The Pan-African Society of Cardiology (PASCAR)
Department of Medicine Faculty of Health Sciences
University of Cape Town
Observatory 7925
Cape Town, South Africa

PO Box 26716, Monument Park, 0105 South Africa

<u>African Union Communiqué on Eradication of ARF and RHD</u>

<u>Action Group 1 Meeting Minutes</u>

22 February 2017, Skype

Time: 16h00 – 17h00 (South African Time)

1. **Welcome and Opening Remarks –** Mark Engel
2. **Attendees**: Mark Engel (ME), Jonathan Spector (JS), Steven Justus (SJ), Joris van Dam (JVD), Lwazi Mhlanti (LM) and Janette Lombard (JL)
3. **No RSVP**: John Musuku (JM), Abdi Alisalad (AA)

4. **Summary of meeting**
   - <u>E-Register App</u>
     - o **JS**: What is the idea for what it's going to be used for?
       - ▪ **ME**: Discussion was to use this tool to collect data to be used as a register – Primary purpose is to provide data to AU & WHO relating to RHD in Africa
         - <u>Scientific tool</u>: where data could be collected from the Remedy study (Remedy done)
           - o Issue: we need to get ethic approval to run as research study
           - o Doctors doesn't want others to be able to see patient data
         - <u>Management tool</u> will enable Dr to have an idea of patients
           - o Most doctors prefer this app as management tool
           - o Some calling for more detailed app to be used as scientific tool, (will then need ethic permission)

       - ▪ **JS**: Thought it was being devised in context of the roadmap, as tool to aid patient management, to help improve health outcomes
         - Being build in design of clinical use VS data collection and research purposes
         - Quite limited functionality as practising physician to use to manage RHD patients

       - ▪ **ME**: Various clinicians gave input to what must come out and what is practical for using app in busy clinic (Liesl Z and Bongani M)
         - Some requested a more detailed app (as comprehensive as possible for their scenario)
         - We looked at minimum data to be requirement to collect data to be used to alert governments and policy makers in RHD in Africa
         - Issue: People doesn't want to spend 20 minutes to collect data, but current version can be expanded and relooked at

       - ▪ **JS:** From research/science point of view; it collects some data, but not all data (little incomplete)
         - This doesn't make their lives easier, it's doing double data (on research side) it's a duplicating system
         - Current version can provide some data for research and reporting purposes, but pretty limited functionality to take care of patient with RHD
       - ▪ **JS** understand that we want to keep it simple, but it needs to improve the health need for patients with RHD (we determine how comprehensive it can be)

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- The need for the clinicians to take care of their patients better (was one of the promises the E-register could be)
- Data could be extractable with information for research and reporting purposes
  - But have the patient clinical needs in mind first
- The app needs to make people's lives easier; they must want to buy in because of the benefit
  - If they see true value in taking care of their patients, app will have different level of success (roll-out and sustainability)

- **ME**: Revisit the "Complete patient model" - with functionality (to see last 2/3 visits and events)
  - We can go back to JvD original version (as being like the Remedy study with pages of various fields to be filled in) – feel of meetings were they didn't want to fill in all those form

- **JvD**: One way to resolve this – go out in field and use current app (and relook other requirements)
  - Use app to collect data on site, at point of care (we could add few fields)
  - When back at office, relook at patient follow-up and data (as in Zambia)
  - Easy to add columns and fields when we see the need

- **ME**: Dashboard will enable us to pull out that information, but should it be handy on the app at the time when you see the patient?
  - JS not concerned about that, but the utility of the tool to take care of the patient
  - Please provide bare minimum that would make it seem that we are fulfilling that role

- **ME:** The older version had a "SELECT EXISTING PATIENT" option
  - **JvD**: Yes, but would only enable one to add data to patient, and not view patient data
    - In Zambia, tool was being used by nurses, not doctors
    - In current setting, you can't view data to e.g. number of penicillin to order, number of patient to treat (because of giant spreadsheet, have to shift through all the folders)
    - Could add "VIEW PATIENT DATA" to giant cloud (and choose what data fields to be viewed when chosen)
      - **ME**: The "View" function; does it fall under the look up tables? JvD – don't know (Zambia collecting data from RHD negative patients, ran into technical limitation for selecting table) - Is possible for limited patients
      - Look up table will impact contract and other options going forward (limited in functionality)

- <u>Dimagi</u>
  - <u>Project spaces</u> – where data will sit for each country
    - Project spaces will have password and coding that will allow people within that project space to see all data within project space
    - If data of two different countries located within one project space, they will have access across the platform, to view data from other site – people complains about that – each country will need own project space
    - **Community** based software; in own project space, limited to one country for their use (for ethics& confidentiality) – free and will allow up to 10 mobile users to access data of that project space

