



MEMORANDUM OF UNDERSTANDING

in respect of research cooperation between the

SOUTH AFRICAN MEDICAL RESEARCH COUNCIL

a statutory science council established in terms of the laws of the Republic of South Africa, situated at Francie van Zijl drive, Parow Valley, Western Cape, South Africa, herein represented

by **Professor Glenda Gray** in her capacity as President of the Council

(hereinafter referred to as “SAMRC”) through its

NON-COMMUNICABLE DISEASES RESEARCH UNIT herein represented by

Professor Andre P. Kengne in his capacity as Director of the Unit

(hereinafter referred to as “NCDRU”)

and

[Title, Full name of Collaborator] in his capacity as [Position]

[Address of Collaborators Institution]

the NCDRU and [Title, Full name of Collaborator] shall hereinafter be jointly referred to as the
“Parties”;

PREAMBLE

WHEREAS, the Parties recognise that due to a lack of data in various regions in Africa or the limitations of available data, the true magnitude of Chronic Kidney Disease (CKD) is not known. In recent years, there has been an increase in the number of reports on CKD prevalence across different regions in Africa; however, these studies remain largely underpowered, and taken individually cannot address the variations and time trends in the prevalence and determinants of CKD between countries.

And Whereas, the Parties recognise that cooperation among scientists, throughout Africa, would be critical in developing sustainable and regionally relevant solutions related to the burden of CKD. The Parties further recognise that the strength of such a collective endeavour has far-reaching potential:

- (i) such as harnessing individual participant data (IPD) from numerous studies, conducted across Africa,
- (ii) overcoming the small sample size of independent studies, thus increasing the statistical power;

The Parties agree that this collaborative endeavour is of particular importance as it will supplement the current knowledge on CKD by providing an updated and comprehensive synthesis of data on the magnitude of CKD in the African region.

Now therefore, the Parties intend to cooperate in accordance with the terms of this Memorandum of Understanding (MoU) and have reached the following understanding:

1. INTERPRETATION

1.1 Headings of clauses shall be deemed to have been included for purposes of convenience only and shall not affect the interpretation of this Agreement.

1.2 In this Agreement, unless inconsistent with the context, the following words and expressions shall have the meanings assigned to them hereunder:-

1.2.1 **“Dataset library”** means the document which needs to accompany the

dataset, listing the variables contained in the dataset, along with the definition and unit measure of each variable.

- 1.2.2 “**Pooling**” means combining the raw data received from various sources.
- 1.2.3 “**Computer database**” means electronic version of the pooled data which will be kept centrally, at the SAMRC’s, NCDRU in Cape Town, South Africa.
- 1.2.4 “**Deidentified**” means that the identifiable variables will be removed prior to submission of these datasets to the head office of the consortium.

Article I – Role of Parties

Subject to the terms hereof, [Title, Full name of Collaborator] agrees to contribute original data of at least 300 (three-hundred) participants, at IPD level, to the Chronic Kidney Disease in Africa (CKD-Africa) Collaboration, accompanied by the dataset library to facilitate pooling, which will happen centrally at the SAMRC, NCDRU. The deidentified data will be held at the SAMRC, NCDRU, in Cape Town, South Africa, in a computer database in a secure facility, and in a manner that maintains participants’ confidentiality.

[Title, Full name of Collaborator] will act as the *de facto* member in the consortium and if data on more than 500 participants are supplied, an additional member can be invited to the consortium at the discretion of [Title, Full name of Collaborator].

Article II – Areas of Focus

The Parties intend to address the gap in knowledge related to the burden of CKD in the context of Africa.

In order to give effect to the above, the Parties shall endeavour to:

- a) conduct scientific meetings, workshops and symposia for identifying priority areas/programmes of research, and capacity building activities.

