NON-COMMUNICABLE DISEASES RESEARCH UNIT (NCDRU)

Dear ……..(name of potential collaborator)

Re: Call for participation in the CKD-Africa Collaboration network

With this letter, we would like to extend an invitation to you to join the Chronic Kidney Disease in Africa (CKD-Africa) Collaboration, which is an initiative led by the Non-Communicable Diseases Research Unit of the South African Medical Research Council. This is a novel collaborative effort aimed at advancing evidence-based medicine within the field of chronic kidney disease (CKD) in the context of Africa.

As you are aware, CKD is a global public health problem, seemingly affecting African countries disproportionately. Unfortunately, due to the lack of data from various African countries or the limitations of available data, the burden of CKD in Africa is still unknown. Over recent years, there has been an increase in the number of reports on CKD prevalence across Africa; however, these studies remain largely underpowered, and taken individually cannot address the between-country variations and time trend in the prevalence of CKD. It is thus difficult to generalize the available evidence and to provide evidence-based recommendations. In order to overcome these limitations, we have established the CKD-Africa Collaboration, through which we will seek to address these limitations by collating data, at individual participant data (IPD) level, from existing African studies, in order to answer vital research questions related to the CKD burden. The goal of this collaboration is to create a formal platform for cooperation between researchers and cohorts that facilitates high-quality studies on the burden of CKD in Africa, with the strength of such a collective endeavor having far-reaching potential.

To date, the network has curated data from 39 studies conducted in 12 African countries, totalling 35,747 participants, and we are very interested in …….(study of interest).

As a basis we use the WHO STEPS Instrument for data request, so we ask collaborators to supply data on the following variables (if they captured it in their studies):

1. **Demographic and general information**: Gender, age, level of education, employment, income (estimate of total household income), indicators of the study setting (rural vs. urban), variables reflecting the design (if complex design used)
2. **Behavioral measurements:** Tobacco use, alcohol consumption, diet and dietary salt intake, physical activity, personal and family history of (raised blood pressure, diabetes, raised total cholesterol, cardiovascular disease, chronic kidney disease), received lifestyle advise, list of chronic medication use (including traditional medicine)
3. **Past medical history:** Any previous dialysis treatment for acute kidney injury
4. **Physical measurements**
    - Blood pressure and heart rate, weight, height, waist circumference, hip circumference, blood glucose, blood lipids
    - Measures of kidney function: creatinine, urea, urinary albumin excretion (also urinary protein creatinine ratio), cystatin C
    - Measures of CKD impact: serum electrolytes (Na+, K+, Cl-, calcium, phosphates), haematological profile, serum protein,
    - Other biological markers: markers of inflammation (CRP, fibrinogen etc)

THE SOUTH AFRICAN MEDICAL RESEARCH COUNCIL
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- Kidney imaging (e.g. ultrasound of the kidney for size, echogenicity and corticomedullary differentiation)
- Histology of kidneys (i.e. renal biopsy report)

We are aware of the enormous workload on primary investigators, therefore to keep the burden minimal we request electronic databases, including formats such as Excel, CSV, Dbase format, or formats of common statistical software, which would be accompanied by a library identifying variables. Thereafter, we will be in touch with you, regarding specific questions related to methodology, as we harmonies the datasets received. We would like to emphasis that the data you contribute to the consortium will remain your sole property. The data will thus only be used in combination with other data received and will not be shared with a third party. Furthermore, as a collaborator in this project, you will co-author all manuscripts in which your data was used and if you contribute a dataset with >500 participants, you can nominate an additional investigator, who will also join the consortium as a permanent collaborator. This information is documented in the memorandum of understanding that I have attached to this letter.

If you wish to participate or know of investigators who would be interested to participate, please feel free to contact us.

Kindest regards

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