

MINUTES FOR STEERING COMMITTEE MEETING HELD ON FRIDAY, 16TH

OCTOBER, 2020

PRESENT:

Julie Makani

Eunice Obiageli Nnodu

Titilope Adeyemo

David Nana Adjei

Olayemi Edeghonghon

Zoey Fiaxe

Petronilla Ozumba (IHVN)

Vivian Paintsil

Najibah Aliyu

Josephine Mgya

Nathan Siebu

ABSENT

Flora Ndobho

Mahmoud Sani

William Kudzi

Justina Agula

Solomon Ofori-Acquah

Gordon Awandare

Kofi Anie

Ellis Owusu-Dabo

Ryan Minster

Najibah Aliyu

AGENDA

1. REVIEW OF PREVIOUS MEETING MINUTES

- Previous meeting minutes was reviewed by David.
- About matters arising from the previous meeting, Julie suggested that community engagement in Ghana, Nigeria and Tanzania be added to the minutes of the previous meeting.

2. UPDATES FROM COLLABORATIVE SITES

- **Accra:** In the process of retrieving folders of participants from the medical records for further information to complete the verification of participants on Project 1.
No additional recruitments have been made. Personal Protective Equipment (PPE) is required by law for Project Staff to start recruitment for Paediatrics and Adult Clinics. Concerning verifications, patients will be reached to confirm some vital information if the needed information is not found in their medical records.
- **Kumasi:** For over one thousand two hundred (1200) patients enrolled, 13 participants are yet to be verified due to some challenges encountered. Some patients would be contacted for further information and also, they would go into their data system for needed information. With regards to lab work, an additional 80 DNA has been extracted summing up to a total of 290 DNA extracts that are subject to quality checks. The laboratory technicians would be included in the main meeting to present their results.
- **Kano:** Echo machine has been repaired so recruitment has resumed for Project 1. A total of 583 participants have been enrolled. Under project 1b, 5 have been enrolled. Verification is up-to-date

- **Lagos:** Concluded the Paediatric verification exercise and the enrolment in the first quarter of 2019. They are in the process of following up on participants. Submitted their scope of work for project 3 which has been confirmed by Solomon.
- **Abuja:** The scope of work has not been confirmed. A medical officer is needed at the site to get access to patients. Also, pediatricians and a research nurse (consultant) need to be involved at the Teaching Hospital to follow up on patients. Adults and pediatric patients are enrolled in the study and to make follow up possible, a consultant needs to be a part of the team. Henceforth, pediatricians need to be involved. Fifty (50) patients have been enrolled for Project 1b, some are yet to be uploaded onto REDCap.

3. AOB

Scope of work

- Olayemi elucidated that they had a pediatrician who was part of the SickleGenAfrica Team. They already had a pediatric hematologist and an Adult hematologist working with the research work.
- There was a suggestion that nurses and pediatricians be brought on board to make it easier to follow up on patients.
- There was a discussion about the relevance of enrolling full-time staff from the beginning of the project to ensure the balance of activities and the budget of SickleGenAfrica. Balancing project staff as well as integration and capacity building within the various institutions and the hospitals involved was emphasized to ensure long-term continuity. There was a suggestion to specify the budget allocated for year one (1), two (2), three (3), and four (4) and if found to be inadequate, a discussion could be held with the Hub or the NIH for a solution.

- The team was reminded that the key point of the committee was to be dedicated to ensuring the success of the project. The site coordinators were encouraged to share their experiences, connections, and networks to enhance a better perspective of the project.
- Vivian reported that with the scope of work, physicians and nurses were required to be involved in the follow-ups as emphasized by the other sites as it served as a challenge.

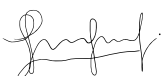
4. GENERAL COMMENTS

- The Tanzanian site had challenges with the sample shipment.
- Writing of experiential reports with regards to collecting, processing, and shipping samples to Accra which is very valuable for other sites and other studies in Africa.
- Publication strategy will be discussed in the next meeting to ensure sites on how to publish at the site level and on the social level.
- There was a suggestion to discuss how to partner with adult physicians and adult hematologists to develop capacity in the SickGenAfrica in the next meeting.
- It was recommended that Petronilla take an active part in writing the reports due to her experience in sample shipping.

Secretary to the Committee: Eunice Agyemang



Chairman to the Committee: David Nana Adjei



**MINUTES FOR STEERING COMMITTEE MEETING HELD ON FRIDAY, 30TH
OCTOBER, 2020**

PRESENT

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Kofi Annie

Ellis Owusu-Dabo

Gordon Awandare

AGENDA

1. UPDATES FROM ALL SITES

- **Accra:** In the process of extracting data from patients' folder to complete verification. Waiting to receive PPEs to continue with Project 1b and Project 2. There is a debate on the modalities to be taken on the Haemoglobin phenotypes as to whether it should be used on all the participants or on demand.
- **Dar es Salaam:** Have not yet started with Project 1b. Site is enrolling 203 nurses to have a one-on-one training section for all of them. Data verification is ongoing as they continue recruitments for Project 1a. Sample verification reports will be submitted next week. With regards to community engagement, they are continuing to support the health services in the health facilities. Telecommunications is being used to message recruited participants on Project 1b.
- **Kano:** They have resumed recruitments, but it was suspended last week due to civic arrests happening in the country. With regards to Adult recruitments, 597 have been enrolled under Project 1 and 3. Under Project 1b, 25 have been recruited. About to organize a meeting under community engagement. Echo machine has been fixed and working well.
- **Core lab:** Samples have been received from Dar and audited. There will be a meeting to resolve issues arising for the from the sample audit. Hb Electrophoresis have been conducted on samples from Dar and have been grouped into Adult and Paediatric units. 100 samples have been analysed. The machine used for proteins analysis has been repaired. Have resumed the analysis of the Accra samples, (DNA samples that have passed the DNA quality checks). 219 patients' samples have been analysed. DNA extraction in Accra has been suspended for two months because the machine used for the quality checks have to be recalibrated. DNA extraction in Kumasi is ongoing. By the first quarter of next year, the DNA samples would be shipped to Dubai for

