000)**
10. World Diabetes Foundation: **Principal Investigator**; Mar 2009 – Feb 2012; *Improving the lives of diabetics in Nairobi's slums through access to quality health care*. **(Grant amount: USD 200,000)**
11. Doris Duke Charitable Foundation; **Core team member**; Oct 2008-Mar 2009; *The partnership for a healthy Nairobi – improving the quality of health services for residents in three Nairobi slums Planning grant*. (**Grant amount: USD 149,923**)

12. Wellcome Trust; **Principal Investigator**; Jan 2008 to Dec 2010; *Assessing the linkages between socioeconomic status, perceived personal risk, and risk factors for cardiovascular and related non-communicable diseases in a population of slum dwellers in Nairobi, Kenya*. (**Grant amount: GBP 307,949**)

Language proficiency:

Language	Speaking	Reading	Writing
English	✓	✓	✓
Swahili		✓	

I, (Kyobutungi Catherine), certify that the information provided here in is correct to the best of my knowledge as of **(16/06/2019).**



CV of (Gershim Asiki)

Proposed Position in Research:	Study Manager
Proposed role in the study:	Kenya team lead
Organisation:	African Population & Health Research Center (APHRC)
Name of Staff:	Gershim Asiki
Profession:	Research Scientist
Date of Birth:	18 August 1975
Years with Organisation:	2 years
Nationality:	Ugandan
Membership in Professional Societies:	International Society of Social Paediatrics (ISSOP)
Detailed Tasks Assigned in Study:	Supports a cohesive team to ensure that the study is efficiently implemented and contributes to dissemination of the results through publications and policy engagement Also participates in proposal writing to fundraise for further research in the same theme. Also mentors junior researchers and represents the Centre at high – level national, regional and international forums, including relevant technical working groups and expert committees

Education & Qualifications:

Qualification	Awarding Institution	Country	Year
PhD	Karolinska Institutet	Sweden	2016
M.Sc. International Health	University College London	UK	2007
Medicine and Surgery (MBChB)	Makerere University	Uganda	2000

Employment Record:

From (year)	To (Year)	Position	Employer
August 2019	To date	Research Scientist	African Population and Health Research Center, Nairobi
2017	July 2019	Associate Research Scientist	African Population and Health Research Center, Nairobi
2015	2017	Technical Advisor	ICAP at Columbia University
2008	2015	Senior Scientist	Medical Research Council/Uganda Virus Research Institute
2007	2008	Project Medical Officer	Infectious Diseases Institute, Uganda
2001	2006	Medical Officer	Nyapea Hospital, Uganda
2000	2001	Internship	Mulago National Referral Hospital

Summary of research experience:

Asiki has a research experience of 10 years, first worked with the British Medical Research Council (MRC) Unit in Uganda (2008-2015), leading research projects (population based studies and clinical trials) on HIV and non-communicable diseases in vulnerable rural farming and fishing populations in Uganda. He later joined ICAP at Columbia University (2015-2017) as a Technical advisor and provided technical support to country-wide Population based HIV Impact Assessments (PHIAs) in Uganda, Namibia and Cameroon. He currently works at APHRC as an Associate Research Scientist in the Health and Systems for Health Unit focusing on generating evidence to drive stronger and more resilient systems for improved health of vulnerable populations. He provides scientific leadership to programs and projects, supports a cohesive team and ensures projects in thematic area of NCDs are efficiently implemented and , contributes to policy engagement and strategic planning as may be needed, Leads and contributes to proposal development and fundraising for research projects in the unit, mentors junior researchers and facilitates in the Centre's training programs as needed, represents the Centre at high – level national, regional and international forums, including relevant technical working groups and expert committees, contributes to institutional publications

1. Nonterah EA, Boua PR, Klipstein-Grobusch K, **Asiki G**, Micklesfield LK, Agongo G, Ali SA, Mashinya F, Sorgho H, Nakanabo-Diallo S, Debpuur C. Classical Cardiovascular Risk Factors and HIV are Associated With Carotid Intima-Media Thickness in Adults From Sub-Saharan Africa: Findings From H3Africa AWI-Gen Study. Journal of the American Heart Association. 2019 Jul 16;8(14):e011506.
2. **Asiki G**, Newton R, Marions L, Kamali A, Smedman L. The effect of childhood stunting and wasting on adolescent cardiovascular diseases risk and educational achievement in rural Uganda: a retrospective cohort study. Global health action. 2019 Jan 1;12(1):1626184.
3. O'Hara G, Mokaya J, Hau JP, Downs LO, McNaughton AL, Karabarinde A, **Asiki G**, Seeley J, Matthews PC, Newton R. Liver function tests and fibrosis scores in a rural population in Africa: estimation of the burden of disease and associated risk factors. medRxiv. 2019 Jan 1:19000968.
4. Stockdale L, Nash S, Nalwoga A, Gibson L, Painter H, Raynes J, **Asiki G**, Newton R, Fletcher H. HIV, HCMV and mycobacterial antibody levels: a cross-sectional study in a rural Ugandan cohort. Tropical Medicine & International Health. 2019 Feb;24(2):247-57.
5. Vojnovic I, Pearson AL, **Asiki G,** DeVerteuil G, Allen A, editors. Handbook of Global Urban Health. Routledge; 2019 May 9.
6. Davis C, Mgomella GS, Filipe AD, Frost EH, Giroux G, Hughes J, Hogan C, Kaleebu P, **G.Asiki,** McLauchlan J, Niebel M. *New highly diverse hepatitis C strains detected in sub-Saharan Africa have unknown*

susceptibility to direct-acting antiviral treatments. Hepatology. 2018 Nov 2.
7. Chajès V, Gibson LJ, Biessy C, Slimani N, **G. Asiki**, Dossus L, Wild CP, Newton R. *Trends of serum phospholipid fatty acids over time in rural Uganda: evidence of nutritional transition?.* British Journal of Nutrition. 2018 Nov 27:1-7.
8. Kalyesubula R, Hau JP, **G. Asiki**, Ssebunya B, Kusemererwa S, Seeley J, Smeeth L, Tomlinson L, Newton R. *Impaired renal function in a rural Ugandan population cohort.* Wellcome Open Research. 2018 Nov 19;3.
9. Wekesah FM, Nyanjau L, Kibachio J, Mutua MK, Mohamed SF, Grobbee DE, Klipstein-Grobusch K, Ngaruiya C, Haregu TN, **Asiki G**, Kyobutungi CK. *Individual and household level factors associated with presence of multiple non-communicable disease risk factors in Kenyan adults*. BMC public health. 2018 Nov;18(3):1220.
10. Gichu M, **Asiki G**, Juma P, Kibachio J, Kyobutungi C, Ogola E. *Prevalence and predictors of physical inactivity levels among Kenyan adults (18–69 years): an analysis of STEPS survey 2015*. BMC public health. 2018 Nov;18(3):1217
11. Mohamed SF, Mwangi M, Mutua MK, Kibachio J, Hussein A, Ndegwa Z, Owondo S, **Asiki G**, Kyobutungi C. *Prevalence and factors associated with pre-diabetes and diabetes mellitus in Kenya: results from a national survey*. BMC public health. 2018 Nov;18(3):1215.
12. Haregu TN, Wekesah FM, Mohamed SF, Mutua MK, **Asiki G**, Kyobutungi C. *Patterns of non-communicable disease and injury risk factors in Kenyan adult population: a cluster analysis*. BMC public health. 2018 Nov;18(3):1225.
13. Warren, E., E. Nankya, J. Seeley, S. Nakamanya, **G. Asiki,** V. Simms, A. Karabarinde, and H. Larson, *A mixed-method pilot study to improve patient satisfaction in rural Uganda.* Development in Practice, 2018. **28**(5): p. 615-623.
14. Stockdale, L., S. Nash, A. Nalwoga, H. Painter, **G. Asiki,** H. Fletcher, and R. Newton, *Human cytomegalovirus epidemiology and relationship to tuberculosis and cardiovascular disease risk factors in a rural Ugandan cohort.* PloS one, 2018. **13**(2): p. e0192086.
15. Ssemwanga, D., N.A. Doria-Rose, A.D. Redd, A.R. Shiakolas, A.F. Longosz, R.N. Nsubuga, B.N. Mayanja, **G. Asiki,** J. Seeley, and A. Kamali, *Characterization of the Neutralizing Antibody Response in a Case of Genetically Linked HIV Superinfection.* The Journal of infectious diseases, 2018. **217**(10): p. 1530-1534.
16. Sallah, N., A.L. Palser, S.J. Watson, N. Labo, **G. Asiki**, V. Marshall, R. Newton, D. Whitby, P. Kellam, and I. Barroso, *Genome-wide sequence analysis of Kaposi's Sarcoma-associated Herpesvirus shows diversification driven by recombination.* The Journal of infectious diseases, 2018.
17. Ndinda, C., T.P. Ndhlovu, P. Juma, **G. Asiki,** and C. Kyobutungi, *The evolution of non-communicable diseases policies in post-apartheid South Africa.* BMC public health, 2018. **18**(1): p. 956.
18. Nash, S., V. Tittle, A. Abaasa, R.E. Sanya, **G. Asiki**, C.H. Hansen, H. Grosskurth, S. Kapiga, and C. Grundy, *The validity of an area-based method to estimate the size of hard-to-reach populations using satellite images: the example of fishing populations of Lake Victoria.* Emerging themes in epidemiology, 2018. **15**(1): p. 11.
19. Nalwoga, A., S. Cose, S. Nash, W. Miley, **G. Asiki**, S. Kusemererwa, R. Yarchoan, N. Labo, D. Whitby, and R. Newton, *Relationship Between Anemia, Malaria Coinfection, and Kaposi Sarcoma-Associated Herpesvirus Seropositivity in a Population-Based Study in Rural Uganda.* The Journal of infectious diseases, 2018. **40**: p. 1-5.
20. Mohamed, S.F., P. Juma, **G. Asiki,** and C. Kyobutungi, *Facilitators and barriers in the formulation and implementation of tobacco control policies in Kenya: a qualitative study.* BMC public health, 2018. **18**(1): p. 960.
21. Kusemererwa, S., A. Abaasa, M. Onyango, A.M. Nel, M. Isaacs, and **G. Asiki**, *Contraceptive preference among women at risk of HIV acquisition in a preparatory screening study for a phase III microbicide trial in south western Uganda.* AIDS and Behavior, 2018: p. 1-8.
22. Juma, P.A., C. Mapa-Tassou, S.F. Mohamed, B.L.M. Mwagomba, C. Ndinda, M. Oluwasanu, J.-C. Mbanya,

M.J. Nkhata, **G. Asiki,** and C. Kyobutungi, *Multi-sectoral action in non-communicable disease prevention policy development in five African countries.* BMC public health, 2018. **18**(1): p. 953.

