

## DATA TRANSFER AGREEMENT

Regarding Data from the Centre of Excellence for Sickle Cell Disease Research and Training  
University of Abuja, Abuja, Nigeria

For the Sickle Pan African Research Consortium Project in Nigeria (SPARCO)



Between

The Recipient

University of Cape Town (UCT)

And

The Provider

The Centre of Excellence for Sickle Cell Disease Research and Training University of Abuja,  
Abuja, Nigeria

DATA TRANSFER AGREEMENT



THIS DATA TRANSFER AGREEMENT (the "Agreement") is made and entered into as of the day of Day of 7<sup>th</sup> July, 2022 (the "Effective Date"), by and between the Centre of Excellence for Sickle Cell Disease Research and Training University of Abuja, Mohammed Maccido Road, University of Abuja Main Campus, Airport -Giri Expressway, Abuja Federal Capital Territory, Nigeria, ("PROVIDER") and the University of Cape Town (UCT) having an address at Bremner Building, Lovers Walk, Rondebosch, 7700, Cape Town, South Africa (the "RECIPIENT"). In response to the RECIPIENT's request for the transfer of Data, PROVIDER is willing to provide such Data, subject to the following terms and conditions:

To abide by all terms and conditions of the Nigerian National Code for Health Research Ethics and to certify that the RECIPIENT (identified below) organization has accepted and signed an unmodified copy of this agreement. The RECIPIENT organization's Authorized Official will also sign this letter if the RECIPIENT SCIENTIST is not authorized to certify on behalf of the RECIPIENT organization. The RECIPIENT SCIENTIST (and the Authorized Official of RECIPIENT, if necessary) should sign both copies of this letter and return one signed copy to the PROVIDER. The PROVIDER SCIENTIST will forward a copy of this agreement to the National Health Research Ethics Committee of Nigeria. The PROVIDER SCIENTIST will send the DATA to the RECIPIENT SCIENTIST as outlined in the research protocol approved by the HREC. The parties executing this Implementing Letter certify that their respective organizations are conversant with and accept the authority of the Nigerian National Code for Health Research Ethics (NCHRE), and further agree to be bound by its terms, for the transfer specified above. Please fill in all of the blank lines below:

**1. TITLE OF RESEARCH: Sickle Cell Disease Consortium (SPARCO) in Sub-Saharan Africa (SSA)**

**2. Health Research Ethics Committee (HREC) ASSIGNED PROTOCOL NUMBER:**

     NHREC/01/01/2017      (National Health Research Ethics Committee)

**3. ORIGINAL DATA (Enter description):**

Data on children and adults with sickle cell disease enrolled into the SPARCO registry from the collaborating centres in Nigeria

**4. PROVIDER (Organization providing the DATA)**

a. Name of Organization: The Centre of Excellence for Sickle Cell Disease Research and Training, University of Abuja

b. Street Address: Mohammed Maccido Road, University of Abuja Main Campus, Airport -Giri Expressway

c. City/State: Abuja/ Federal Capital Territory

d. Phone/Fax: +2348055270797

e. E-mail:      [registrar@uniabuja.edu.ng](mailto:registrar@uniabuja.edu.ng)     

f. Signature of Head of Provider Institution/Date:

*Abdullahi G. A. Allal*  
*5/8/2022*

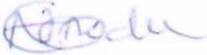
**5. PROVIDER SCIENTIST**

a. Name and Title: Professor Obiageli Eunice Nnodu


b. Street Address: Mohammed Maccido Road





- c. University of Abuja Main Campus, Airport -Giri Expressway
- d. City/State: Abuja/Federal Capital Territory
- e. Phone/Fax: +2348130610603
- f. E-mail: oenrodu@gmail.com
- g. Signature/Date:  7<sup>th</sup> July 2022

6. RECIPIENT SCIENTIST

- a. Name and Title: Ambroise Wonkam
- b. Street Address: Division of Human Genetics, Faculty of Health Sciences, University of Cape Town
- c. City/State: Cape Town
- d. Country: South Africa
- e. Phone/Fax: 0214066307
- f. E-mail: ambroise.wonkam@uct.ac.za
- g. Signature/Date:  25/08/2022

7. RECIPIENT ORGANIZATION CERTIFICATION (Organization receiving the DATA)

I hereby certify that the RECIPIENT organization has accepted and signed the DATA Transfer Agreement (this may be the RECIPIENT SCIENTIST if he/she is authorized by the RECIPIENT organization)

- a. Name of Organization: University of Cape Town
- b. Street Address: Bremner Building, Lovers Walk, Rondebosch, 7700
- c. City/State: Cape Town
- d. Country: South Africa
- e. Phone/Fax: +27 21 650 3865
- f. E-mail: warda.sablay@uct.ac.za
- g. Signature of authorized official/Date: \_\_\_\_\_
- h. Name and Title: Warda Sablay