PASCAR Governing Council - Prof Bongani Mayosi, South Africa, President; Prof Samuel Omokhodion, Nigeria, Immediate Past Secretary General, Dr Benedict Anisiuba, Nigeria, Secretary General; Prof Karen Sliwa-Hahnle, South Africa, Treasurer; Prof Patrick Commerford, South Africa, Editor (Cardiovascular Journal of Africa); Prof Serigne Ba, Senegal, Vice-President West; Dr Saad Subahi, Sudan, Vice-President North; Prof Ana-Olga Mocumbi, Mozambique, Vice-President South; Prof Elijah Ogola, Kenya, Vice-President East; Dr Anastase Dzudie, Cameroon, Acting Vice-President Central; Dr Harun Otieno, Kenya, Assistant Secretary General East; Dr Awad Mohamed, Sudan, Assistant Secretary General North; Prof Johan Brink, South Africa, Assistant Secretary General South and Prof Toure Ali Ibrahim, Niger, Assistant Secretary General West.
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- **Standard** and **Pro Package**: still operates within own project space
- **Advanced package**: no benefit - 4 project spaces, but data will not be confidential/limited & will not be controlled by login users

- **ME** through that all new sites, start in community pricing package, as their functionality increases, migrate to next package on deal
  - CommCare app can also be migrated downwards to community package (data can be exported, to be brought out)
  - To make it sustainable, with functions we may add, we must try to stay in Community realm
  - **JvD**: In both an Approach and Licensing perspective: Start with community prescription and as site advanced features, then relook upgrade package (when contributing/benefitted the RHD programme)

- **SJ:** Multiple community packages in single country?
  - **ME:** Yes, each project space, can be limited to a single site – problem; won't see each other site's data (clinical management; patient move from one site to another site)
  - **JvD:** Giant spreadsheet in cloud, different spreadsheets, can manually transport spreadsheets from one project space to another
    - Some countries will use one community subscription, other separate independent licenses – depending on cultural, linguistic, etc. needs.

  - **SJ:** When exporting our data to e.g. PASCAR – do we get unified country dataset back – ME: Yes, each app basically on same structure, can be merged easily (when on same structure)
  - **SJ:** Need to be coordination at country level around the variations from community packages to get unified dataset back (starting with isolated small projects in Tanzania, not national scope) Community package would work fine

- <u>Marketing Strategy</u>

  - **ME:** In previous meeting, we spoke of the usefulness of app, beyond tertiary hospitals, (integrated patient management system) app aimed for those beyond the bounds of those technology
  - How can we get app to those not already part in studies (INVICTUS, Remedy) or attached to universities
    - We should think about, coding to achieve that will make it very attractive for someone to want to use the app for their patient management
  - ME: Dylan (assisting in E-register) contacted all people who recently published in Africa around RHD with letters (e.g. case studies, unrelated to multi centre collaborative studies)
    - ID'd 14 people (introducing the app and team) received few bounce back emails; 1 person interested
  - Target Local Cardiac Society Meeting (PASCAR) – to get on program to present the app
    - e.g. Angola: received good responses – about 50 persons interested
    - Interested in pregnancy maternal care app
    - Gloria testing the Portuguese App
  - We want to work with CHH Task Force – on compiling national programmes across Africa
    - Identify key people in National programmes
    - AG 1 will do presentations online to those who are interested

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- Pilot Site Feedback

    - **Mozambique** (Portuguese Version): Tested in Maputo (staff member of Prof Ana Mocumbi') positive feedback
        - Community space for Portuguese community in Mozambique
    - **Tanzania:**
        - Dr John Meda gave few suggestions, have been applied
        - SJ ready to start with app as soon as May (feedback from the field by end of 2017) maternal based work
    - **Botswana:** Dr Muita tested app, was happy
    - **Mauritius list:** Razeen was there (currently in China) – Lwazi will follow up with Razeen on list for users who took tablets
    - **Cairo:** Few people who downloaded the app
        - Ghana (Prof Charles Yankah (CY) from Germany): Looking for Zambian App, for screening study
        - JS going to Ghana next week, will meet with CY

- Different Apps
    - School app, English App, Portuguese app, shortly have the French app, working on the Beta version (improved clinical management)
    - Template for translator for Swahili – need translator

5. **Next steps, specific tasks:**

    - **JS & SJ**: Please provide bare minimum that would make it seem that we are fulfilling the utility of the tool to take care of the patient management
    - **SJ:**
        i. Tell ME when ready to set up community space (almost instantaneous, week needed for set up)
        ii. Speak to project team in country on when we can get started (Program Team to communicate with ME)
    - **JvD:**
        i. Will provide list of fields in the giant spreadsheet in the cloud, for JS to choose from (for more functionality)
        ii. Follow up on JS on clinical usefulness, get elements that we might use for next Beta app

    - **ME:** We'll take the suggestions from App users and update every 6 months (with annual renewal on packages)
    - **LM**:
        i. Will follow up with Rezeen on Mauritius list for users who took tablets
        ii. Sent SJ the Template Translator excel spreadsheet to create app on ME's side
    - **JL:**
        i. Introduce Prof Charles Yankah to JS - will visit Ghana in few weeks (done)
        ii. Add marketing strategy on CHH Agenda, to ID the key people in countries to target
            1. Provide contacts details of the persons who sent the 8 letters to MOH

6. **Any other business**
7. **Closed with thanks**