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26. Amugsi, D.A., Z.T. Dimbuene, **G. Asiki,** and C. Kyobutungi, *Quantile regression analysis of modifiable and non-modifiable drivers' of blood pressure among urban and rural women in Ghana.* Scientific reports, 2018. **8**(1): p. 8515.
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54. **Asiki, G.,** J. Seeley, C. Srey, K. Baisley, T. Lightfoot, K. Archileo, D. Agol, A. Abaasa, K. Wakeham, and M.N. Routledge, *A pilot study to evaluate aflatoxin exposure in a rural Ugandan population.* Tropical medicine & international health, 2014. **19**(5): p. 592-599.
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64. Seeley, J., J. Nakiyingi-Miiro, A. Kamali, J. Mpendo, **G. Asiki,** A. Abaasa, J. De Bont, L. Nielsen, and P. Kaleebu, *High HIV incidence and socio-behavioral risk patterns in fishing communities on the shores of Lake Victoria, Uganda.* Sexually transmitted diseases, 2012. **39**(6): p. 433-439.
65. Ssemaganda, A., K. Wakeham, C. Doughty, R. de Tute, **G. Asiki,** E. Roman, R. Newton, A. Jack, P. Hillmen, and P. Kaleebu, *3.14 The Influence of Genetic Background and Infectious Exposure on the Development of Chronic Lymphocytic Leukaemia and Other B-Cell Malignancies: Evidence from High-Sensitivity Screening in Leeds and Rural Uganda.* Clinical Lymphoma, Myeloma and Leukemia, 2011. **11**: p. S205-S206.
66. **Asiki, G**., J. Mpendo, A. Abaasa, C. Agaba, A. Nanvubya, L. Nielsen, J. Seeley, P. Kaleebu, H. Grosskurth, and A. Kamali, *HIV and syphilis prevalence and associated risk factors among fishing communities of Lake Victoria, Uganda.* Sexually transmitted infections, 2011: p. sti. 2010.046805.
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Selected successful grant application

1. Global HIV vaccine Enterprise grant: Participation in a simulated preventive HIV Vaccine trial of individuals from fishing communities along the shores of Lake Victoria in Uganda.
   Awarded in 2011; Amount: 15,000 Canadian Dollars.
   Role: Lead applicant; Status: Completed
2. MRC grant: Observational HIV Studies Programme in Rural Uganda / General Population Cohort/ MC_U950080926. Awarded in 2012; Amount 800,000 GBP
   Role: Co-applicant; Status: Completed
3. HIV Research Trust grant: Building the capacity for managing a large database from a rural general population cohort in Uganda. Awarded in 2013; Amount: 4000 GBP.
   Role: Lead applicant; Status: Completed.
4. GSK Grant: Prevalence of liver fibrosis among HIV positive people in a rural Ugandan population.
   Awarded in 2014; Amount 72,000 Euros
   Role: Co-applicant; Status: Completed.
5. IAVI investigator initiated USAID project grant: Biometric finger print technology for identification of prospective HIV prevention trial participants from fishing communities and enhancing retention in Future trials. Awarded in 2015. Amount 72,000 USD
   Role: Lead Applicant; Status: Completed
6. Global Challenges Exploration (Bill and Melinda Gates Foundation): Timeliness of administering Birth-dose Vaccines in Nairobi urban slums. Awarded in 2018. Amount 100,000 USD
   Role: Lead Applicant; Status: Implementation phase
7. SANOFI: Evaluating a service model for the management of hypertension and diabetes among low and middle- income patients enrolled on M-TIBA in Nairobi, Kenya. Awarded in 2018. Amount=200,000 Euros.
   Role: Co-Applicant; Status: Implementation phase
8. **Joep Lange Institute**: Enhancing Universal Health coverage in Kenya through digital innovations: A Financial and Health Diaries evaluation study of the mobile health wallet for pregnant women in Nairobi and Kisumu. Awarded 2018. Amount=185,000 Euros.
   Role: Co-Applicant; Status: Preparatory stage.
9. Joep Lange Institute: Chronic disease management: an entry point for bridging the gap between population and health care needs for non-communicable diseases (ncd) in low and middle income countries Sub- Saharan Africa. Awarded 2018. Amount=165,000 Euros.
   Role: Co-Applicant; Status: Preparatory stage.
10. National Institute for Health Research-UK: Epilepsy Pathway Innovations in Africa (EPInA)
    Awarded 2019. Amount=700,000 GBP
    Role: Site PI; Status: Preparatory stage.

Language proficiency:

Language	Speaking	Reading	Writing
English	✓	✓	✓
Swahili	✓	✓	✓

I, **(Gershim Asiki),** certify that the information provided here in is correct to the best of my knowledge as of **(16/06/2019).**

CV of (Shukri F Mohamed)

Proposed Position in Research:	study Officer
Proposed role in the study:	Coordination oversight
Organisation:	African Population & Health Research Center (APHRC)
Name of Staff:	Shukri F Mohamed
Profession:	Research officer
Date of Birth:	June 15th 1975
Years with Organisation:	9
Nationality:	Kenya
Membership in Professional Societies:	International Epidemiology Association (IEA) International Union for the Scientific Study of Population (IUSSP)
Detailed Tasks Assigned in Study:	Coordinate the activities for the study.

Education & Qualifications:

Qualification	Awarding Institution	Country	Year
Doctor of Philosophy (PhD)	Warwick University	UK	Ongoing
Master of Public Health (MPH)	Johns Hopkins Bloomberg School of Public Health	USA	2006
Doctor of Pharmacy Degree (PharmD)	University of Maryland, School of Pharmacy	USA	2004
Associate Degree in Science (AS)	Northern Virginia Community College, Alexandria	USA	2000

Employment Record:

From (year)	To (Year)	Position	Employer
September 2010	present	Research officer	African Population & Health Research Center (APHRC)
Mid-March 2010	September 2010	Research intern	APHRC
August 09	mid-October 09	Internship	APHRC
April 08	- -July 2009	Intern	National AIDS/STDS Control Programme Kenya (NASCOP)
2004	March 2008	Pharmacist	Giant Pharmacy, USA

Summary of research experience:

Dr Shukri Mohamed is a public health specialist with over 8 years' experience in research, project planning and management, and also has four years of clinical pharmacy practice experience. She also has strong skills in

proposal writing, project management, project implementation, data quality assurance, data analysis and scientific writing. Dr Mohamed has authored 20 peer reviewed publications. She attained a Masters in Public Health from the Johns Hopkins Bloomberg School of Public Health and a Doctor of Pharmacy Degree from the University of Maryland School of Pharmacy. Her areas of interest include include non-communicable disease prevention and control with an emphasis on cardiovascular disease, health systems research and translating research to policy and action. Dr Mohamed has served on a number of expert/technical working group such as the technical working group on non-communicable diseases prevention policies and the Kenya Cancer Research track group. Dr. Mohamed is also successfully coordinated the first ever special issue on data from WHO STEPS survey for Kenya.

Publications:

1. **Mohamed, S. F**., Mutua, M. K., Wamai, R., Wekesah, F., Haregu, T., Juma, P., Nyanjau, L., Kyobutungi, C., … Ogola, E. (2018). Prevalence, awareness, treatment and control of hypertension and their determinants: results from a national survey in Kenya. BMC public health, 18(Suppl 3), 1219. doi:10.1186/s12889-018-6052-y
2. **Mohamed SF**, Mwangi M, Mutua MK, Kibachio J, Hussein A, Ndegwa Z, Owondo S, Asiki G, Kyobutungi C. Prevalence and factors associated with pre-diabetes and diabetes mellitus in Kenya: results from a national survey. BMC public health. 2018 Nov;18(3):1215.
3. Wekesah FM, Nyanjau L, Kibachio J, Mutua MK, **Mohamed SF**, Grobbee DE, Klipstein-Grobusch K, Ngaruiya C, Haregu TN, Asiki G, Kyobutungi CK. Individual and household level factors associated with presence of multiple non-communicable disease risk factors in Kenyan adults. BMC public health. 2018 Nov;18(3):1220.
4. Haregu TN, Wekesah FM, **Mohamed SF**, Mutua MK, Asiki G, Kyobutungi C. Patterns of non-communicable disease and injury risk factors in Kenyan adult population: a cluster analysis. BMC public health. 2018 Nov;18(3):1225.
5. Ali, S. A., Soo, C., Agongo, G., Alberts, M., Amenga-Etego, L., Boua, R. P., Choudhury, A., Crowther, N. J., Depuur, C., Gómez-Olivé, F. X., Guiraud, I., Haregu, T. N., Hazelhurst, S., Kahn, K., Khayeka-Wandabwa, C., Kyobutungi, C., Lombard, Z., Mashinya, F., Micklesfield, L., Mohamed, S. F., Mukomana, F., Nakanabo-Diallo, S., Natama, H. M., Ngomi, N., Nonterah, E. A., Norris, S. A., Oduro, A. R., Somé, A. M., Sorgho, H., Tindana, P., Tinto, H., Tollman, S., Twine, R., Wade, A., Sankoh, O., **Mohamed SF**, … Ramsay, M. (2018). Genomic and environmental risk factors for cardiometabolic diseases in Africa: methods used for Phase 1 of the AWI-Gen population cross-sectional study. Global health action, 11(sup2), 1507133.
6. **Mohamed SF**, Juma P, Asiki G, Kyobutungi C. Facilitators and barriers in the formulation and implementation of tobacco control policies in Kenya: a qualitative study. BMC public health. 2018;18(1):960. https://doi.org/10.1186/s12889-018-5830-x.
7. Juma PA, Mapa-tassou C, **Mohamed SF**, Matanje Mwagomba BL, Ndinda C, Oluwasanu M, et al. Multi-sectoral action in non-communicable disease prevention policy development in five African countries. BMC public health. 2018; 18(1):953. https://doi.org/10.1186/s12889-018-5826-6.
8. Juma PA, **Mohamed SF**, Matanje Mwagomba BL, Ndinda C, Mapa-tassou C, Oluwasanu M, et al. Non-communicable disease prevention policy process in five African countries authors. BMC public health. 2018; 18(1):961. https://doi.org/10.1186/s12889-018-5825-7.
9. Wisdom JP, Juma P, Mwagomba B, Ndinda C, Mapa-Tassou C, Assah F,… **Mohamed SF**, et al. Influence of the WHO framework convention on tobacco control on tobacco legislation and policies in sub-Saharan Africa. BMC public health. 2018; 18(1):954. https://doi.org/10.1186/s12889-018-5827-5.
10. Asiki, G., Shao, S., Wainana, C., Khayeka–Wandabwa, C., Haregu, T. N., Juma, P. A., **Shukri Mohamed**,…. Kyobutungi, C. (2018). Policy environment for prevention, control and management of cardiovascular diseases in primary health care in Kenya. BMC Health Services Research, 18, 344. http://doi.org/10.1186/s12913-018-3152-4
11. Haregu, T., **Mohamed, S**., Muthuri, S., Khayeka-Wandabwa, C., & Kyobutungi, C. (2018). Body mass index and wealth index: Positively correlated indicators of health and wealth inequalities in Nairobi slums. Global Health,