sequencing. Kumasi samples will be moved to Accra for electrophoreses. There is an arrangement that the technician in Kumasi would spend some time in the core lab in Accra.

- **Abuja:** For Project 1b, 55 have been enrolled. There are some challenges with Project 2, therefore they need a lab technician. No required details for the lab tests. Suggested to budget for someone to get the details of the tests.

VERIFICATION AND DATA QUALITY

The Ag. Chair asked members to use this period to clean all data sets which will be used for publication and to generate research questions. A point was made to contact participants to get complete data for verification.

PUBLICATIONS

The chair asked that this agenda be deferred because Solomon and Kofi were not present. Solomon and Kofi were to update members on the two papers submitted to them. The chair emphasised on generating site-specific research questions to submit to the publication committee for approval.

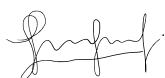
AOB

Community engagement would be site-specific. The chair asked that site coordinators that are unable to go on RedCap should inform him to be activated.

Secretary to the Committee: Miss. Eunice Agyemang



Chairman to the Committee: Dr. David Nana Adjei



MINUTES FOR STEERING COMMITTEE MEETING HELD ON FRIDAY, 11TH

DECEMBER 2020

PRESENT

David Nana Adjei

Olayemi Edeghonghon

Kofi Annie

William Kudzi

Titilope Adeyemo

Ellis Owusu-Dabo

Najibah Aliyu

Gordon Awandare

Vivian Paintsil

Ryan Minster

Fredrick Luoga

Nathan Siebu

Eunice Agyemang

Naana Asiedu

ABSENT WITH APOLOGIES

Josephine Mgya

ABSENT

Solomon Ofori-Acquah

Julie Makani

Mahmoud Sani

Petronilla Ozumba (IHVN)

AGENDA

1. UPDATES FROM VARIOUS SITES

Dar es Salaam: Had a meeting with the Hub to report the number of samples that were shipped to Ghana and the number of patients involved. Community engagement was done through telephone consultations and they are planning to have physical interactions with patients to discuss what samples were used for when they were collected and the future activities to be undertaken.

Accra: Had a meeting with the Research Coordinator on how to retrieve outstanding data from patients. Has not been able to do much because of the election but would apparently resume work when everything settles down.

Kano: Has started enrolling participants for project 1 and project 3. So far, 666 adults have been enrolled. Twenty-eight (28) participants are yet to be verified under project 1. Najibah reported that 50 more samples have not been uploaded on REDCap because the echoes have not been done.

Lagos: There were staffing issues in relation to funding and is looking forward to resolving the problem in the new year.

Kumasi: Apart from verifications, there has not been much work going on at the site. Ezekiel has sent lab results to William to be audited.

Core lab: There would be a meeting next week to resolve issues on sample audits from Dar es Salaam. Samples from Dar are undergoing electrophoresis, 96 samples have been analysed and their haemoglobin levels estimated. DNA extraction is ongoing in Kumasi. Extra 60 samples have been extracted, summing up to a total of 451 buffy coats. Arrangements are nearly complete and there has been an estimate for dry ice since samples need to be shipped from Kumasi to Accra for storage and analysis. DNA extraction is on hold in Accra. Reagents for Kumasi and Accra have been ordered.

Protein analysis is on hold because of the shortage of reagents. The process of procuring the Next Generation Sequencing is ongoing and the contract has been sent to the vendor to sign and Solomon would sign the portion for SickGenAfrica.

COMMUNITY ENGAGEMENT

- Dar and Korle Bu had done year two community engagement.
- Community engagement was moved to next year because there were issues with connectivity and materials for patients. Kofi informed the committee that community engagement did not only mean focus groups but there were other things which could be included to keep patients well-informed. For example, having a newsletter and a site-specific video clip for patients. It was agreed that the video will be ready by the end of the year.
- It was raised that the newsletter would be convenient for Kumasi site because there was no set up for a video clip.
- In Dar es Salaam, the video clip would be sent in advance to be translated from English to Swahili.

PUBLICATIONS

- **Updates on community engagement paper:** Kofi reported that the paper was under revision to be resubmitted.
- **Design paper:** There was no update on this paper because of the delay caused by the pandemic.
- The chair entreated all sites to finish up with verifications to utilize the data available on REDCap.

- Sites to provide 2-3 research questions by the start of next year to be formulated into papers.
- Data to be made ready for use at various sites.
- The chair informed the group that the publications committee approves a research question or paper before data is requested through the coordinating centre.
- Next meeting was scheduled for 8th January 2021 and subsequently would be held on the first Friday of every month.

Secretary to the Committee: Miss. Eunice Agyemang



Chairman to the Committee: Dr. David Nana Adjei