- the Parties intend to be responsible for their own costs, unless otherwise decided in writing, including travel costs for their respective employees participating in any activities pursuant to this MoU;
- b) promote the exchange of technical expertise, and information;
- c) publish scientific findings, organise training activities, hold consultations and engage in any other forms of cooperation identified jointly that would help in establishing and implementing research projects that will promote:
 - the generation of research evidence to inform programme efforts and policy considerations e.g. disease surveillance and epidemiology, disease management strategies, implementation and operational research activities, etc.
 - the creation of a knowledge platform to:
 - enhance rigour of research methodologies;
 - streamline regulatory hurdles; and
 - enhance scientific capabilities e.g. biostatistics, bioinformatics, health systems, manufacturing, grant management, etc.

Article III - Non-Exclusivity

The Parties understand that this relationship is not exclusive. In addition to the Parties, it is anticipated that there will be participation in the activities contemplated in this MoU by other entities. These entities will include individuals and institutions in the public, private and academic sectors, as well as state, provincial and/or local governments in all participating African countries, experts from other countries, international organisations, non-governmental organisations, etc.

Article IV- Ethical Issues and Data sharing

Both Parties acknowledge the importance of the protection of human participants in research. Both Parties warrant that they have adopted laws and regulations on the protection of human participants involved in research. Both Parties intend to undertake all activities contemplated in terms of this MoU in accordance with all applicable laws, regulations and policies of their respective countries.

The CKD-Africa Collaboration will be based on the principle that each Party will retain national ownership of their data. However, the Parties will give the NCDRU access to their data, which will not be shared with any third party.

Investigators should also share their findings with the relevant institutions articulating how the work informs policy and practice. The Parties shall encourage the investigators to put the data arising from the work into open access i.e. encouraging the sharing and access of data amongst the investigators and the research community as per the policies of the respective countries.

Article V - Intellectual Property Rights, Commercialisation and Publications

Intellectual Property Rights

- a) The Parties shall ensure appropriate protection of any intellectual property generated from cooperation pursuant to this MoU, consistent with national and international legislation and agreements.
- b) In case of research results obtained through joint activities, the ownership of intellectual property rights shall be sought by both the Parties. Once granted, these rights shall be jointly owned by the Parties and the investigators
- c) The Parties shall not assign any rights and obligations arising out of the intellectual property generated from interventions/activities arising under the MoU to any third party without the prior written consent of the other Party to this MoU.

Publication

- a) The other Party to this MoU will act as co-author to all publications generated using data supplied by the other Party to this MoU. If the data supplied by the other Party is not used in a publication, the other Party will not be included as a co-author.

- b) Any publication, document and/or paper arising out of joint work conducted by the Parties pursuant to this MoU must acknowledge both the SAMRC and the other Party to this MoU.
- c) The use of the name, logo and/or official emblem of a Party on any publication, document and/or paper by the other Party shall require prior permission of the Party whose emblem will be utilised. It must however be ensured that the official emblem and logo of the respective Parties are not misused.

Article VI – Final provisions

This MoU is not intended to create any binding obligations under the laws of the Parties or under international law. Specific projects and activities under this MoU will be subject to the availability of personnel, appropriated funds and other resources. Any difference in interpretation of this MoU should be resolved by mutual discussion.

Article VII – Term of this MOU

This MoU is at-will and may be modified by mutual consent by the Parties.

This MoU shall become effective upon signature by the Parties and will remain in effect until modified or terminated by any one of the Parties by mutual consent. In the absence of modification to the MoU, the Parties mutually agree that this MoU shall be terminated once all publications have been published in peer-reviewed journals.

Either Party may discontinue cooperation in terms of this MoU at any time and shall endeavour to provide written notice to the other Party in this regard. Any existing arrangements/agreements in place pursuant to this MoU shall not be affected by such termination and shall be dealt with according to that specific arrangement/agreement.

For the [COLLABORATORS
INSTITUTION]

[Title, Full name of Collaborator]
[Position]

Place: _____

Date: _____

For the NON-COMMUNICABLE
DISEASES RESEARCH UNIT, SOUTH
AFRICAN MEDICAL RESEARCH
COUNCIL

Prof Andre P. Kengne
Director

Place: _____

Date: _____