Epidemiology and Genomics, 3, E11. doi:10.1017/gheg.2018.10

12. Asiki, G., **Mohamed, S. F**., Wambui, D., Wainana, C., Muthuri, S., & Ramsay, M. (2018). Sociodemographic and behavioural factors associated with body mass index among men and women in Nairobi slums: AWI-Gen Project. Global Health Action, 11(Suppl 2), 1470738. http://doi.org/10.1080/16549716.2018.1470738Sayed, Shahin, Molo, Zahir …….Catherine Kyobutungi, **Shukri Mohamed**, Tilahun Haregu….2017. Ethnicity and Breast Cancer Characteristics in Kenya. *Breast Cancer Research Treatment*.
13. Sayed, Shahin, Molo, Zahir …….Catherine Kyobutungi, Shukri Mohamed, Tilahun Haregu….2017. Ethnicity and Breast Cancer Characteristics in Kenya. Breast Cancer Research Treatment.
14. Juma, P. A., **Mohamed, S. F**., Wisdom, J., Kyobutungi, C., & Oti, S. (**2016)**. Analysis of Non-communicable disease prevention policies in five Sub-Saharan African countries: Study protocol. *Archives of Public Health*, *74*(1), 25.
15. **Shukri F Mohamed**, Blessing Uchenna Mberu, Djesika Amendah et.al (**2016**). Rapid Urbanization, Urban Food Deserts and Food Security in Africa, 978-3-319-43566-4, 369699_1_En (8)".
16. **Shukri F Mohamed**, Chima Izugbara, Ann Moore et.al. Estimated Incidence of Induced abortion in Kenya. BMC Pregnancy and Child Health **2015**, **15**:185 doi:10.1186/s12884-015-0621-1.
17. Abdhalah Ziraba, Chimaraoke Izugbara, Brooke A. Levandowski, Hailemichael Gebreselassie, Michael Mutua, **Shukri F Mohamed**, Carol Egesa, Elizabeth W. Kimani-Murage. Unsafe abortion in Kenya: a cross-sectional study of abortion complication severity and associated factors. BMC Pregnancy and Child Health **2015**.
18. Kimani-Murage EW., Schofield, L., Wekesah, F., **Mohamed, S**., Mberu, B., Ettarh, R., Kyobutungi, C, & Ezeh, A. Vulnerability to food insecurity in urban slums: Experiences from Nairobi, Kenya. Journal of Urban Health **2014**.
19. Lilly Schofield, **Shukri F Mohamed**, Elizabeth Wambui Kimani-Murage et.al. *Spotting the invisible crisis: early warning indicators in urban slums of Nairobi, Kenya.* Field exchange **2013**.
20. Djesika Amenda, Stephen Buigut, & **Shukri Mohamed**. *Coping Strategies among Urban Poor: Evidence from Nairobi, Kenya. Plos One **2013**.*

Language proficiency:

Language	Speaking	Reading	Writing
English	✓	✓	✓
Swahili	✓	✓	✓
Somali	√	√	√

I, **(Shukri F Mohamed),** certify that the information provided here in is correct to the best of my knowledge as of **(14/06/2019).**

CV of (Isaac Kisiangani)

Proposed Position in Research:	Study Officer
Proposed role in the study:	Study Coordinator and M & E officer
Organisation:	African Population & Health Research Center (APHRC)
Name of Staff:	Isaac Simiyu Kisiangani
Profession:	Research officer
Date of Birth:	
Years with Organisation:	8 months
Nationality:	Kenya
Membership in Professional Societies:	Member of African Organization for Research & Training in

	Cancer (AOTIC)
Detailed Tasks Assigned in study:	Coordinate the activities for the study. He will manage the day to day project management. He will participate in data analysis and scientific writing.

Education & Qualifications:

Qualification	Awarding Institution	Country	Year
Bsc. Medical Laboratory Science	Jomo Kenyatta University of Agriculture & Technology	Kenya	July 2010
MSc in Public Health	Jomo Kenyatta University of Agriculture & Technology	Kenya	November 2016

Employment Record:

From (year)	To (Year)	Position	Employer
August 2018	Present	Research officer	African Population & Health Research Center (APHRC)
July 2011	July 2018	Assistant Research Officer	Kenya Medical Research Institute (KEMRI)

Summary of research experience:

Publications:

1. Stroke distribution patterns & characteristics in Kenya's leading public health tertiary institutions: Kenyatta National Hospital & Moi teaching & Referral Hospital: Cardiovascular Journal Of Africa; Vol. 29(2), Mar/April 2018, pg. 68-72.
2. Prevalence of malnutrition among preschool children (6-59 months) in Western Province, Kenya: Journal of Public Health & epidemiology; Article Number - A80EE2047913 Vol.6(11), pp.398-406, Nov2014
3. Assessment of iron status among preschool children (6 to 59 months) with and without malaria in western province, Kenya: Pan African Medical Journal: Article Number: 68562014070553-4560: doi:10.11604/pamj.2015.21.62.4560
4. Prevalence of anaemia and associated factors among preschool children (6-59 months) in western province, Kenya: Public Health Journal vol.1. No.1, 2015, pp.28-32.
5. Predictors of insulin resistance among urban population in kenya: 7th KEMRI Annual Scientific Health (KASH) conference (2017).

Language proficiency:

Language	Speaking	Reading	Writing
English	✓	✓	✓

Swahili	✓	✓	✓
Bukusu	√		

I, **(Isaac Kisiangani),** certify that the information provided here in is correct to the best of my knowledge as of **(14/06/2019).**

APPENDIX II: FGD AND IDI GUIDES

Interview Guide - IDI

Study Title: **Exploring key stakeholders' perspectives on effective community engagement strategies to facilitate reporting aggregate genomic results to groups and communities: The AWI-Gen Case Study**

Kichwa cha Mradi**: *Kuchunguza mtazamo muhimu wa washikadau kwaushirikiano wa jamii kuhusu mikakati ya ufanisi ya jamii kuwezesha taarifa ya jumla ya genomic kwa vikundi na jamii: Utafiti wa AWI-Gen***

[Target GroupStudy coordinators; researchers and field assistants]

Introduction

- Welcome the participant and briefly describe objectives of the study
- Review Study Info Sheet & provide copy of Consent Form for signature
- Outline the format of interview

Section A: Background of interviewee

Interviewee ID	Level of education	Length of service	Genomic training

Section B: Knowledge/Experiences with genomic studies

1. Can you please tell me about the genomic research study you were involved in? *Tafadhali nieleze kuhusu mradi wa utafiti wa genomic ambao ulihusishwa?*

    a. Probe for H3Africa Study: what is the study about? What does it involve? Why is the study important? What is your role?

Dadisi kuhusu mradi wa H3Africa: Mradi ilikua kuhusu nini? Ina husisha nini? Kwa nini huu mradi ni muhimu? Jukumu lako ni nini?

2. Did you encounter any issues explaining the study to research participants and staff members?
   Je, umekumbana na matatizo yoyote ukielezea juu ya mradi washiriki na wafanyikazi?

    a. Which aspects of the study were problematic?
       Ni sehemu gani zinazojumiusha mradi huu yalikua na tatizo?

3. How did you resolve any concerns raised by the participants? Probe for concerns by staff members?
   Ni vipi uliweza kusuluhisha matatizo yoyote yaliotolewa na washiriki?
   Dadisi: Matatizo yalioletwa na wafanikazi?

4. Please describe the community engagement activities that were carried out during the study
   Tafadhali eleza shughuli za ushirikwishaji wa jamii yaliofanywa wakati wa mradi huo?

5. What worked well during your community engagement activities?
   Ni nini kilichofanyika vizuri wakati wa shughuli za ushirikishaji wa jamii?

6. What specific challenges did you encounter with your CE activities?
   Ni changamoto zipi maalum ulikumbana nazo wakati wa shughuli za ushirikishaji wa jamii?

7. How did you resolve these challenges?
   Uliweza kisuluhisha vipi changamoto hizi?

Section C: Returning research results to participants
Kurudisha matokeo/majibu kwa washiriki

8. Are you familiar with any policy documents on returning research findings to research participants involved in genomics research?
   Je! Unajua hati ya sera yoyote kuhusu kurudisha matokeo ya utafiti kwa washiriki wa utafiti wanaohusika na utafiti wa genomic.

9. In your view, what is the value of returning research results to participants?
   Kwa maoni yako, ni nini umuhimu wa kurudishia matokeo ya utafiti kwa washiriki wa utafiti?

10. What kinds of results should be returned to participants and why?
    Matokeo/Majibu ya aina gani yanapaswa kurejeshwa kwa washiriki wa utafiti? Kwa nini?
    a. Probe for individual research results and aggregate results
       Dadisi kuhusu matokeo ya utafiti ya mtu binafsi na matokeo ya watu jumla

11. Who should be involved in returning research results to research participants and communities?
    Ni akina nani wanahusika na kurejesha matokeo ya utafiti washiriki wa utafiti na jamii?

12. What challenges should be anticipated when returning research results to participants and their communities?
    Ni changamoto zipi zinazopaswa kutarajiwa wakati wa kurejesha matokeo ya utafiti kwa washiriki na jamii?

Section D: Role of community engagement in supporting
Jukumu la ushirika wa jamii katika kusaidia

13. In your view, what is the role of community engagement in genomic research in general?
    Kwa maoni yako, ni nini, jukumu la ushirikishaji wa jamii kwa utafiti za genomic kwa ujumla?

14. In what key ways can community engagement support the return of research results to participants and their communities?
    Ni njia gani ushirikishaji wa jamii unaweza kusaidia kurejesha matokeo ya utafiti kwa washiriki na jamii?

15. What specific CE methods would you recommend for returning research results to participants and their communities?
    Ni njia gani za ushirikishaji wa jamii unazopendekeza za kuregesha matokeo ya utafiti kwa washiriki na jamii?

16. What would count as good ethical practice when returning research results to participants?
    Ungezingatia nini kama mazoea mazuri ya maadili wakati wa kuregesha matokeo kwa washiriki?

Section E: Closing Remarks

17. Based on our discussions, what recommendations would you give for addressing the key challenges related to genomic studies?
Kwa kuzingatia mazungumzo yetu, ni mapendekezo gani unaweza kutoa kushughulikia changamoto muhimu zinazohusiana na tafiti za genomic?

18. Is there anything that we have not covered that you will like to mention?
Kuna chochote ambacho hatukujumuisha ungependa kutaja?

