

# Kenya - Exploring key stakeholders' perspectives on effective community engagement strategies to facilitate reporting aggregate genomic results to groups and communities: The Kenya Case study, CEBioGEN

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Report generated on: June 27, 2025

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## Overview

### Identification

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#### ID NUMBER

DDI-KEN-APHRC-CEBioGEN-2019-V1.0

### Version

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#### VERSION DESCRIPTION

#### PRODUCTION DATE

2024-11-21

#### NOTES

N/A

### Overview

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#### 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-GenCE) study (i) elicited key stakeholders' views on the value and purpose of CE in genomics, (ii) identified 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 also feed into further development of several H3Africa guidelines and policies on consent, CE and feedback of findings. The study employed a mixed social science methodology to address the study research questions. In Kenya we conducted this study in three phases over a period of four years. This study budget is \$19,008 for one year.

#### UNITS OF ANALYSIS

Key Community stakeholders

### Scope

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#### NOTES

The scope includes: Background of participants, Knowledge/experience with community engagement, Experience with genomic research, Returning research results to participants, Role of community engagement in supporting knowledge sharing,

### Coverage

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#### GEOGRAPHIC COVERAGE

County Coverage (Nairobi County/Informal settlements of Korogocho and Viwandani)

#### UNIVERSE

The survey covered sampled key community stakeholders

## Producers and Sponsors

### PRIMARY INVESTIGATOR(S)

Name	Affiliation
Catherine Kyobutungi, PhD	APHRC
Dr. Anita Ghansah, PhD	University of Ghana

### OTHER PRODUCER(S)

Name	Affiliation	Role
Gershim Asiki, PhD	APHRC	CO-Investigator
Shukri Mohamed, MPH	APHRC	Kenya Site Study Coordinator
Isaac Kisiangani, MPH	APHRC	Kenya Site Research Officer
Dr. Pauline Tindana, PhD	University of Ghana - Ghana	Overall Study Manager

### FUNDING

Name	Abbreviation	Role
National Institutes of Health (NIH) - (USA) - under the Human Heredity and Health in Africa (H3A) Initiative	NIH	Funder

### OTHER ACKNOWLEDGEMENTS

Name	Affiliation	Role
Joy Chepkemboi	African Population and Health Research Center	Data Documentation Officer
Bonface Ingumba	African Population and Health Research Center	Data Governance Officer

## Metadata Production

### METADATA PRODUCED BY

Name	Abbreviation	Affiliation	Role
African Population and Health Research Center	APHRC		Documentation of the DDI

### DATE OF METADATA PRODUCTION

2024-11-21

### DDI DOCUMENT VERSION

Version 1.0 (November 2024)

### DDI DOCUMENT ID

DDI-KEN-APHRC-CEBioGEN-2019-V1.0

## Sampling

### Sampling Procedure

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**Study Design and Sampling Strategy**

a) **Study design:** Employed a mixed social science methodology to address our research questions. Drawing insights from Creswell's interpretation of pragmatism, adopted 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 included qualitative study that utilized 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 involved simultaneous or sequential collection of both numerical and textual information to best understand the research problem. The quantitative arm tested the general acceptability of various of the various CE methods feedback.

b) **Study site (geographical)** The study in Kenya was 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 first approached 56 of these participants, 20 of these were involved in IDIs, while 36 were involved in FGDs. Interviews continued until we either contacted all 56 individuals or reached saturation. We obtained the contact information of those who refused participation from the AWI-Gen research team. Depending on the numbers involved, we purposively approached 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 NUHDSS 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 also conducted IDIs with these individuals who declined to participate in the AWI-Gen study.

### Deviations from Sample Design

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N/A

### Response Rate

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N/A

### Weighting

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N/A

# Questionnaires

## Overview

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The study used questionnaires targeting community members, fieldworkers, study coordinators, and ethics committee members. These questionnaires were developed in English and translated into Kiswahili. The design was based on previous similar studies and standard models, with stakeholder input to ensure cultural appropriateness. Stakeholders' feedback was incorporated into the final version, and any testing or revision reports were provided as External Resources. Pre-testing was also conducted to refine the tools before full implementation.

## Data Collection

### Data Collection Dates

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Start	End	Cycle
2019-11-11	2020-02-27	N/A

### Data Collection Mode

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Face-to-face [f2f]

### Questionnaires

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### Supervision

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Interviewing was conducted by two interviewers. All coordinated field data collection activities. Additionally, they maintained field control documents, and sent recordings and field notes to the central office.

## Data Processing

### Data Editing

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N/A

### Other Processing

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N/A

## Data Appraisal

### **Estimates of Sampling Error**

N/A



## **File Description**

## Variable List



## Documentation

### Questionnaires

#### FGD AND IDI GUIDES\_AWIGEN CE.pdf

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Title	FGD AND IDI GUIDES_AWIGEN CE.pdf
Author(s)	African Population and Health Research Center
Date	25/06/2025
Country	KENYA
Language	ENGLISH and SWAHILI
Contributor(s)	Catherine Kyobutungi, PhD and Dr. Anita Ghansah, PhD
Publisher(s)	APHRC
Filename	FGD AND IDI GUIDES_AWIGEN CE.pdf

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### Other materials

#### CEBioGEN Community engagement protocol-AMREF-ESRC-Revised\_Final.pdf

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Title	CEBioGEN Community engagement protocol-AMREF-ESRC-Revised_Final.pdf
Author(s)	African Population and Health Research Center
Date	25/06/2025
Country	KENYA
Language	ENGLISH
Contributor(s)	Catherine Kyobutungi, PhD and Dr. Anita Ghansah, PhD
Publisher(s)	APHRC
Filename	CEBioGEN Community engagement protocol-AMREF-ESRC-Revised_Final.pdf

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#### Combined CEBioGen Transcripts.docx

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Title	Combined CEBioGen Transcripts.docx
Author(s)	African Population and Health Research Center
Date	27/06/2025
Country	KENYA
Language	ENGLISH
Contributor(s)	Catherine Kyobutungi, PhD and Dr. Anita Ghansah, PhD
Publisher(s)	APHRC
Filename	Combined CEBioGen Transcripts.docx

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