**Date:** 06 Nov, 2019

**Time:** During 4th SCDO Meeting in Cape Town

**Platform:** GoToMeeting

**Duration:** 1 hour

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|  | **Participants** | **Role** | **Attendance** |
| **SPARCO** | |  |  |
| **1** | Julie Makani | SPARCO PI | Present |
| **2** | Malula Nkanyemka | SPARCO coordinator | Present |
| **4** | Solomon Fiifi Ofori-Acquah | SPARCO Adviser | Absent |
| **5** | Raphael Sangeda | SPARCO Data Manager | Absent |
| **6** | Kwaku Ohene-Frempong (KOF) | Standards of Care Lead | Apology |
| **7** | Alex Osei-Akoto | Ghana Site PI | Apology |
| **8** | Obiageli Nnodu | Nigeria Site PI | Present |
| **9** | Emmanuel Balandya | Tanzania Site PI | Apology |
| **10** | Vivian Painstil | Ghana Site Co- PI | Apology |
| **11** | Emmanuel Aso-Adjei | Ghana Representative | Present |
| **SADaCC** | | |  |
| **1** | Ambroise Wonkam | SADaCC PI (Chair) | Present |
| **2** | Nicky Mulder | SADaCC Co-PI | Present |
| **3** | Vicky Nembaware | SADaCC Project Coordinator (Co-Secretary) | Present |
| **4** | Gaston Mazandu | SADaCC Development Manager | Apology |
| **5** | Mario Jonas | SADaCC Bioinformatician | Apology |
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| **1** | Shimian Zou | NHLBI | Present (part of the meeting) |

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| **Area** | **Items** | **Discussions** | **Action Items** |
| **SADaCC** | **SADaCC** | **Coordination:** Next consortium meeting week 12-14 March, 2019. The meeting will be held over 3 days, with a Fellows’ day and two days of reviewing progress and manuscript writing.  Website being updated regularly.  - Groups to be invited to the next SickleInAfrica Meeting  a) WHO-Afro  b) REACH Consortium  c) ARISE  d) REDS III  e) ASH Newborn Screening  -The SCDO workshop is currently ongoing and well attended by over 44 participants. All SPARCo sites were represented, however many more SCDO members joined the working group including countries like Zimbabwe, Zambia, Malawi etc. Participants worked on harmonizing their data elements using the SCDO data elements and based on a Standard Operating Procedure and python script.  **Database:** Data quality checks plans and training ongoing. The site visit team is finalizing the report on the Nigeria and Ghana site visit.  **SCDO:** SCDO publication out soon.  Translations English into French and Portuegese pipelines being created by Jade the lead curato.  Simplifying the SCDO into layman’s terms.  **Research:** Syntia presented at the Global Forum for Bioethics and Research in Singapore on Gene editing  -Vicky has been invited to present on SADaCC - Big Data Analytics by the TWAS programme during the next Science Forum Conference in Pretoria.  **Training:** The SCDO meeting invited a cohort of Big Data trainees from SPARCo and SCDO members’ countries. Looking at possible collaborations with ARISE.s |  |
| **Consortium key milestones** | **Database WG** | Enrollment ongoing. Data quality checks. Follow-ups continuing. Site visits just took place. |  |
| **Standards of care WG** | Revisions to the guidelines going well with SPARCo. SCDO members at the consortium requesting for the most recent versions of the guidelines.  Working on metrics of assessing impact of the guidelines. |  |
| **Skills Development WG** | Fellows being identified to work on the 5 priority areas. |  |
| **Research planning WG** | A marker paper is being developed – invited to submitto Lancet. Surveys being developed (Pneumoccocal prophylaxis infections and Hydroxyrea usage. Norvatis and Ghana government being launched this week. |  |
| **Coordination & Management WG** | Malula is getting up to speed and looking forward to the meeting in November. Changes in personnel in Ghana and Tanzania. Sustainability – WHO high level engagement went well (see details under Tanzania). |  |
|  | **Site updates** | These updates will be part of the meeting report. |  |
|  | **NHLBI** | Shimian advised the group to focus on their current deliverables. |  |
| **General Items** | **AOB** |  |  |