Thank you very much for your insightful inputs to this study
Asante sana kwa ufahamu wako kina katika utafiti huu.

*Study Title**: Exploring key stakeholders' perspectives on effective community engagement strategies to facilitate reporting aggregate genomic results to groups and communities: The AWI-Gen case study***

IDI GUIDE FOR ETHICS COMMITTEE MEMBERS

Section A: Background of participants

Participant ID	Agency represented	Level education	Length of Service	Ethics training
1				
2				
3				

Section B: Knowledge/experience with community engagement

1. What do you understand by community engagement? Probe: Tell me about the different ways of community engagement that you have come across.

2. How do you assess the community engagement aspect of research proposals? Probe for the specific things that are expected (or the IRB looks out for).

3. In your view, how can community engagement be made effective?

Section C: Experience with genomic research

4. Tell me about the H3Africa study protocol you reviewed and approved. Probe for: what is the study about? What does it involve? Why is the study important?

5. What were the ethical issues you encountered during the review of the study protocol? Which parts of the protocol were problematic? What made these parts problematic?

6. How did you resolve these ethical issues?

7. Can you tell me about the community engagement activities that were specified in the protocol?

8. Where the stated community engagement activities appropriate? Why?

Section D: Returning research results to participants

9. What are your views on returning research findings to research participants involved in genomics research? Probe: what do you consider to be the value of returning research results to participants?

10. What kinds of results should be returned to participants and why? Probe for individual research results and aggregate results separately.

11. How should researchers return research results to research participants and communities? Probe: who should be involved in returning research results and how.

12. What challenges should researchers anticipate when returning research results to participants and their communities?

13. How can these challenges be resolved?

Section E: Role of community engagement in supporting knowledge sharing

14. What will you say is the role of community engagement in genomic research in general?

15. How was community engagement communicated in the H3Africa protocol you reviewed?

16. How can we use community engagement to facilitate the return of research results to;

    I. Research participants

    II. Communities

17. What advice do you give researchers regarding how to return research results to participants and their communities?
18. What are the good ethical practices researchers should follow when returning research results to participants?

Closing Remarks

19. From our discussion, what recommendations will you give on the role of community engagement in returning genomic research results to participants and communities?

20. Is there anything that we have not covered on the role of community engagement in returning genomic research results that you would like to mention?

Thank you for participating in this discussion.

Study Title: Exploring key stakeholders' perspectives on effective community engagement strategies to facilitate reporting aggregate genomic results to groups and communities: the Kenya case study

Kichwa cha Mradi**: *Kuchunguza mtazamo muhimu ya washujikadao juu ya mikakati bora ya kushirikisha jamii ilikuwezesha kutoa repoti ya matokeo ya jumla za masomo ya mwili (Genomic) kwa vikundi na jamii.***

IDI GUIDE FOR COMMUNITY LEADERS

Introduction

- Welcome the participant and briefly describe objectives of the study
- Review Study Info Sheet & provide copy of Consent Form for signature
- Outline the format of interview

Section A: Background of respondent

Interviewee ID	Education	Community Name	Role in community	Length of service

Section B: Experience with research studies and participation
Uzoefu na kushisriki kwenye utafiti

1. Please tell me about the AWI-Gen study your community participated in.
    i. Probe: How did you hear about the study? Did you personally take part in the study?

    Tafadhali nieleze kuhusu Utafiti wa AWI-Gen ambayo jamii yako ilishiriki?

    Dadisi: Ulisikia aje kuhusu utafiti huu? Je, wewe binafsi ulishiriki kwenye utafiti huo?

2. As a community leader how did you feel about your community's
    i. participation in the study?
    Kama kiongozi wa jamii ulihisi vipi kuhusu kushirikishwa kwa jamii yako?

3. How has your experience in that research affected your interest in research studies?

Je, uzoefu wako umekuaje wako katika utafiti huo umeathiri kivipi jinsi unavyo pendelea masomo ya utafiti?

4. Have you ever experienced a situation or a study where you felt you or the community was not engaged properly?
   Je, umewahi kuwa na hali or kuwa kwenye utafiti ambapo haukujisikia wewe ama jamii yako hamkuhusishwa vizuri?

5. How would you want your community to be engaged in research studies?
   Je, ni vipi ungetaka jamii yako kuhusishwa katika utafiti?

Section C: views on nature of research study
Maoni kuhusu vipengele za utafiti

6. What do you think of research studies that involve taking blood samples?
   Ni nini unafikiria kuhusu utafiti zinazohusika na kuchukua sampuli za damu?

7. What about research studies that involve following participants over a long period of time?
   Vipi kuhusu tafiti yanayohusisha kufuata washishiriki kwa muda mrefu?

8. 8. Would you be willing to give your sample for a research study? What are your reasons?
   Je, ungekubali kutoa sampuli yako kwa ajili ya utafiti? Sababu zako ni zipi?

9. What concerns do you have regarding giving your sample for research?
   Una wasiwasi gani katika wa kutoa sampuli yako kwa utafiti?
   Probe for:
   Dadisi:

   a. Type of sample
      Aina ya sampuli.
   b. How often sample is taken
      Ni mara ngapi sampuli inachukiliwa.
   c. What sample will be used for
      Nini sampuli itatumika kufanya.
   d. Where the sample goes to
      Ni wapi sampuli itakwenda.

10. How do these opinions affect participation of community members in research?
    Haya maoni yana athiri kivipi kushiriki kwa jamii kwenye utafiti?

11. Tell me some of the things you hear your community memebers say regarding what researchers usually do with blood samples.
    Niambie baadhi ya mambo umeyayasikia wanajamii wanasema kuhusu ni nini ambacho watafiti hufanya na sampuli za damu?
12. Tell me your own opinion regarding what researchers usually do with blood samples.
    Nieleze juu ya maoni yako kuhusu ni nini watafiti hufanya na sampuli za damu?
13. Has this thinking affected your participation in any genomic research in the past?
    Haya mawazo yameathiri kivipi kushiriki kwako kwenye utafiti wowote wa masomo ya maumbile (genomic) katika siku za nyuma?
14. In what ways can your participation in a genomic research study affect you? Probe for effect on family.
    Ni kwa njia gani kukishiriki kwako kwenye utafiti za masomo ya maumbile (genomic) yamekuathiri?
    Dadisi: Athari kwa familia.

15. How do community members feel about participating in the same research study with other members of the community?
    Je, wanajamii wanahisi aje kuhusu kishiriki utafiti sawa na wanajamii wengine?

Section D: Contact and engagement
Uwasiliano na kushirikishaji

16. How was your community contacted about the study?
    Uwasiliano kuhusu utafiti ulifanywa vipi kwa wanajamii?

17. Would you like to be contacted the same way in future research studies? Why?
    Je, Ungependelea kufanyiwa uwasiliano kwa njia ile ile katika utafiti za siku zijazo?

19. How does the way a community is contacted for a study affect participation? Probe for how it affects the quality of information given to researchers?
    Ni kwa jinsi gani uwasiliano inavyofanywa kuhusu utafiti hu athiri kivipi wanajamii kushiriki kwa utafiti?
    Dadisi: Ni vipi inavyo athiri ubora wa habari inayotolewa kwa watafiti?
20. Can your community refuse to participate in a research study after they have been contacted by the researchers? Probe for:
    What would make the community to refuse?
    Has the community ever refused to participate in a research study?
    Je, jamii yako inaweza kukataa kushiriki kwenye utafiti baada ya kuwasiliana na watafiti?
    Dadisi: Ni nini kinachoweza kuwafanya jamii kukata?
    Je wanajamii wamewahi kukataa kushiriki kwa utafiti?

21. Is there anything else you will like to add on the way you wish to be contacted?
Kuna kitu kingine ungependelea kuongezea kuhusu njia ambayo ungependa kuwasiliana?

Section E: Returning results
Kurudisha matokeo.

22. Can you tell me what the community thinks about returning aggregate research results? Probe for the value of returning research results to communities.
Je, unaweza kuniambia nini jamii inafikiria kuhusu kurudisha matokeo ya jumla?

23. What will the returned results mean to you?
Matokeo yanayorudishwa yana maana gani kwako?

24. How can that affect your way of life as a community?
Je, hiyo inaweza adhiri njia ya maisha kivipi kama jamii?

25. In your opinion, what are the possible merits and demerits of returning results to study communities? Probe for merits and demerits.
Kwa maoni yako, ni faida gani na hasara gani ya kurudisha matokeo kwenye jamii zakufanyiwa utafiti?
Dadisi: Juu ya Faida na hasara.

26. To what extent will you agree with the assertion that community engagement is very crucial in returning genomic results to communities?
Je, ni kwa kiasi gani utakubaliana na madai kwamba ushirikishaji wa jamii ni muhimu sana kurudisha matokeo ya masomo ya maumbile (genomic) kwa jamii?

27. Will you participate in a study because you know results will be returned to you at the end of the day?
Je, Utashiriki katika utafiti kwa sababu unajua matokeo yatarudishwa kwako mwishoni wa siku?

28. Anything else on returning results and the value you place on results that you will like to add?
Kuna chochote ungependa kuongezea kwenye kurudisha matokeo na thamani unayoweka kwenye matokeo ungependa kuongezea?

Section F: Methods of returning results
Njia za kurudisha matokeo

29. How would you want results to be returned to you?
Ungependelea aje matokeo yarudi kwako?

30. What would you consider as the best way to return genomic results to communities?
Je, Ungezingatia nini kama njia bora za kurudisha matokeo ya masomo ya maumbile (genomic) kwa jamii?

31. What would you consider as good practice in returning genomic results to communities?
Je, ungezingatia nini kama mazoea mazuri ya kurudisha matokeo ya masomo ya maumbile (genomic) kwa jamii?

32. Will your participation in subsequent research studies be affected by the way results were returned to you?
Je, kushiriki kwako kwenye utafiti zifuatazo yataathiriwa kivipi kwa njisi ulivyo rudishiwa matokeo?

33. Anything else on methods of returning results?
Kuna chochote kingine juu ya njia ya kurudisha matokeo?

Section G: Recommendations and closure

34. How would you advise genomic researchers to carry out genomic studies in communities?
Je, Unaweza shauri kivipi watafiti wa masomo ya maumbile (genomic) kufanya utafiti za masomo ya maumbile (genomic) katika jamii?

35. What would you recommend as the best way to engage communities for genomic research studies?
Unapendekeza nini kama njia bora ya kushirikisha jamii katika tafiti za masomo ya maumbile (genomic)?

36. What do you think researchers can do to enhance their success in genomic cohort studies?
Unafikiri watafiti wanaweza kufanya nini ili kuongezea mafanikio yao katika tafiti ya kufuatilia kikundi juu ya masomo ya maumbile (genomic)?

