

Dar es Salaam Urban Cohort (DUCS)

Data Access Procedures and Cohort Use

Introduction

Tanzania like many other sub-Saharan countries is faced with rapid urbanization and double disease burden amidst poverty and health crises. Yet, evidence-based data from urban areas to enable policy and decision makers to allocate the necessary resources are hard to come by. There is therefore clear need for accurate sources of data from the urban community for planning and implementation of health system strengthening at district level. The Dar es Salaam Urban Health Cohort (DUCS) was initiated in 2011 to establish and maintain a Demographic Surveillance System that will monitor health and socio-demographic events over time in Dar es Salaam, Tanzania. These include births, deaths, marriages, migration, water supply and sanitation, socioeconomic status, and food insecurity at the household level, Census methodology is being used with an additional tracking down of the residents for migratory patterns, environmental exposures, vital events, disease trends and outcomes of health interventions. The platform has collected in-depth data on non-communicable diseases such as hypertension, diabetes and on communicable diseases such as HIV/AIDS from this uniquely designed surveillance site covering a population of over 100,000 residents living in over 20,000 households in the Ukonga and Gongolamboto wards of Ilala district in Dar es Salaam.

The DUCS also provides a framework for research and evaluation of interventions as well as training researchers and service providers on longitudinal data collection, analysis and interpretation and guides information dissemination for health policy in matters of disease prevention and control in Tanzania and other developing countries.

Over the years, DUCS has accumulated large data sets from the platform and from a variety of nested studies within the platform, which, together form a unique database for current and future analysis to uncover root causes of some of the most intriguing health issues for which young and experienced scientists can help to resolve. DUCS is therefore prepared to avail such data to faculty and students, both local and foreign, to provide solutions to that end.

Procedures for accessing DUCS data

The following information outlines the procedures required for external researchers, MUHAS students, and academic staff to request for DUCS data for use in research and publications. The data files will be made available to Principal Investigators (PI) who satisfy specific criteria and are approved by the DUCS data committee. The DUCS management reserves the rights to deny a data request, particularly if the research proposal overlaps with any previous or ongoing DUCS initiatives.

Data Files

The data files are stored in the MUHAS savers and can be provided in formats that are friendly to users such as: Excel, CSV, SPSS and STATA, depending on the need of the researcher. In addition, each data file will be accompanied by a summary of the respective research proposal including objectives, corresponding codebook showing the variables, data collection date as well as the questionnaire used. This information will be available in the DUCS webpage within MUHAS.

Required criteria for accessing data

External researchers, students, and academic staff who need to request DUCS to provide data collected from the DUCS platform for secondary individual analyses must submit the following information:

1. Research proposal outlining the following
 - a. Abstract (less than 120 words) Brief summary of the proposal showing background, objectives, methods and expected results
 - b. Introduction/Background (of less than 600 words) Briefly explaining the problem the researcher wishes to address.
 - c. Research Questions to be answered by the researcher in his or her research
 - d. Objectives of the research
 - e. Methods and Procedures (less than 500 words) *Explaining which particular data set is required, how the data will be accessed and which variables will be needed to answer the research questions and objectives.*
2. Dissemination Plan (less than 300 words) *Describing specific plans for dissemination and/or publication of the findings*
3. Curriculum Vitae (CVs) of the PI and other key researchers who are submitting the proposal for data request.

Requirement after accessing the data

External researchers, students, and academic staff who have been given permission to access the DUCS data must sign the following forms. (Forms can be available from DUCS research office or DUCS webpage).

