

DATA TRANSFER AGREEMENT

Regarding Data from the SPARCo Uganda Sickle Cell Registry

Between

The Recipient

The Muhimbili University of Health and Allied Sciences.

Dar es Salaam Tanzania

And

The Provider

The Sickle Pan African Research Consortium Project in Uganda (SPARCo)

Data Transfer Agreement Governing the Transfer of Data for the Sickle Pan African Research Consortium Project (SPARCo)

DATA TRANSFER AGREEMENT

THIS DATA TRANSFER AGREEMENT (the "Agreement") is made and entered into as of the day of 29 October, 2021 (the "Effective Date"), by and between Sickle Pan African Research Consortium (SPARCo) Project in Uganda ("PROVIDER") and The Muhimbili University of Health and Allied Sciences, Dar es Salaam Tanzania

having an address at

Attention:

Sickle Cell Programme,
Department of Haematology and Blood Transfusion.
School of Medicine,
Muhimbili University of Health and Allied Sciences (MUHAS)
1 Kipalapala Street, Upanga.
P.O.Box 65001, Dar es Salaam, Tanzania
Tel: +255 746 399 914
Email: info@blood.ac.tz

(the "RECIPIENT").

In response to the RECIPIENT's request for the transfer of Data, the PROVIDER is willing to provide such Data, subject to the following terms and conditions:

- To abide by all terms and conditions of the School of Medicine Research Ethics Committee and the Uganda National Council of Science and Technology.
- 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 copies of this agreement to the School of Medicine Research Ethics Committee and the Uganda National Council of Science and Technology.
- The PROVIDER SCIENTIST will send the DATA to the RECIPIENT SCIENTIST as outlined in the research protocol that will be approved by the School of Medicine Research Ethics Committee.

The parties executing this agreement certify that their respective organizations are conversant with and accept the authority of the School of Medicine Research and Ethics Committee and the Uganda National Council of Science and Technology, and further agree to be bound by its terms, for the transfer specified above.

1. TITLE OF RESEARCH: Sickle Pan-African Research Consortium (SPARCo) Uganda: Strengthening Capacity for Clinical Care, Research and Training in Sickle Cell Disease - SCRT Project.
2. SOMREC ASSIGNED PROTOCOL NUMBER:.....
3. ORIGINAL DATA (Enter description):

Data on children and adults with sickle cell disease enrolled into the Mulago Hospital Sickle Cell Clinic, Jinja Regional Referral Sickle Cell Clinic, Lira Regional Referral Sickle Cell Clinic and Mbale Regional Referral Sickle Cell Clinic.

4. Data Contents: We are supplying a total of 7,000 data points over the 5-year duration of the project. Each data point contains several variables including – Unique ID, sociodemographic variable, clinical signs and symptoms, patient characteristics, treatment, laboratory results as well as patient follow up, and admission data.

5. PROVIDER (Organization providing the DATA)

Name of Organization: The Sickle Pan African Research Consortium Project in Uganda (SPARCo)

Street Address: Upper Mulago Hill Road

Institution: Department of Paediatrics & Child Health, College of Health Sciences, Makerere University

City/State: Kampala

Country: Uganda

Name of Provider Scientist: Professor Sarah Kiguli

Telephone Contact: +256772588044

Email address: skwalube@yahoo.co.uk

Signature/Date:

S. Kiguli 12/11/2021

6. RECIPIENT SCIENTIST

Prof Julie Makani

Sickle Cell Programme,

Department of Haematology and Blood Transfusion,

School of Medicine,

Muhimbili University of Health and Allied Sciences (MUHAS)

1 Kipalapala Street, Upanga,

P.O.Box 65001, Dar es Salaam, Tanzania

Tel. +255 743 961 162

Email: jmakani@blood.ac.tz

Signature:

J. Makani

Date: 11th November 2021

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)

Directorate of Research and Publication,
Muhimbili University of Health and Allied Sciences,
Street Address: 9 United Nations Road, Upanga,
P.O Box 65001,
Dar es Salaam, Tanzania
Tel: +255-22-2150302/6 Ext: 1016
Email: drp@muhas.ac.tz

Signature of authorized official/ *[Signature]* Date: 15/11/2021
Name and Title: *Bruno Sanga*
DRP



8. In response to the terms of the research protocol titled "Sickle Pan-African Research Consortium (SPARCo) Uganda: Strengthening Capacity for Clinical Care, Research and Training in Sickle Cell Disease - SCRT Project."

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 agreement only. Within the context of this research proposal only, the DATA, their modifications and progenies 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 Uganda National Council of Science and Technology, 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. Confidentiality of patients shall be strictly observed.

f. The data shared shall not contain names or any identifiers of the patients in the registry

g. The DATA is to be stored at RedCap 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.

h. 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.

i. 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 Uganda National Council of Science and Technology 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.



BANK PARTICULARS

BANK NAME: NBC BANK

ADDRESS: P O BOX 65515, DAR ES SALAAM, TANZANIA

ACCOUNT NAME: MUHAS SMALL RESEARCH PROJECTS (TZS)

ACCOUNT CURRENCY: TANZANIAN SHILLINGS

ACCOUNT NUMBER: 041103002171 MUHIMBILI BRANCH

SWIFT CODE: NLCBTZTXXXXX

CORRESPONDING BANK ABA/SWIFT CODE (DOMESTIC BANK):BKTRUS33

CORRESPONDING BANK: CITY NEW YORK COUNTRY : USA

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