37. Is there anything else about genomic research in general you will like to add; the way you wish to be engaged, the way you will like the study to be conducted, the way you will like results to be returned and the importance you place on results?
Je, kuna kitu kingine kuhusu tafiti za masomo ya maumbile (genomic) kwa ujumla ungependa kuongezea; Njia ambayo ungetaka kushirikishwa, Jinsi ungependa utafiti ufanyike, Jinsi ungependa maokeo kurudishwa na umuhimu unayoweka kwenye matokeo?

Thank you for participating in this study/ Asante kwa kushiriki katika huu utafiti

Study Title***: Exploring key stakeholders' perspectives on effective community engagement strategies to facilitate reporting aggregate genomic results to groups and communities: the Kenya case study***

Kichwa cha Mradi**: *Kuchunguza mtazamo muhimu ya washukadao juu ya mikakati bora ya kushirikisha jamii ilikuwezesha kutoa repoti ya matokeo ya jumla za masomo ya mwili (Genomic) kwa vikundi na jamii.***

FGD GUIDE FOR PARTICIPANTS OF AWI-Gen.

Introduction

- Welcome the participant and briefly describe objectives of the study
- Review Study Info Sheet & provide copy of Consent Form for signature
- Outline the format of interview

Section A: Background of participants

Participant ID	Age	Education	Occupation	Religion
1.				
2.				
3.				
4.				
5.				

Section B: Experiences with the consent process of AWI-Gen
Uzoefu na hatua za kupokea kibali ya kushiriki kwa AWI-Gen

1. Please describe how you were invited to participate in the AWI-Gen study?
   Tafadhali elezea jinsi ulivyo alikwa kushiriki katika utafiti wa AWI-Gen?
2. What do you think about the way you were invited to participate in the study?
   Una mtazamo gani kuhusu jinsi ulivyo alikwa kushiriki katika utafiti huu?
3. What suggestions would you make to improve the way you were invited to participate in the study?
   Ni mapendekezo gani unayoweza kufanya ili kuboresha njia uliyoalikwa nayo kushiriki kwenye utafiti huu?
4. What were you told was the purpose of the study?
   Ulielezwa nini kuhusu kusudi la utafiti huu?
5. What were you told your participation would involve?
   Ulikuwa umeelezwa ni nini ushiriki kwako utahusisha katika utafiti huu?
6. What do you think about the information you were given? Probe if respondent asked questions or if they thought they needed more information to help them decide whether to participate or not?
   Ni nini unafikiria kuhusu ujumbe uliyopewa?
   Dadisi: Wewe kama mushiriki uliuliza maswali au ulifikiria ulikua unahitaji ujumbe zaidi kukuwezesha kufanya maaamuzi ili ushiriki au la?
7. How did you feel making the decision to participate in the study? Probe if respondent felt he or she had a choice or if it was voluntary.
   Ulipofanya uamuzi kushiriki kwenye utafiti huu, ulihisi vipi?
   Dadisi: Muhojiwa alihisi kua ana uchaguzi au la ama alikua na hiari?
8. How would you describe the relationship between you and the research team?
   Je! Unaweza kuelezeaje uhusiano kati yako na timu ya waliokua wakifanya utafiti?
9. How did you feel telling the research person about yourself or giving your sample out?
   Ulihisi vipi kumwambia mtafiti kujihusu wewe mwenyewe au kutoa sampuli yako nje?
10. Is there anything else you will like to add on the way you were invited to participate in the study that we have not talked about?
    Kuna kitu kingine chochote ungependelea kuongezea kuhusu njia uliyoalikwa kushiriki katika utafiti ambao hatujazungumuzia?

Section C: Views on participation
Maoni kuhusu kushiriki

11. Please tell me what you think about the AWI-Gen study. Probe for views on longitudinal cohort studies.
    Tafadhali nielezee ni nini unachokifikiria kuhusu ya utafiti Wa AWI-Gen? Dadisi maoni kuhusu utafiti wa muda mrefu za makundi.
12. Why did you agree to participate in the AWI-Gen study?
    Kwa nini ulikubali kushiriki katika utafiti wa AWI-Gen?
13. How did you feel about participating in the study?
    Ulihisi vipi kuhusu kushiriki kwenye utafiti?
14. How did participation in the study affect you? Probe for the effect on the family.
    Je! Kushiriki kwenye utafiti huo ulikuadhiri vipi?
    Dadisi: athari kwenye familia.
15. What have been the benefits in participating in the study? Probe for the risks of participation.
    Ni nini imekua faida ya kushiriki kwa utafiti huu?
    Dadisi: kuhusu mathara ya kushiriki kwenye utafiti.
16. What do you think about the way the study was conducted?
    Unafikiria nini, kuhusu jinsi utafiti ulivyo fanywa?
    Probe for views on the process of enrolment and feedback of findings.
    Dadisi kuhusu maoni juu ya usajili na maoni juu ya matokeo.
17. How did you feel participating in the same research study with other community members?
    Ulihisi vipi kushiriki kwa utafiti huo pamoja na wanajamii wengine?
18. Is there anything you will like to add on your participation in the study that I have not asked?
    Kuna kitu chochote ambacho ungependa kuongezea kuhusu kushiriki kwako kwa utafifi ambao sija kuuliza?

Section D: Views on returning results
Maoni kuhusu kurudisha matokeo

19. What do you think about returning results to research participants?
    Una maoni gani kuhusu kurudisha majibu ya matokeo ya utafiti kwa washiriki wa utafiti?
20. How did you feel when you were given your results from the study?
    Ulihisi vipi wakati ulipewa matokeo yako kutoka kwa utafiti?
21. How useful are the results to you?
    Matokeo yana umuhimu gani kwako?
22. How have the results affected you? Probe for the effect on the family.
    Matokeo hayo yamekuathiri kivipi? Dadisi: Athari kwa familia.
23. What do you think about genomic studies returning results to participants? Probe for views on returning results to communities.
    Unafikiria nini kuhusu masomo ya maumbile ya (genomic) kurudisha matokeo kwa washiriki?

Dadisi: Kuhusu kurudisha matokeo kwa jamii.

24. What do you think about returning personal results to research participants?
    Unafikiria nini kuhusu kurudisha matokeo ya kibinafsi kwa washiriki?
25. What do you think about returning general results of all participants to individuals? Probe for returning general results to communities?
    Unafikiria nini kuhusu kurudisha matokeo ya jumla kwa washiriki wote kwa watu binafsi?
    Dadisi: Kurudisha matokeo ya jumla kwa jamii
26. How has the return of your research results affected your future participation in genomic studies?
    Je, ni jinsi gani kurudishwa kwa motokeo ya utafiti yameathiri kushiriki kwako ya siku zijazo kwa utafiti wa masomo ya maumbile (genomic)?

Section E: Methods of returning results

27. Please describe how your results on the AWI-Gen study were returned to you? Probe for the return of the results to the community.
    Tafadhali elezea jinsi matokeo ya utafiti wa AWI-Gen yalirudi kwako?
    Dadisi: Kurudi kwa matokeo kwa jamii.
28. What do you think about the way the results were returned to you? Probe for what they think about the return to communities. Probe for cultural appropriateness of the approach.
    Ni nini unafikiria kuhusu jinsi matokeo yalirudi kwako?
    Dadisi: Kuhusu ni nini wanafikiria kuhusu kurudisha kwa jamii.
    Dadisi: Mbinu inayofaa kitamaduni.
29. What suggestions would you make to improve the process of returning research results to participants? Probe for suggestions for returning results to communities.
    Ni mapendekezo gani unayoweza kufanya ili kuboresha utaratibu wa kurudisha matokeo ya utafiti kwa washiriki?
    Dadisi: Pendekezo la kurudisha matokeo kwa jamii.
30. How does the way the results were returned to you affect your participation in future genomic studies? Probe for the effect on future community participation in Genomic studies. Would you participate or otherwise, in studies because of how results were returned to you?
    Je! Ni jinsi gani matokeo yaliorejeshwa kwako yana athiri kushiriki kwako katika kushiriki kwa utafiti wa masomo ya maumbile (genomic)?
    Dadisi: Kuhusu athari ya kushiriki kwa jamii siku zijazo kwenye utafiti za masomo ya maumbile (genomic).
    Je, unaweza kushiriki au la, kwa utafiti kwa sababu ya njia matokeo yalivyo rudishwa kwako?

31. What will you say is the best way to return genomic results to individual participants?
    Je, ungeweza kusema ni njia gani bora zaidi ya kurudisha matokeo ya utafiti ya masomo ya maumbile (genomic) kwa watu binafsi?
32. In your view, what will you say is the most preferred method of returning genomic results to communities?
    Kwa maoni yako, ungeweza kusema ni njia gani iliyopendekezwa zaidi ya kurudisha matokeo ya masomo ya maumbile (genomic) kwa wanajamii?
33. Is there anything you will like to add on the methods of returning research results to participants and communities that I have not asked?
    Je, Kuna lolote ungependa kuongezea kuhusu njia za kurudisha matokeo ya utafiti kwa washiriki binafsi na jamii ambayo sijakuuliza?

Section F: Recommendations and closure

34. How would you advise research teams to engage communities or participants in their studies?
    Je, ni vipi unaweza kushauri timu ya wanaofanya utafiti kushirikisha jamii au wanaoshiriki katika utafiti yao?

35. What do you think research teams can do to enhance community participation in genetic cohort studies?
    Unafikiria ni nini timu za wanaofanya utafiti zinaweza kufanya ili kuongeza kushiriki kwa jamii katika masomo ya kufuatilia kikundi cha uzazi?
36. Is there anything about genetic studies in general you will like to add; the way you are engaged, the study, the way results are returned and the importance participants place on results?
    Kuna chochote kuhusu masomo ya maumbile kwa ujumla ungependa kuongezea; jinsi unavyoshiriki, utafiti, jinsi matokeo yamerejeshwa na umuhimu ya washiriki kuwekwa kwa matokeo?

Thank you for participating in this discussion/ Asante kwa kushiriki kwenye mazungumzo

APPENDIX III: CONSENT FORMS FOR FGDS AND IDIS

CEBIOGen Study 1: Study Information Sheet and Consent Form

Study Title: **Exploring key stakeholders' perspectives on effective community engagement strategies to facilitate reporting aggregate genomic results to groups and communities: The AWI-Gen Case Study**

Consent form for Researchers/Field Assistants-IDI

Introduction

Hello, my name is [name of research assistant] and I am a research assistant from the African population and Research Centre (APHRC, Nairobi). I am here today to discuss a new research study we are conducting with researchers, members of research ethics committees, community leaders and research participants in genomic research.

What is this research about?

The purpose of this research is to explore attitudes and preferences of research participants and their families in genomic research study on cardiometabolic diseases on feeding back individual genetic research findings, to examine the role of community engagement in facilitating the return of aggregate results and also explore stakeholders‟ views on methods for feeding back aggregate genomic results in Kenya.