1. Agreement form for the use of data.
2. Security pledge for data access.

Data provisions for proclamation

All granted requests for data from DUCS shall be subject to the following provisions:

- All identifying information about the study population will be removed from the dataset before DUCS releases data to the researcher. This is for the purpose of confidentiality.
- Datasets shall be made available as established by DUCS
- Data will be analyzed and disseminated only as stipulated in the proposal submitted to DUCS during application period.
- The researcher must not sublet data obtained from the DUCS platform to other researchers without written permission from the DUCS management.
- The researcher must invite at least one of the researchers involved in the original data collection as a co-author to help provide institutional memory of the data. If none is available, the one providing the data (Data manager or his/her assistant must be involved as a co-author.
- Agreements for the use of data from the DUCS platform will expire 12 months after the date of approval to allow other researchers who may be interested in the same topic to apply for access to the same data. Within the 12-month period, a researcher may publish data requested from DUCS. Beyond that period the researcher needs to apply for a six-month extension to DUCS, giving reasons why an extension is necessary. For PhD students' application for extension shall be made every year with reasons to justify the need for keeping the data for a further extended period.
- All publications resulting from these data must explicitly state that the original dataset was collected by the DUCS platform and that permission was granted with acknowledgements.

- The PI is required to provide DUCS with an electronic copy of any research report/publication

Data Accessing/Sharing Fees

External researchers, MUHAS students, and academic staff who request data collected by DUCS, will pay fees for accessing the data. The DUCS data committee will determine the amount of fees to be paid depending on the nature of the project. The data sharing fees will be different depending on the following criteria.

s/n	Applicant type	Fee (Tsh)	Fee (Us dollar)
1.	Tanzanian researchers	2,000,000	
2.	External researchers (non-Tanzanian)		2,000
3.	Undergraduate students	100,000	
4.	Masters' students	250,000	
5.	PhD Candidate	1,500,000	
6.	MUHAS staff or faculty	300,0000	

Review and Approval Timeline

All data request applications will be assessed and approved by the DUCS data committee. Once DUCS receives the application for accessing data, it will inform the PI within five (5) working days whether the application needs further clarification and whether requested data are available. If the PI is satisfied with the data provided, he/she will sign data accessing form and will be notified and given the data set within 5 working days after completing all the procedures and requirements as stated above.

Use of DUCS for Primary data collection

Required criteria for collecting primary data from the DUCS Platform

External researchers, students, and academic staff who need to request DUCS to allow for primary data collection from the DUCS platform for research purposes must submit the following information:

1. Research proposal outlining the following
 - a. Abstract (less than 120 words) Brief summary of the proposal showing background, objectives, methods and expected results
 - b. Introduction/Background (of less than 600 words) Briefly explaining the problem the researcher wishes to address.
 - c. Research Questions to be answered by the researcher in his or her research
 - d. Objectives of the research
 - e. Methods and Procedures (less than 500 words). *Explaining which particular data set is required, how the data will be accessed and which variables will be needed to answer the research questions and objectives.*
2. Dissemination Plan (less than 300 words) *Describing specific plans for dissemination and/or publication of the findings*
3. Curriculum Vitae (CVs) of the PI and other key researchers who are submitting the proposal.
4. IRB approval for the study

Primary data collection Fees

Academic staff and MUHAS students, who wish to collect primary data from the DUCS platform, will pay between 200,000 to 500,000 Tsh as the cost for using DUCS cohort depending on the nature of the research. External researchers non-Tanzanian they will pay 15% of the total budget. For external researchers before data are provided the Data Sharing and Transfer Agreements procedures and other procedures will be followed.

NB: These fees do not include the cost of data collection in the field.

Review of Applications

All proposals requesting to use the DUCS cohort data or platform will be assessed and approved by the DUCS data committee. Once DUCS receives the proposal for data use or field data collection, it will inform the researcher within 5 working days whether or not the proposal meets the requirements for access before proceeding to the next steps.

If the researcher opts to collect primary data from the platform, he/she is advised to use the DUCS resident data collection staff or part of the team because these are familiar with data collection and locating the sampled populations.

For purposes of building a robust database with the possibility of future follow-up, all data whether on paper, electronic on tablets or on tapes collected from the DUCS platform shall be stored and archived in the DUCS servers which are housed at MUHAS. Hence researchers are responsible for ensuring that they submit all collected data to DUCS for storage and archiving.