**KEMRI/WELLCOME TRUST RESEARCH PROGRAMME**

**INTERNAL REQUEST FORM FOR KIDMS AND STUDY-SPECIFIC DATA**

[Conditions and Limitations of Data Sharing](http://baraza/sites/doc/ResearchPoliciesAndGuidelines/Data%20Sharing%20Terms-and-Conditions.pdf?Web=1)

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| **1. REQUESTOR DETAILS** | | | | |
| **Name** | David Amadi | | **Department** | KHDSS |
| **2. INVESTIGATORS Names of all investigators who will have access to data (begin with Principal Investigator)** | | | | |
| **Names** | | **Roles** | | **Institutions** |
| 1. David Amadi 2. Prof Anthony Scott | | Student  Supervisor | |  |
| **3. IS THIS APPLICATION COMPLETELY COVERED BY AN EXISITING APPROVED PROPOSAL OR PROPOSAL REVIEWED BY ANOTHER SCIENTIFIC AND/OR ETHICS REVIEW COMMITTEE?** | | | | |
| **If yes: Give name of scientific/ethics review committee, date of approval, title of proposal, name of PI and end date of proposal:** | | | | |
| **If no: outline any plans to apply for scientific/ethical approval:** | | | | |
| **4. DESCRIPTION TYPE OF DATA REQUIRED (INCLUDE DETAILS OF STUDY THAT HOLDS THE DATA YOU REQUIRE IF APPLICABLE i.e. study number, study title and PI name)** | | | | |
| Dataset to contain mortality information from KHDSS and adult ward admission at three time periods I.e. 2015, 2016 and 2017 for women at reproductive age  Variable of interest include:   * Sex, age, date of admission, discharge diagnosis,admin\_ward | | | | |
| **5. OBJECTIVES OF DATA USE INCLUDING TIME FRAME** | | | | |
| * Determine risk factors associated with mortality | | | | |
| **6.ANY RISKS/SENSITIVITIES OR BENEFITS OF ANALYSIS, including to Data Subjects and groups of Data Subjects** | | | | |
| * The results will allow policy makers to generate actionable recommendation, prediction and generate new hypothesis. | | | | |
| **7. PLANNED OUTPUTS OF ANALYSIS** | | | | |
| * Presentation at conferences and publication | | | | |