What does it involve?

As a researcher/field assistant, we will like to interview you on your views and experiences on issues. Your views will contribute to the development of recommendations for good research practices on returning research results to research participants and their families.

If you agree to take part in this study, we will interview you alone for about one hour. You will be asked to discuss your experiences with H3Africa AWI-Gen study and the challenges you encountered during the study. You will also be asked to share some of the challenges you faced during this process and what you think are the best ways of addressing these challenges. We will also ask you to share your views on best ethical practices for sharing genomic research results with research participants and communities.

If you agree, the discussion will be tape-recorded to assist later in writing up the information. You will not be identified by name on the tape.

Are there any disadvantages or advantages involved in taking part?
The advantage of taking part in this research is that it will give you the opportunity to contribute to the generation of new knowledge that will help govern genomics research in Africa as well as best practices for engaging research communities in medical research.

We are requesting one hour of your time for the interviews.

Who will have access to the information you give?
The information you give us will be kept confidential. To ensure this, your personal information will only be available to the investigators on this study. Interviews will be transcribed anonymously and the records will also be destroyed after we have worked with them.

What will happen if you refuse to participate?
Your participation in this study is completely voluntary. You have the right to withdraw from the study at any time. If during the interview, there is something that you do not understand, you should talk to the principal investigator or a member of the research team. You can skip any question that you do not want to answer.

What if you have any questions?
For information about this study, you can contact the researchers who are responsible:

Catherine Kyobutungi, PhD: Kenya Site PI, APHRC Email: ckyobutungi@aphrc.org , Kenya. Gershim Asiki, PhD: Co-Investigator (Study Manager), APHRC. Email: gasiki@aphrc.org

If you want to ask someone independent anything about this research, please contact:

The Administrator,
AMREF Ethics and Scientific Review Committee (ESRC)
Wilson Airport, Langata Road
Mobile No: 0795746777
P.O Box 30125-00100
Nairobi, Kenya

CONSENT FORM – INDIVIDUAL INTERVIEW PARTICIPANTS

Formal Title: Exploring key stakeholders' perspectives on effective community engagement strategies to facilitate reporting aggregate genomic results to groups and communities: The Kenya Case Study

I have had the study explained to me. I have understood all that has been read and had my questions answered satisfactorily. I understand that I can change my mind at any stage.

☐ *please tick* **I agree to be interviewed**

☐ *please tick* **I agree for the interview to be tape-recorded**

Representative Signature: _____ **Date**

Representative: _____ **Time:**

Name ***(please print name)***

I certify that I have followed the study procedures to explain this study to the participant, and that he/she understands the nature and the purpose of the study and consent to the discussion. He/she has been given opportunity to ask questions which have been answered satisfactorily.

Signature: _____ **Date**

Designee/investigator's _____ **Time:**

Name *(please print name)*

EVERY PARTICIPANT SHOULD NOW BE GIVEN A SIGNED COPY TO KEEP

CEBIOGen Study 1: Study Information Sheet and Consent Form

Kichwa cha Mradi**:** ***Kuchunguza mtazamo muhimu wa washikadao juu ya ushirikiano wa jamii juu ya mikakati ya ufanisi ya jamii kuwezesha taarifa ya jumla ya genomic kwa vikundi na jamii.***

Consent form for Researchers/Field Assistants-IDI

Utangulizi
Habari, jina langu ni [Jina la mtafiti msaidizi] na mimi ni msaidizi wa utafiti kutoka African population And Health Research Centre (APHRC, Nairobi). Niko hapa leo kujadili utafiti mpya tunaedesha na watafiti, wanachama wa kamati za madili ya utafiti, viongozi wa jamii na washiriki wa utafiti katika utafiti wa Genomic (masomo ya maumbile)

Utafiti huu ni kuhusu nini?
Kusudi la utafiti huu ni kuchunguza mitazamo na mapendekezo ya washiriki wa utafiti na familia zao katika utafiti wa masomo ya maumbile na magonjwa ya cardiometabolic katika kurudisha matokeo ya maumbile ya kibinadamu, ili kuchunguza jukumu la ushikishaji wa jamii katika kuwezesha kurudi kwa matokeo wa jumla na pia kuchunguza maoni ya washikajidau" Juu ya njia za kurudisha matokeo ya jumla juu ya masomo ya maumbile nchini Kenya.

Inahusisha nini?
Kama Mtafiti/ mtafiti msaidizi, tungependa kukuhoji kuhusu maoni yako na uzoefu wako juu ya masuala. Maoni yako yatachangia maendeleo kwa mazoea mzuri ya utafiti juu ya kurudisha matokeo ya utafiti kwa washiriki na familia zao.
Ikiwa utakubali kushiriki katika utafiti huu, tutakuhoji wewe pekee kwa muda wa saa moja. Utaulizwa kujadili mazoea yako, Kwenye mradi wa H3Africa, AWI-Gen an changamoto uliyokumbana nayo wakati Wa mradi huu. Tutakuuliza kutaja baahdi ya maoni yako kuhusu changemoto ulizokabiliana nazo wakati wa mchakato hu una unafikiri ni njia bora za kukabiliana na changamoto hizi. Pia tutakuuliza kushiriki maoni yako juu ya mazoea bora ya kimaadili kwa kushirikiana matokeo wa genomic na washiriki wa utafiti na jamii.

Ikiwa unakubaliana, mazungumuzo itarekodiwa kwa mkanda ili kusaidia baadaye kuandika taarifa. Hautambulika kwa jina kwenye tepu.

Je, kuna faida yoyote hasara zinazohusika kushiriki?

Faida ya kushiriki katika utafiti huu ni kwamba itakupa nafasi ya kuchangia kuundwa kwa ujuzi mpya ambayo itasaidia kusimamia utafiti za genomic baraani Africa pamoja na mazoea bora ya kushiriki katika jamii za utafiti wa matibabu.

Tunaomba saa moja ya muda wako kwa mahojiano?

Nani ataruhusiwa kupata maelezo utakayotoa?

Habari utakayaotupa yatawekwa kwa siri. Ili kuhakikisha hili, Maelezo yako binafsi yatakuwa tu na mtafiti mkuu wa Mradi hili. Mahojiano yatasajiliwa bila kujulikana/bila jina na kumbukumbu kuharibiwa baada ya kufanya kazi nao.

Ni nini kitatokea ikiwa utakataa kushiriki?
Kushiriki kwako kwa utafiti ni kwa hiari kabisa. Una haki ya kujiondoa kwenye utafiti wakati wowote. Ikiwa wakati wa mahojiano kuna kitu ambacho haujakielewa, unapaswa kuzungumza na mtafiti mkuu au kati ya moja wa timu ya watafiti. Unaweza kuruka swali lo lote usilopenda kulijibu.

Ni nini ikiwa una maswali?
Kwa habari kuhusu utafiti huu unaweza kuwasiliana na watafiti ambao wanajibika:
Daktari Catherine Kyobutungi, Mtafiti mkuu kutoka kituo cha kufanya utafiti cha African Population and Health Research Center (APHRC) Kwa nambari……Pia unaweza kuwasiliana kwa barua pepe kupitia mtandao na : ckyobutungi@aphrc.org.
Gershim Asiki, PhD: Naibu Mtafiti Mkuu (Meneja wa mradi), APHRC, Kwa barua pepe kupitia mtandao kwa : gasiki@aphrc.org. Kenya.

Ikiwa wataka kuuliza mtu huru/ asiyehusika na utafiti huu chochote kuihusu tafadhali wasiliana na:

Msimamizi,
AMREF Ethics & Scientific Review Committtee (ESRC),
Wilson Airport, Langata road
Nambari ya simu +254 20 6994000
Sanduku la posta Box. 30125-00100
Nairobi, Kenya.

CEBIOGen Study: Study Information Sheet and Consent Form

Study Title: **Exploring key stakeholders' perspectives on effective community engagement strategies to facilitate reporting aggregate genomic results to groups and communities: The Kenya Case Study**

Consent form for Ethics Committee Members-FGD

Introduction

Hello, my name is [name of research assistant] and I am a research assistant from the African population And Health Research Centre (APHRC, Kenya) I am here today to discuss a new research study we are conducting with researchers, members of research ethics committees and research participants in genomic research.

What is this research about?
The purpose of this research is to explore attitudes and preferences of research participants and their families in genomic research on cardiometabolic diseases on feeding back individual genetic research findings, to examine the role of community engagement in facilitating the return of aggregate results and also explore stakeholders' views on methods for feeding back aggregate genomic results in Nairobi.

What does it involve?
As an ethics committee member, we will like to discuss with you your views and experiences on these issues. Your views will contribute to development of recommendations for good research practices on returning research results to research participants and their families.

If you agree to take part in this study, we will have a discussion with you and other members of your ethics committee for about one hour. You will be asked to discuss your experiences with H3Africa AWI-Gen study protocol and the ethical challenges you encountered in reviewing the protocol. You will also be asked to share some of the challenges you faced during this process and what you think are the best ways of addressing these challenges. We will also ask you to share your views on best ethical practices for sharing genomic research results with participants, families and communities.

If you agree, the discussion will be tape-recorded to assist later in writing up the information. You will not be identified by name on the tape.

Are there any disadvantages or advantages involved in taking part?
The advantage of taking part in this research is that it will give you the opportunity to contribute to the generation of new knowledge that will help govern genomics research in Africa as well as best practices for engaging research communities in medical research.

We are requesting one hour of your time for the interviews.

Who will have access to the information you give?
The information you give us will be kept confidential. To ensure this, your personal information will only be available to the investigators on this study. Interviews will be

transcribed anonymously and the records will also be destroyed after we have worked with them.

What will happen if you refuse to participate?

Your participation in this study is completely voluntary. You have the right to withdraw from the study at any time. If during the discussion, there is something that you do not understand, you should talk to the principal investigator or a member of the research team. You can skip any question that you do not want to answer.

What if you have any questions?
For information about this study, you can contact the researchers who are responsible: Catherine Kyobutungi, PhD: Kenya Site PI, APHRC Email: ckyobutungi@aphrc.org , Kenya. Gershim Asiki, PhD: Co-Investigator (Study Manager), APHRC. Email: gasiki@aphrc.org

If you want to ask someone independent anything about this research please contact:

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AMREF Ethics & Scientific Review Committtee (ESRC)
Wilson Airport, Langata Road
Mobile No: 0795746777
P.O Box 30125-00100
Nairobi, Kenya

CONSENT FORM – FOCUS GROUP DISCUSSION PARTICIPANTS

Formal Title: **Exploring key stakeholders' perspectives on effective community engagement strategies to facilitate reporting aggregate genomic results to groups and communities: The Kenya Case Study**

I have had the study explained to me. I have understood all that has been read and had my questions answered satisfactorily. I understand that I can change my mind at any stage.

