# Indigenous linguistic and cultural concepts of heritability and comprehension of genomics research in Africa (INDIGENE study).

African Collaborative Center for Microbiome and Genomics Research

# Comprehension of Genomics in Africa

- Human genomics research in Africa is growing
- This growth has been accompanied by concerns that potential participants may not have adequate comprehension of genomics research sufficient for them to give valid informed consent.
- These concerns arise because many native languages do not have words for “genes, genomics etc.”.
- And African countries have high levels of general and health illiteracy and may not readily appropriate words from other languages.

# Comprehension of informed consent

- It has been suggested therefore that most of the general population may not adequately understand genomics research
- This lack of understanding may affect willingness of people to enroll in genomics research projects
- It also raises questions about the validity of the consent that is obtained in the course of the research
- If those who have participated in genomics research do not show evidence of sufficient comprehension of the research and the consent they gave, those consent may be invalid

# Origin of words and concepts

- Understanding and communicating new ideas to general population often require use of new words
- These words, including those used to communicate the process and outcomes of genomics research arise in a variety of ways. For example, new coinage, loanwords, sound or action symbolism etc.
- These words are disseminated to the society through the mass media and other means of communication.
- Genomics research in Africa can use similar routes to introduce new words and ideas to effectively communicate and improve comprehension of genomics in African societies

# Study objective

- The Indigenous linguistic and cultural concepts of heritability and comprehension of genomics research in Africa (INDIGENE study) project is designed to identify words and concepts used by native speakers in Nigeria to describe transmission of diseases and traits across generations
- The study will then use ideas and words from how people communicate these ideas and concepts to develop a “modified” consent form.
- A randomized comparison of the modified and standard consent form will be done to evaluate the impact on comprehension of informed consent

# Aim one

- **Study linguistic and cultural concepts of transmission of traits and diseases and how these can be used to improve comprehension of genomics of non-communicable diseases in indigenous communities in Nigeria**
  - Conduct key informant interviews (KII) and focus group discussions (FGD).
  - Evaluate the use of linguistic and cultural concepts to improve comprehension of informed consent for genomics of Cervical Cancer research in Nigeria.

# Aim two

- **Incorporate cultural and linguistic concepts of transmission of traits and diseases into informed consent process for genomics of cervical cancer research in Nigeria and evaluate the impact on comprehension.**
  - Compare the comprehension of consent forms incorporating new concepts with standard consent forms for genomics research of cervical cancer in Nigeria.
  - Evaluate the perception and satisfaction of research participants with modified compared with standard consent forms.

# Methods

- Focus Group Discussions
  - 10 focus group discussions have been completed in three semi-rural communities in Abuja Nigeria - Karamanjiji, Kunchigworo and Angwuragwu Communities.
  - 50 males and 50 females from diverse ethnic groups and religions who are 18 years and above participated in the research
- Interviews were transcribed in Native languages and translated to English Language
- Computer assisted qualitative data analysis was done using ATLAS.ti

# Women's focus group discussion

# Men's focus group discussion

# Methods

- Key Informant Interviews
  - We conducted KII with 50 Opinion Leaders in the same communities
  - There were 27 males and 23 females from different religious and socio-economic backgrounds.
- The interviews were conducted in English and Native languages.
- Interviews were transcribed and those that were conducted in native languages were translated to English Language
- Computer assisted qualitative data analysis was done using ATLAS.ti

# Key Informant Interview in progress

# Results

- Participants volunteered local concepts that are used to describe and discuss heritable trait in their local dialects.
- Heritable traits were described in terms character traits and physical traits.
- Participants attributed heritability to “blood” – not in terms of the physical product but of an essence within individuals that carries “heritable information”
- Participants used words like “isii, obara, eje, meyi, amii, jini, asok, kubura” in local languages to describe this.

# Results

- They suggested that the male “blood” or heritable essence can often but not always be “dominant”  and that “recessive” traits may be due to “weaker” female essence
- Many participants reported awareness of cultural concepts related to the presence of traits derived from grandparents in a child
- Names such as Babatunde, Iyabo, Nnanna, Nnenne, Ekaete are given to children who are believed to have inherited traits from grandparents
- Given that these names are also used for births that occur close to recent deaths of grandparents, these terms may reflect more of replacement of the recently departed than heritability

# Results

- Some participants suggested that shared environment may lead to acquisition of heritable traits e.g. when the a pregnant woman spends a lot of time with non-family members
- This was described as “afo igba ngo” meaning a child looks like the person the pregnant woman stays with the most, beside her partner.
- They suggested that several disease were heritable e.g. psychiatric illnesses, epilepsy, fevers, hypertension, diabetes, cancer etc.
- They thought these diseases may run in some families because of “ancestral misfortune”- some antecedent events in the family.

# Conclusions

- Our study continues to explore the ways that Nigerian indigenous people discuss heritable traits and conditions in order to use these to enhance the consent process in genomics research
- Our participants demonstrate an understanding that traits and attributes can be transmitted through a heritable essence whose locus, they often identify as “blood”
- They also had cultural concepts of dominant and recessive traits, and possibly sex-linked traits

# Remarks

- We are continuing with our data analyses from the qualitative part of our study
- Concepts, words and phrases exist in local African languages that indicate awareness and knowledge of heritable characteristics.
- These can be harnessed to explain genomics and improve comprehension of informed consent in the populace

# Conclusion

- The absence of specific words is not a barrier to comprehension, adoption or utilization. Many African communities do not have a native word for cell phones and this has not affected its widespread use
- Words like transcriptome, genomics etc. grow out of scientific research and are disseminated in the general population through engagement of scientists with their communities through mass media and public fora. African scientists need to do this too.

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