Conditions and limitations for data sharing

1. You understand and acknowledge that custodianship of the Data is held jointly by the Programme and the Ministry of Health in Kilifi, and will be retained by the Programme and the Ministry of Health in Kilifi in case of any data transfer to a Recipient.
2. You understand and acknowledge that the Data is experimental in nature, and that access to the Data is provided without any representations or warranties of any kind in relation to the Database or the Data.
3. You will only access the Database and use the Data for the Agreed Purpose and shall not use the Data in such a way that damage or distress is or is reasonably likely to be caused to any Data Subjects.
4. The Data relates directly to individual Data Subjects and is strictly confidential. Data from subjects will be shared in a fully anonymised form without access to personal identifiers, including names and/or specialised roles. Geographic identifiers for subjects will routinely be aggregated to the level of the sub location or similarly de-identified. Consideration of requests for data with greater granularity will be informed by the local importance of the research question and the ability to protect the confidentiality of individuals and communities.
5. You shall only disclose the Data to your Data Users. You shall take all reasonable measures to ensure that your Data Users shall not make copies of the whole or any part of the Data without your consent, and shall keep a written record of any such copies sufficient to permit you to fulfil your obligations under clauses 3 and 7 of this Agreement. You shall not transfer or disclose any part of the Data to any other person or body.
6. You understand and acknowledge that the Data is protected by copyright and other intellectual property rights. Except as reasonably required to carry out Your research with the Data for the Agreed Purpose You shall not duplicate, or sell, or offer for sale or transfer or offer to transfer all or part of the Data, on any media.
7. You agree at all times to keep strictly confidential, and ensure that the Data Users keep confidential the information and Data pertaining to Data Subjects. In particular, You undertake not to use, or attempt to use, or permit anyone other than the Data Users to use the Data on its own or in conjunction with other data, to seek to discover the identity of any Data Subjects, to compromise or otherwise infringe the confidentiality of information on Data Subjects and their right to privacy.
8. You accept that the Data is protected by and subject to national and international laws, and that You are responsible for ensuring compliance with any applicable laws.
9. You agree that you will submit a summary report and any other information reasonably requested to the KEMRI Wellcome Trust Research Programme for the purposes of monitoring data use on the understanding that such information, data, results, and conclusions contained within will be treated as confidential information belonging to the Recipient.
10. This agreement is not transferable and You may not purport to assign it (in whole or in part) without the written consent of the KEMRI Wellcome Trust Research Programme.
11. If You commit a material breach of this Agreement or for any persistent breach of this Agreement, the KEMRI Wellcome Trust may terminate this Agreement immediately by notice in writing, without prejudice to its accrued rights and remedies.
12. You accept that it may be necessary for the KEMRI Wellcome Trust Research Programme to alter the terms of this Agreement from time to time in order to address new concerns. In this event, the KEMRI Wellcome Trust Research Programme will contact You to inform You of any changes and You agree that Your continued use of the Data shall be dependent on the parties entering into a variation of the Agreement.
13. If requested to do so by the Data Governance Committee, the KEMRI Wellcome Trust Research Programme may terminate this Agreement at any time by giving one month’s notice in writing to You.
14. Your duty to protect the confidentiality of the Data received under this agreement shall survive termination of this Agreement and shall continue in full force and effect indefinitely.
15. Upon termination of this Agreement you will permanently delete all copies of the Data from your computer systems and storage devices and will ensure that all Your Data Users shall also permanently delete such copies. You may retain aggregate information on the proviso that such aggregate information does not allow any individuals or groups of individuals who are the subject of the Data to be identified with reasonable effort.
16. You may publish Your results arising from the use of the Data for the Agreed Purpose providing the Data itself is not disclosed. Aggregate or generic information generated from the Data may be published on the provisos that: i) such aggregate or generic information does not allow Data Subjects or groups of Data Subjects to be identified with reasonable effort; ii) no damage or distress is or is reasonably likely to be caused to any Data Subjects or groups of Data Subjects; iii) the Data will not be used in any way that could reasonably be expected to lead to ethnic stigmatisation; and iv) no attempt will be made to identify the Data Subjects.
17. You agree to acknowledge the KEMRI Wellcome Trust Research Programme or appropriate Programme researchers (via authorship or an acknowledgment statement) in any work based in whole or part on the Data publications arising from the use of the Data.
18. You agree that if your application is approved, information about the proposed research use can be posted on the KEMRI Wellcome Trust Research Programme’s public website. The information may include Your name and institution, the title of the project, and a non-technical summary of the research question.
19. You recognise that nothing in this Agreement shall operate to transfer to You any intellectual property rights relating to the Data. You have the right to develop intellectual property based on comparisons with Your own data.

**Definitions in the agreement above:**

“Recipient” means the principal researcher named above; “Recipient Institution” means the organisation named above at which the Recipient is employed, affiliated or enrolled; “Data Users” means those officers, employees and students of the Recipient Institution, who work directly with the Recipient and have a need to use the Data for the performance of their work with respect to the Agreed Purpose, and have agreed to comply with this Agreement, as named in the application; “Database” the KIDMS database containing clinical and demographic and health surveillance data on Data Subjects; “Data Subjects” the individuals who have contributed their data to the Database; “Data” the data within the Database; “Agreed Purpose” means the medical research purpose(s) approved by the Data Governance Committee in writing; “Publications” means, without limitation, articles published in print journals, electronic journals, reviews, books, posters and other written and verbal presentations of research.

**Statement of agreement:** I agree to the above conditions and limitations for sharing data as requested in this application:

Name:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ Date:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Signature: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_