☐ *please tick* **I agree to join the discussion**

☐ *please tick* **I agree for the discussion to be tape-recorded**

Representative Signature: _____ **Date**

Representative: **Time:**

Name _____ ***(please print name)***

I certify that I have followed the study procedures to explain this study to the participant, and that he/she understands the nature and the purpose of the study and consent to the discussion. He/she has been given opportunity to ask questions which have been answered satisfactorily.

Signature: _____ **Date**

Designee/ investigator's **Time:**

Name _____ *(please print name)*

EVERY PARTICPANT SHOULD NOW BE GIVEN A SIGNED COPY TO KEEP

CEBIOGen Study 1: Study Information Sheet and Consent Form

Study Title: **Exploring key stakeholders' perspectives on effective community engagement strategies to facilitate reporting aggregate genomic results to groups and communities: The Kenya Case Study**

Consent form for Community Leaders-IDI

Introduction
Hello, my name is [name of research assistant] and I am a research assistant from the African Health Research Centre (Nairobi). I am here today to discuss a new research study we are conducting with researchers, members of research ethics committees, community leaders and research participants in genomic research.

What is this research about?
The purpose of this research is to explore attitudes and preferences of research participants and their families in genomic research study on cardiometabolic diseases on feeding back individual genetic research findings, to examine the role of community engagement in facilitating the return of aggregate results and also explore stakeholders‟ views on methods for feeding back aggregate genomic results in Kenya.

What does it involve?
As a community leader, we will like to interview you about your views and experiences on these issues. Your views will contribute to the development of recommendations for good research practices on returning research results to research participants and their families.

If you agree to take part in this study, we will interview you alone for about one hour. You will be asked to discuss your experiences with the H3Africa AWI-Gen study and the challenges your community encountered during the study You will also be asked to share some of the challenges you faced during this process and what you think are the best ways of addressing these challenges. We will also ask you to share your views on best ethical practices for sharing genomic research results with participants, families and communities.
If you agree, the discussion will be tape-recorded to assist later in writing up the information. You will not be identified by name on the tape.

Are there any disadvantages or advantages involved in taking part?
The advantage of taking part in this research is that it will give you the opportunity to contribute to the generation of new knowledge that will help govern genomics research in Africa as well as best practices for engaging research communities in medical research.

We are requesting one hour of your time for the interviews.

Who will have access to the information you give?
The information you give us will be kept confidential. To ensure this, your personal information will only be available to the investigators on this study. Interviews will be transcribed anonymously and the records will also be destroyed after we have worked with them.

What will happen if you refuse to participate?
Your participation in this study is completely voluntary. You have the right to withdraw from the study at any time. If during the interview, there is something that you do not understand, you should talk to the principal investigator or a member of the research team. You can skip any question that you do not want to answer.

What if you have any questions?
For information about this study, you can contact the researchers who are responsible: Catherine Kyobutungi, PhD: Kenya Site PI, APHRC Email: ckyobutungi@aphrc.org , Kenya. Gershim Asiki, PhD: Co-Investigator (Study Manager), APHRC. Email: gasiki@aphrc.org

If you want to ask someone independent anything about this research please contact:

The Administrator,
AMREF Ethics & Scientific Review Committtee (ESRC)
Wilson Airport, Langata Road
Mobile No: 0795746777
P.O Box 30125-00100
Nairobi, Kenya

CONSENT FORM – INDIVIDUAL INTERVIEW PARTICIPANTS

Formal Title: **Exploring key stakeholders' perspectives on effective community engagement strategies to facilitate reporting aggregate genomic results to groups and communities: The Kenya Case Study**

I have had the study explained to me. I have understood all that has been read and had my questions answered satisfactorily. I understand that I can change my mind at any stage.

☐ *please tick* **I agree to be interviewed**

☐ *please tick* **I agree for the interview to be tape-recorded**

Representative Signature:	_____	**Date**
Representative:		**Time:**
Name	_____ ***(please print name)***	

I certify that I have followed the study procedures to explain this study to the participant, and that he/she understands the nature and the purpose of the study and consent to the discussion. He/she has been given opportunity to ask questions which have been answered satisfactorily.

Signature:	_____	**Date**
Designee/ investigator's		**Time:**
Name	_____ *(please print name)*	

EVERY PARTICPANT SHOULD NOW BE GIVEN A SIGNED COPY TO KEEP

Study Title: **Exploring key stakeholders' perspectives on effective community engagement strategies to facilitate reporting aggregate genomic results to groups and communities: The Kenya Case Study**

Kichwa cha Mradi**: *Kuchunguza mtazamo muhimu ya washukadao juu ya mikakati bora ya kushirikisha jamii ilikuwezesha kutoa repoti ya matokeo ya jumla za masomo ya mwili (Genomic) kwa vikundi na jamii.***

Consent form for Community Leaders-IDI

Utangulizi

Habari, jina langu ni [Jina la mtafiti msaidizi] na mimi ni msaidizi wa utafiti kutoka African Population And Health Research Centre (APHRC, Nairobi). Niko hapa leo kujadili utafiti mpya tunaedesha na watafiti, wanachama wa kamati za madili ya utafiti, viongozi wa jamii na washiriki wa utafiti katika utafiti wa Genomic (masomo ya maumbile)

Utafiti huu ni kuhusu nini?

Kusudi la utafiti huu ni kuchunguza mitazamo na mapendekezo ya washiriki wa utafiti na familia zao katika utafiti wa masomo ya maumbile (genomic) na magonjwa yanayo husiana na moyo (cardiometabolic) katika kurudisha matokeo ya utafiti wa maumbile ya kibinadamu, ili kuchunguza jukumu la ushirikishaji wa jamii katika kuwezesha kurudisha matokeo ya jumla na pia kuchunguza maoni ya washikajidau" Juu ya njia za kurudisha matokeo ya jumla juu ya masomo ya maumbile nchini Kenya.

Inahusisha nini?

Kama kiongozi wa jamii, tungependa kukuhoji kuhusu maoni yako na uzoefu wako juu ya masuala haya. Maoni yako yatachangia kuboresha mapendekezo kwa mazoea mzuri ya utafiti juu ya kurudisha matokeo ya utafiti kwa washiriki na familia zao.

Ikiwa utakubali kushiriki katika utafiti huu, tutakuhoji wewe pekee kwa muda wa saa moja. Utaulizwa kujadili mazoea yako, Kwenye mradi wa H3Africa, AWI-Gen na changamoto uliyokumbana nayo wakati Wa mradi huu. Tutakuuliza kutaja baahdi ya maoni yako kuhusu changamoto ulizokabiliana nazo wakati wa shughuli hii na una unafikiri ni njia zipi bora zaidi za kukabiliana na changamoto hizi. Pia tutakuuliza kushiriki maoni yako juu ya mazoea bora zaidi ya kimaadili ya kutoa matokeo ya masomo ya maumbile (genomic) kwa washiriki, familia na jamii.

Ikiwa unakubaliana, mazungumuzo itarekodiwa kwa mkanda ili kusaidia baadaye kuandika taarifa. Hautatambulika kwa jina kwenye tepu.

Je, kuna faida yoyote hasara zinazohusika kushiriki?

Faida ya kushiriki katika utafiti huu ni kwamba itakupa nafasi ya kuchangia kuundwa kwa ujuzi mpya ambayo itasaidia kusimamia utafiti za masomo ya maumbile (genomic) baarani Africa pamoja na mazoea bora ya kushiriki katika jamii za utafiti wa matibabu.

Tunaomba saa moja ya muda wako kwa mahojiano.

Nani ataruhusiwa kupata maelezo utakayotoa?
Habari ambayo utatupa yatawekwa kwa siri. Ili kuhakikisha hili, maelezo yako binafsi yatakuwa tu na mtafiti mkuu wa Mradi hili. Mahojiano yatasajiliwa bila kujulikana/bila jina na kumbukumbu kuharibiwa baada ya kufanya kazi nao.

Ni nini kitatokea ikiwa utakataa kushiriki?
Kushiriki kwako kwa utafiti ni kwa hiari kabisa. Una haki ya kujiondoa kwenye utafiti wakati wowote. Ikiwa wakati wa mahojiano kuna kitu ambacho haujakielewa, unapaswa kuzungumza na mtafiti mkuu au kati ya moja wa timu ya watafiti. Unaweza kuruka swali lolote usilopenda kulijibu.

Ni nini ikiwa una maswali?
Kwa habari kuhusu utafiti huu, unaweza kuwasiliana na watafiti ambao wanajibika:

Daktari Catherine Kyobutungi, Mtafiti mkuu kutoka kituo cha kufanya utafiti cha African Population and Health Research Center (APHRC) Kwa nambari……Pia unaweza kuwasiliana kwa barua pepe kupitia mtandao na, ckyobutungi@aphrc.org.

Gershim Asiki, PhD: Naibu Mtafiti Mkuu (Meneja wa mradi), APHRC, Kwa barua pepe kupitia mtandao kwa : gasiki@aphrc.org. Kenya.

Ikiwa wataka kuuliza mtu huru/ asiyehusika na utafiti huu chochote kuihusu tafadhali wasiliana na:

Msimamizi,
AMREF Ethics & Scientific Review Committtee (ESRC),
Wilson Airport, Langata road
Nambari ya simu +254 20 6994000
Sanduku la posta Box. 30125-00100
Nairobi, Kenya.

CONSENT FORM – INDIVIDUAL INTERVIEW PARTICIPANTS

Kichwa cha Mradi**: *Kuchunguza mtazamo muhimu wa washikajidao juu ya ushirikiano wa jamii juu ya mikakati ya ufanisi ya jamii kuwezesha taarifa ya jumla ya genomic kwa vikundi na jamii.***

Nimepata kuelezewa kuhusu utafiti huu. Nimeelewa yote niliyosomewa na kuridhika na majibu ya maswali yote niliokua nao. Ninaelewa kuwa ninaweza kubadilisha mawazo yangu wakati wowote

□Tafadhali weka alama **Nimekubali kuhojiwa.**

□Tafdhali weka alama **Nimekubali mahojiano inaweza kurekodi sauti**

Sahihi ya Mshiriki: **Tareh e**

Sa _____

Jina la Mshiriki: **saa:**

_____
(Tafadhali chapisha jina)

Nathibitisha kuwa nimefuata taratibu za kuelezea utafiti huu kwa mshiriki, na kwamba anaelewa asili na kusudi ya utafiti na kukubali majadiliano. Yeye amekua na fursa ya kuuliza maswali ambayo yamejibiwa kwa kuridhisha.