8. In response to the terms of the research protocol titled SickleInAfrica

\_\_\_\_\_, the PROVIDER asks that the RECIPIENT and the RECIPIENT SCIENTIST agree to the following:



a. The above DATA is being made available to the RECIPIENT for the sole purpose of research outlined in the protocol named in this letter only. Within the context of this research proposal only, the DATA the modifications and products are jointly owned by the parties to this agreement.

b. The DATA will not be further distributed to others without the PROVIDER's written consent. The RECIPIENT shall refer any request for the DATA to the PROVIDER. To the extent supplies are available, the PROVIDER or the PROVIDER SCIENTIST agrees to make the DATA available, under a separate DATA TRANSFER AGREEMENT, to other scientists who wish to replicate the RECIPIENT SCIENTIST's research.

c. The RECIPIENT agrees to use the DATA in compliance with all applicable statutes and regulations, including, for example, the Nigerian National Code for Health Research Ethics, 1992 UN Convention on Biological Diversity and those relating to research involving the use of human and animal subjects or recombinant DNA.

d. The DATA is provided at no cost other than as specified in the research protocol.

e. The DATA is to be stored at

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and used by the RECIPIENT SCIENTIST and collaborators under the RECIPIENT SCIENTIST's direct or delegated supervision as specified in the research protocol approved by the Institutional HREC.

f. Without written consent from the **PROVIDER**, the **RECIPIENT** and/or the **RECIPIENT SCIENTIST** may NOT provide **MODIFICATIONS** for **COMMERCIAL PURPOSES**. It is recognized by the **RECIPIENT** that such **COMMERCIAL PURPOSES** may require a commercial license from the **PROVIDER** and the **PROVIDER** has no obligation to grant a commercial license to its ownership interest in the **DATA** incorporated in the **MODIFICATIONS**.

g. If the **RECIPIENT** desires to use or license the **DATA** or **MODIFICATIONS** for **COMMERCIAL PURPOSES**, the **RECIPIENT** agrees, in advance of such use, to negotiate in good faith with the **PROVIDER** to establish the terms of a commercial license. It is understood by the **RECIPIENT** that the **PROVIDER** shall have no obligation to grant such a license to the **RECIPIENT**, and may grant exclusive or non-exclusive commercial licenses to others, or sell or



assign all or part of the rights in the **DATA** to any third party(ies), subject to any pre-existing rights held by others.

i. The **RECIPIENT AND PROVIDER** as joint owners are free to file patent application(s) claiming inventions made by the **RECIPIENT** through the use of the **DATA**.

j. The **RECIPIENT** agrees to use the **DATA** in compliance with all applicable statutes and regulations, including Nigerian National Code for Health Research Ethics and institutional regulations and guidelines.

The **RECIPIENT** and the **RECIPIENT SCIENTIST** should sign both copies of this letter and return one signed copy to the **PROVIDER SCIENTIST**. The **PROVIDER** will then forward the **DATA**.





## Appendix

### Section of National Code for Health Research relating to DTA Appendix

#### Section of National Code for Health Research relating to DTA

##### (n) DATA Transfer Agreement

Transfer of DATA out of Nigeria shall require a DATA Transfer Agreement (DTA) detailing the type of DATA, anticipated use, location of storage outside Nigeria, duration of such storage, limitations on use, transfer and termination of use of such materials subject to any law, regulations and enactment in Nigeria.

The purpose of DTA is to protect the interests of local researchers and Nigeria's human and natural resources in all its biodiversity as well as how they can be legitimately used. It ensures that the interests of all relevant parties, human and community participants in research and the Nigerian nation are protected from exploitation and egregious harm.

(a) The DTA shall be signed by all parties involved in the research including local and international principal investigators, heads of local institutions, research sponsors and other relevant parties.

(b) HREC shall review the DTA to ensure consistency with the stated objectives of the research, the contents of the informed consent documents and the principles enumerated above. The HREC shall grant provisional approval pending the submission of DTA to NHREC and receipt of acknowledgement from the NHREC.

(c) The applicant for research review shall file a copy of the DTA and provisional approval by the institutional HREC with the NHREC for record purposes only.

(d) NHREC shall acknowledge receipt of the DTA to the applicant who shall inform the institutional HREC.

(e) Institutional HREC shall grant final approval to research involving international transfer of Nigerian DATA after all other criteria stated in this code for approval of research has been met and upon receipt of acknowledgement of DTA.

(f) The DTA does not vitiate the right of research participants or communities to request that their DATA be withdrawn from research according to the terms of the informed consent process.

(g) Where there is any change in the DTA, a request for amendment of protocol shall be submitted to HREC and HREC shall consider this in the usual manner used for amendment of protocol.