Sahihi ya mtafiti anayepatiana idhini: _____ **Tarehe**

Saa ya:

Jina _____
(Tafadhali chapisha jina)

EVERY PARTICIPANT SHOULD NOW BE GIVEN A SIGNED COPY TO KEEP/ KILA MSHIRIKI ATAPEWA NAKALA ILIYOTIWA SAHIHI KUWAKA

CEBIOGen Study 1: Study Information Sheet and Consent Form

Study Title: **Exploring key stakeholders' perspectives on effective community engagement strategies to facilitate reporting aggregate genomic results to groups and communities: The Kenya Case Study**

Consent form for AWI-Gen Study Paticipants-FGD

Introduction
Hello, my name is [name of research assistant] and I am a research assistant from the African Population And Health Research Centre (Nairobi). I am here today to discuss a new research study we are conducting with researchers, members of research ethics committees and research participants in a genomic research study.

What is this research about?
The purpose of this research is to explore attitudes and preferences of research participants and their families in genomic research study on cardiometabolic diseases on feeding back individual genetic research findings, to examine the role of community engagement in facilitating the return of aggregate results and also explore stakeholders‟ views on methods for feeding back aggregate genomic results in Kenya.

What does it involve?
As a participant in the AWI-Gen study, we will like to interview you on your views and experiences on the study. Your views will contribute to the development of recommendations for good research practices on returning research results to research participants and their families.

If you agree to take part in this study, we will have a discussion with you and other participants of the AWI-Gen study for about one hour. You will be asked to discuss your experiences with H3Africa AWI-Gen study and the challenges you encountered participating in the study. You will also be asked to share some of the challenges you faced during this process and what you think are the best ways of addressing these challenges. We will also ask you to share your views on best ethical practices for sharing genomic research results with participants, families and communities.

If you agree, the discussion will be tape-recorded to assist later in writing up the information. You will not be identified by name on the tape.

Are there any disadvantages or advantages involved in taking part?

The advantage of taking part in this research is that it will give you the opportunity to contribute to the generation of new knowledge that will help govern genomic research in Africa as well as best practices for engaging research communities in medical research.

We are requesting one hour of your time for the discussion.

Who will have access to the information you give?
The information you give us will be kept confidential. To ensure this, your personal information will only be available to the investigators on this study. Interviews will be transcribed anonymously and the records will also be destroyed after we have worked with them.

What will happen if you refuse to participate?
Your participation in this study is completely voluntary. You have the right to withdraw from the study at any time. If during the interview, there is something that you do not understand, you should talk to the principal investigator or a member of the research team. You can skip any question that you do not want to answer.

What if you have any questions?
For information about this study, you can contact the researchers who are responsible: Catherine Kyobutungi, PhD: Kenya Site PI, APHRC Email: ckyobutungi@aphrc.org , Kenya. Gershim Asiki, PhD: Co-Investigator (Study Manager), APHRC. Email: gasiki@aphrc.org

If you want to ask someone independent anything about this research please contact:

The Administrator,
AMREF Ethics & Scientific Review Committtee (ESRC)
Wilson Airport, Langata Road
Mobile No: 0795746777
P.O Box 30125-00100
Nairobi, Kenya

CONSENT FORM – FOCUS GROUP DISCUSSION PARTICIPANTS

Formal Title: **Exploring key stakeholders' perspectives on effective community engagement strategies to facilitate reporting aggregate genomic results to groups and communities: The Kenya Case Study**

I have had the study explained to me. I have understood all that has been read and had my questions answered satisfactorily. I understand that I can change my mind at any stage.

☐ *please tick* **I agree to join the discussion**

□ *please tick* **I agree for the discussion to be tape-recorded**

Representative Signature:	_____	**Date**
Representative:		**Time:**
Name	_____ ***(please print name)***	

I certify that I have followed the study procedures to explain this study to the participant, and that he/she understands the nature and the purpose of the study and consent to the discussion. He/she has been given opportunity to ask questions which have been answered satisfactorily.

Signature:	_____	**Date**
Designee/ investigator's		**Time:**
Name	_____ *(please print name)*	

EVERY PARTICPANT SHOULD NOW BE GIVEN A SIGNED COPY TO KEEP

CEBIOGen Study 1: Study Information Sheet and Consent Form

Study Title: **Exploring key stakeholders' perspectives on effective community engagement strategies to facilitate reporting aggregate genomic results to groups and communities: The Kenya Case Study**

Kichwa cha Mradi**: *Kuchunguza mtazamo muhimu ya washukadao juu ya mikakati bora ya kushirikisha jamii ilikuwezesha kutoa repoti ya matokeo ya jumla za masomo ya mwili (Genomic) kwa vikundi na jamii.***

Consent form for AWI-Gen Study Paticipants-FGD

Utangulizi
Habari yako, jina langu ni [*Jina la mtafiti msaidizi*] na mimi ni msaidizi wa utafiti kutoka African population And Health Research Centre (APHRC, Nairobi). Niko hapa leo kujadili utafiti mpya tunaedesha na watafiti, wanachama wa kamati za madili ya utafiti, viongozi wa jamii na washiriki wa utafiti katika utafiti wa Genomic (masomo ya maumbile)

Utafiti huu ni kuhusu nini?
Kusudi la utafiti huu ni kuchunguza mitazamo na mapendekezo ya washiriki wa utafiti na familia zao katika utafiti wa masomo ya maumbile (genomic) na magonjwa yanayo husiana na moyo (cardiometabolic) katika kurudisha matokeo ya maumbile ya kibinadamu, ili kuchunguza jukumu la kushirikisha jamii katika kuwezesha kurudisha matokeo ya jumla na pia kuchunguza maoni ya washikajidau" Juu ya njia za kurudisha matokeo ya jumla juu ya masomo ya maumbile nchini Kenya.

Inahusisha nini?
Kama Mshiriki wa utafiti wa AWI-Gen, tungependa kukuhoji kuhusu maoni yako na uzoefu wako juu ya masuala haya. Maoni yako yatachangia kuboresha mapendekezo kwa mazoea mzuri ya utafiti juu ya kurudisha matokeo ya utafiti kwa washiriki na familia zao.
Ikiwa utakubali kushiriki katika utafiti huu, tutakua na majadiliano na wewe na washiriki wengine wa AWI-Gen kwa muda wa saa moja na nusu hadi masaa mawili. Utaulizwa kujadili mazoea yako, Kwenye mradi wa H3Africa AWI-Gen na changamoto uliyokumbana nayo wakati wa mradi huo. Pia tutakuuliza kutaja baahdi ya maoni yako kuhusu changamoto ulizokabiliana nazo wakati wa utafiti huu.na unafikiri ni njia gani bora Zaidi kukabiliana na changamoto hizi. Pia tutakuuliza kushiriki maoni yako juu ya mazoea bora Zaidi ya kimaadili kwa kutoa matokeo ya utafiti ya masomo ya maumbile (genomic) na washiriki wa utafiti na jamii.

Ikiwa unakubaliana, mazungumuzo itarekodiwa kwa mkanda ili kusaidia baadaye kuandika taarifa. Hautambulika kwa jina kwenye tepu.

Je, kuna faida yoyote hasara zinazohusika kushiriki?
Faida ya kushiriki katika utafiti huu ni kwamba itakupa nafasi ya kuchangia kuundwa kwa ujuzi mpya ambayo itasaidia kusimamia utafiti za masomo ya maumbile (genomic) barani Africa pamoja na mazoea bora ya kushiriki katika jamii za utafiti wa matibabu.

Tunaomba saa moja na nusu hadi masaa mawili ya muda wako kwa mahojiano.

Nani ataruhusiwa kupata maelezo utakayotoa?
Habari utakayaotupa yatawekwa kwa siri. Ili kuhakikisha hili, maelezo yako binafsi yatakuwa tu na mtafiti mkuu wa Mradi huu. Mahojiano yatasajiliwa bila kujulikana jina na kumbukumbu kuharibiwa baada ya kufanya kazi nao.

Ni nini kitatokea ikiwa utakataa kushiriki?

Kushiriki kwako kwa utafiti ni kwa hiari kabisa. Una haki ya kujiondoa kwenye utafiti wakati wowote. Ikiwa wakati wa mahojiano kuna kitu ambacho haujakielewa, unapaswa kuzungumza na mtafiti mkuu au kati ya moja wa timu ya watafiti wasaidizi. Unaweza kuruka swali lolote usilopenda kulijibu.

Ni nini ikiwa una maswali?
Kwa habari kuhusu utafiti huu, unaweza kuwasiliana na watafiti ambao wanajibika:

Daktari Catherine Kyobutungi, Mtafiti mkuu kutoka kituo cha kufanya utafiti cha African Population and Health Research Center (APHRC) Kwa nambari……Pia unaweza kuwasiliana kwa barua pepe kupitia mtandao na: ckyobutungi@aphrc.org. Kenya Kenya. Gershim Asiki, PhD: Naibu Mtafiti Mkuu (Meneja wa mradi), APHRC, Kwa barua pepe kupitia mtandao kwa : gasiki@aphrc.org. Kenya.

Ikiwa wataka kuuliza mtu huru/ asiyehusika na utafiti huu chochote kuihusu tafadhali wasiliana na:

Msimamizi,
AMREF Ethics & Scientific Review Committtee (ESRC),
Wilson Airport, Langata road
Nambari ya simu +254 20 6994000
Sanduku la posta Box. 30125-00100
Nairobi, Kenya.

CONSENT FORM – INDIVIDUAL INTERVIEW PARTICIPANTS

Kichwa cha Mradi**: *Kuchunguza mtazamo muhimu wa washukadao juu ya ushirikiano wa jamii juu ya mikakati ya ufanisi ya jamii kuwezesha taarifa ya jumla ya genomic kwa vikundi na jamii.***

Nimepata kuelezewa kuhusu utafiti huu. Nimeelewa yote niliyosomewa na kuridhika na majibu ya maswali yote niliokua nao. Ninaelewa kuwa ninaweza kubadilisha mawazo yangu wakati wowote

☐Tafadhali weka alama **Nimekubali kuhojiwa.**

☐Tafdhali weka alama **Nimekubali mahojiano inaweza kurekodi sauti**

Sahihi ya Mshiriki: **Tarehe**

_____

_____

Sa _____

Jina la Mshiriki: **saa:**

_____
(Tafadhali chapisha jina)

Nathibitisha kuwa nimefuata taratibu za kuelezea utafiti huu kwa mshiriki, na kwamba anaelewa asili na kusudi ya utafiti na kukubali majadiliano. Yeye amekua na fursa ya kuuliza maswali ambayo yamejibiwa kwa kuridhisha.

Sahihi ya mtafiti anayepatiana idhini: _____ **Tarehe**

_____ **Saa ya:**

Jina *(Tafadhali chapisha jina)*

EVERY PARTICIPANT SHOULD NOW BE GIVEN A SIGNED COPY TO KEEP/ KILA MSHIRIKI ATAPEWA NAKALA ILIYOTIWA SAHIHI KUWEKA

Appendix IV: **NIH training certificates (attached)**